Handbooks in Health, Work, and Disability

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Handbook of Qualitative Health Research for Evidence-Based Practice

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Foreword

The past 20 years has witnessed an enthusiastic turn towards qualitative research across the social sciences. This enthusiasm was fuelled by a desire for research to develop a sophisticated understanding of everyday human experience and contribute to the enhancement of social and personal well-being. Within the health arena qualitative methods were particularly attractive for the large number of new researchers from the health professions—such as nursing, physiotherapy, and occupational therapy—who had intimate experience of health care. They felt that the prolific body of quantitative health research did not reflect the lived reality of illness.

The initial tentative turn to qualitative health research in the 1990s turned into a veritable flood with the establishment of conferences, societies, and journals devoted to qualitative research. This was coupled with the development of training programs and access to research funding that enabled the growth of substantial qualitative research initiatives.

However, there remains the challenge of moving from research into practice, which has been an increasing consideration of funding agencies (Murray 2013). Indeed, most funding agencies today want to see evidence of impact and ask what research has contributed in terms of policy making and professional practice. This is where many qualitative researchers have often been frustrated.

Many policy makers continue to prefer the findings from quantitative research with its convincing allure of statistics and certainty. Initially, qualitative research was dismissed or, at best, sidelined as being of secondary importance. The promotion of the hierarchy of health research evidence (Guyatt et al. 2000) and the establishment of the Cochrane research database contributed to a certain skepticism around qualitative research. The hierarchy placed systematic reviews and randomized controlled trials (RCTs) at the pinnacle of research and consigned case studies to the base. Qualitative research could be considered, but only as preliminary work. Indeed, this encouraged many qualitative researchers to describe their work as exploratory as if it was possible to develop and test certain hypotheses using quantitative methods subsequently. But times are changing, and qualitative researchers are beginning to better assert the value of their research. This has led to the development of alternative hierarchies of qualitative research evidence (Daly et al. 2007) and the opening up of the Cochrane database to qualitative research (see Noyes et al. 2011).

This leads me to the current handbook, which is a significant achievement and contribution to the continuing debate about the role of qualitative research in shaping health care. At first sight, the idea of a handbook of qualitative health research for evidence-based practice might seem to be an oxymoron. The original move for evidence-based practice was underpinned by an assumption that only evidence that was quantifiable was suitable. This handbook clearly refutes that argument and is a veritable treasure trove of ideas on how qualitative research can inform healthcare policy and practice. In doing so, it challenges many of the hidden assumptions that have underpinned the dominant positivist approach to science.

The term *science* is imbued with the imagery of the physical sciences with reference to laboratories, experiments, measurement, and causal laws. This approach to science evolved in the seventieth century, which was the age of the scientific revolution and a break from a reliance on religion and superstition. This era heralded the development of the scientific method, an empirical approach that centered on careful observation, measurement, and experimentation. As a result, it was possible to develop causal laws that underlay everyday natural processes. This process of science was refined through the concept of hypothesis testing, which was a means of predicting and then testing the relationship between measureable variables. Through the process of careful development of causal laws, it would be possible to develop an understanding of not only the natural world but, increasingly, the human world. However, while this approach underlies biomedicine, throughout the social and human sciences there has been an increasing demand for an alternative approach that would be systematic in its contribution to the development of knowledge but would also allow room for imagination and interpretation. The postmodern movement in the late twentieth century also opened up the debate about the variability of interpretations, such that today there is increasing acceptance that there is room for different approaches to—and interpretations of—research.

Flowing from the classical image of science was the assertion that evidence had to be objective, verifiable, and replicable. It was the steady accumulation of this form of evidence and its careful integration through systematic reviews that would ensure healthcare decision-making would no longer be subject to prejudices but would be based upon incontrovertible fact. However, decision-making is a lot messier (Cartwright and Hardie 2012).

Indeed, despite substantial moves within health care to base decision-making upon such scientific evidence, it is apparent that there are many factors that influence decision-making within health care and elsewhere. These include, for example, the character of different forms of intervention, the views of different client groups, access to resources, and powerful interest groups. This is where qualitative research can provide us with insight into processes. However, as this collection emphasizes, qualitative research is not one approach but many. Although much of it still relies upon interviews, there is increasing enthusiasm about ethnographic, participatory, and other forms of research that have opened up exciting new vistas.

An increasing concern is the interpretation of qualitative data. A superficial approach to qualitative research assumes that it is just the collection and presentation of a collection of client views. Today, we are aware that this is no longer the case. Data analysis involves the careful interpretation of data through the lens of different interpretive frameworks (Flick 2013). Similarly, in their guide to best practice in qualitative research, Daly et al. (2007) have emphasized the importance of the conceptual framework.

This must be combined with an awareness of context. Health and illness and research do not exist in a vacuum. Instead, the very experience of health is socially, historically, and culturally located. It is through qualitative research that we begin to grasp this variability. In the health arena the rise of RCTs will help identify what interventions work but they are less likely to expand on the variability of the effect—the *why* and *when* and *for whom*. As Cartwright and Hardie (2012) emphasize, RCTs can tell us that a certain intervention has worked in a certain setting with a certain population but there is a need for more research to integrate these contextual factors into our understanding. Qualitative research offers an opportunity to better explore that variability.

However, there remains the danger that, in following in the footsteps of quantitative researchers, qualitative researchers will be sucked into the orbit of positivist science and lose their critical edge. Nothing is fixed. We live in a changing world but can play a role in this change. The last 20 years has made us aware of the importance of reflecting upon the purpose and values underlying research. The nature of qualitative research brings us closer to the subject of our research. We can begin to grasp the distress experienced by the sick and the excluded during the very process of our research. The previous distanced approach of the detached scientific investigator is challenged by the more socially engaged qualitative researcher. This makes it even more pressing that qualitative researchers reflect upon these broader social and moral issues.

This book introduces the many methods and approaches that qualitative health researchers can access and demonstrates how they can have an impact. But no approach is without its limitations. As we further develop our methodological sophistication, there is a need for this to be accompanied by ongoing reflexivity and awareness about the nature of that impact and of our role in contributing to a better world.

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Preface

The spiraling costs of health care worldwide, associated with increased public scrutiny and emphasis on accountability for treatment outcomes, have set the evidence-based practice movement in medicine and allied health sciences afoot. However, despite major international efforts to develop practice standards and guidelines based on evidence in the health disciplines, advances in the field have become politicized and stymied by a narrow and reductionist understanding of the concept of evidence (Greenberg and Watson 2006; Hill 2006; Morse 2006).

Current understanding of evidence in health sciences, based essentially on the quantitative research paradigm and a "one size fits all" treatment model, has failed to address unique aspects of social contexts that shape the delivery of health care. Growing numbers of societal healthcare stakeholders are challenging current notions of healthcare evidence as lacking utility due to the neglect of perspectives related to factors such as gender, cultural, disability, diversity, and systemic factors inherent in the provision of health interventions. In 2005, the president of the American Psychological Association (APA) established the Presidential Task Force on Evidence Based Practice in Psychology (EBPP, APA 2006). Based on this report, the APA endorsed the use of multiple types of evidence in identifying effective patient outcomes, noting that different methods permit investigation of questions not well suited to traditional research designs. Similarly, the Mental Health Commission of Canada, citing a need to support a broad range of research approaches, called for research based on appropriate evidence as one of its eight core goals for transforming the mental health system. Expanding the notion of evidence is also essential in order to adequately represent the integrative, interdisciplinary, and biopsychosocial components of the World Health Organization's model of health, with its focus on the complex dynamic interactions among various individual characteristics and environmental factors (WHO 2001; Peterson 2005).

This Handbook is a pioneering attempt to expand the concept of evidence by synthesizing qualitative evidence to date in critical areas of health. We have defined qualitative research as empirical work that focuses on the multidimensionality and context of participants' experiences, and that emphasizes nonlinearity. Thus qualitative researchers are able to answer questions and generate bodies of evidence that are not accessible using quantitative approaches. We invited our authors to revisit and articulate notions and issues of evidence used in health disciplines, with a focus on exploring the growing edges of evidence from qualitative studies and ways it could be used in clinical practice, teaching, and health policy. Specifically we sought to critically examine how health disciplines constitute and use evidence, to highlight the health-related evidence that has been developed in various fields using qualitative health research, and to show how some of this evidence has been used to solve important issues in health care. For these reasons, we expect the Handbook to appeal to scholars, researchers, policy developers, and practitioners responsible for defining evidence in health care and for designing and developing best evidence-informed clinical practices that lead to improved and equitably distributed health outcomes. The readers are likely to include physicians, especially family physicians, psychiatrists, rehabilitation medicine specialists, and occupational physicians, nurses, psychologists of all specialties, social workers, rehabilitation therapists including vocational rehabilitation professionals, occupational therapists, physiotherapists, and counselors in a variety of settings.

The Handbook is divided into three parts. In the first part, the authors have discussed some of the contextual issues such as culture, marginalization, and point of view that are part of the growing discourse about evidence. The second part begins with a chapter on evaluating qualitative research. The authors of the remaining chapters in this part were asked to consider three fundamental conceptual, methodological, and practice questions arising in health research: (1) what constitutes evidence in health interventions; (2) how could the current notion of evidence be expanded to incorporate contributions from qualitative research in their field; (3) how could qualitative evidence enhance health outcomes. The third part begins with a chapter that expands notions of evidence-based practice by showing how qualitative research can be used in healthcare settings and includes a set of chapters where authors provided examples in which evidence from qualitative studies has been used to change various aspects of practice in health care. We conclude the handbook by outlining future directions for qualitative health research, and by inviting individuals to read the book as both a state-of-the-art academic synthesis of the qualitative evidence to date in various areas and as a stepping stone to the use of this newly integrated evidence to inform best practices in healthcare interventions and practice, on par with evidence from quantitative studies.

This Handbook attests to the richness and diversity of qualitative research in health. Such was not always the case, particularly in terms of how the knowledge about and practice of health was reflected in scholarly journals. We, as editors, are pleased by the substantial canon of qualitative health research represented in this Handbook, not only across chapters but also within chapters. At the same time, we acknowledge limitations and gaps that for a variety of reasons are not addressed herein. For example, we welcome and acknowledge the need for further discussion about the importance of context, particularly from indigenous scholars and scholars from developing countries. We also acknowledge that a handbook of this kind may send a tacit message that its contents circumscribe the field of qualitative health research. This is neither our intention nor the outcome. On the contrary, we hope that these chapters are outward and forward looking in how health is conceptualized, researched, and practiced. While we expect that readers will find that we have not emphasized a particular method, model, or approach, we also hope that there is enough consistency to ward off any criticism of 32 stand-alone chapters. We have addressed many substantive health topics, but recognize that we have not been as comprehensive as possible. Ultimately we hope the Handbook encourages researchers, practitioners, and policy makers, as well as students, to continue important conversations about health in a more contextual way that is close to the human, everyday experience of people.

The diversity that we hope is represented in this Handbook reflects some of the differences we share as editors. We come from different backgrounds (rehabilitation, nursing, and psychology), we have engaged in different kinds of qualitative research, and have used different paradigms and methods. We have not agreed on every claim or position taken in the Handbook. But we endorse this work as a whole precisely because it includes well-articulated, challenging, contradictory, and innovative views, which we hope will foster constructive debate about health interventions, followed by enhanced research evidence collection approaches and better clinical practices.

We want to conclude these introductory remarks by thanking others involved in this project for their assistance and cooperation. First and foremost, we thank the chapter authors and co-authors whose contributions to this work have been significant and without which this project would not have come to fruition. We appreciate the quality of their work, their commitment to the project, and their responsiveness to our feedback. We are also highly indebted to Catherine Chlebak, Negin Naraghi, and Louise Young who coordinated the work, corresponded with authors, kept us on track, and did a first copyediting of the chapters. Special thanks are due to Janice Stern of Springer Science + Business Media for her wholehearted support of this work. This work was also supported by a Faculty of Education Research Infrastructure Grant from the University of British Columbia, for which we are grateful. Finally, we thank our family members, colleagues, students, and friends whose inspiration and support was manifest in many, often imperceptible, ways during the course of our engagement with this Handbook.

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Part I

Setting the Stage

Using Qualitative Health Research to Transform the Nature of Evidence

1

Karin Olson, Richard A. Young,
and Izabela Z. Schultz

Clearly the world is in a period of profound change—culturally, environmentally, and technologically. One easily resonates with Dorothy's observation on landing in the Land of Oz and encountering the Good Witch of the North, "Now I know we are not in Kansas anymore." So it is with health care and health research.

In the last two decades, health-care models and systems worldwide have been going through a major evolutionary change to address increased clinical complexity and social and cultural diversity in service delivery, shifting demographic trends, growing demand, decreasing resources, and spiraling costs. These changes involve advancement of an integrative biopsychosocial paradigm replacing the archaic Cartesian biomedical model and increased focus on predictors of health-care outcomes, outcome measurement, evidence-supported policy and practice, as well as cost-benefit analysis of health interventions. All these developments require an approach to research evidence that delivers the type and quality of evidence that can address these growing system-wide challenges.

One potent characteristic of this period of transformation and change in health research is the praiseworthy shift to evidence-based policy and practice, which can be limited and considered reductionistic if tied too exclusively to randomized control trials (RCTs). The other characteristic of this period is a burgeoning corpus of qualitative health research, which speaks to evidence-based practice in ways that are different but equally important as RCTs. Qualitative health research is the subject of this handbook.

The changes that influence and are influenced by qualitative health research are multifaceted. These changes invite researchers, practitioners, and the public to consider health in light of the context in which it is engaged, the experiential meanings that individuals, groups, and cultures ascribe to health, and the very conceptualization of health itself. The research approaches through which one is able to view and obtain this information are rooted in ontological and epistemological understandings that may initially appear a step or two removed from health research as it is currently conducted. These new approaches, however, are core to engaging with the transformations required to solve the challenges facing the health-care systems worldwide.

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1.1 The Place of Context in Evidence

Part I begins with a discussion about the importance of context. Contributors have illustrated how evidence can be expanded when a serious attempt is made to find ways to directly incorporate the voices of those being studied and the added value that this more expansive view can bring to the solution of important health-care problems. Evidence is context bound, however, and thus context must be included in both conceptualizing and interpreting results, particularly when trying to address research questions that focus on marginalized or otherwise vulnerable populations. Two of the contributors in Part I argued for accessing context and the complexity inherent in it by conceptualizing health as goal-directed action, which has both integrative and interdisciplinary implications for research. Shifting to an organizational perspective, the section also includes a chapter in which ways qualitative research could be used to help meet organizational objectives. Part I concludes with the challenge to think more carefully about generalizability, one of the thorny issues in qualitative research, particularly when trying to decide what evidence one actually has. Beginning with the challenges associated with generalizability in quantitative research, the reader is asked to consider generalizability from the standpoint of qualitative studies. This chapter triggered many interesting discussions about generalizability among us as editors and with students in our classes. One nursing student offered a perspective that we had not considered by introducing concepts from research utilization. She noted that while the leap from generalizability to use of research findings may be a long one, it was worth thinking about because it helped to expand traditional notions of generalizability. She went on to point out Estabrooks' (1999) arguments about the forms that the use of research findings may take. While some research findings may be translated into products such as protocols or clinical practice guidelines that could be used to change practice, research may also be used conceptually to alter thinking and "enlighten" the health-care provider by providing new information about what an experience is like or used symbolically for social or political purposes to persuade or support a position or practice. In our view, the findings of qualitative research are particularly suited for these conceptual and symbolic uses.

1.2 Examples of Evidence

Beginning with a chapter about the evaluation of qualitative research, Part II of the handbook is intended to showcase examples of evidence from qualitative research in a broad range of topics within health research. Some contributors discussed the qualitative health research on key subtopics within their fields, while others provided a broader discussion of the qualitative health research in their area for a defined period of time. The reader is encouraged to read this group of chapters as a whole in order to appreciate the variation in definitions of evidence. This variation helps to make the social construction of evidence more explicit. In addition to describing their views of evidence, these contributors were asked to describe their search strategies, so that interested readers could use these summaries as points of departure for their own work and track the subsequently published evidence. By summarizing the qualitative studies in their respective fields, these contributors showed what "counts" as evidence from their perspectives.

The development of valid and reliable strategies for combining studies in order to build evidence is one of the hallmarks of evidence-based practice. Strategies for building evidence from both quantitative and qualitative studies began surfacing in the peer-reviewed literature in the late 1980s and early 1990s. Jenson and Allen (1994) outlined a strategy for synthesizing the results of qualitative research, and groups such as the Cochrane Qualitative and Implementation Methods Group have developed countless additional approaches. A search of Cinahl alone identified over 1000 articles in which the authors sought to use one of these strategies to summarize the results of qualitative studies within a given field. The majority of the contributors in Part II of the handbook used a narrative review strategy.

1.3 Using Evidence from Qualitative Studies to Improve Health Outcomes

Part III of the handbook begins with a chapter that formally extends the discussion about evidence-based practice and research utilization by discussing modes of application and the contributions of qualitative inquiry. The remaining chapters are from leaders in qualitative research and highlight examples of how evidence from qualitative studies has already been used to change clinical practice and education, guide research, and inform policy in key arenas within health-care systems around the world.

The availability of summaries of qualitative studies has raised questions about the nature of the evidence obtained. These are important questions given the interest in health-care environments to use the "best" evidence when making health-care decisions. Some approaches to evaluating evidence consider the evidence available through syntheses of qualitative research as inferior to that obtained from quantitative studies (Peterson et al. 2014), while others argue that the evidence from qualitative studies, although different than the evidence from quantitative studies, is equally valuable (Upsur 2001). The chapters in section three provide support for Upsur's position because they show how evidence from qualitative research was used to solve important health-related questions.

1.4 Take-Home Messages

As you read this book, we would like you to keep two take-home messages in mind. The first one is that the decisions about how evidence is defined and constructed are sociopolitical, and thus not all those working in health care will define evidence the same way. By privileging randomized control trials as the "best" evidence, the evidence obtained from studies that focus on health-care questions not suitable to randomization and/or quantification is excluded. The very features that make randomized control trials useful for some research questions make them useless for generating evidence about other problems in health care.

Rather than limiting one's approach to evidence from randomized control trials only, Upsur argues for generating evidence by matching the design to the nature of the clinical problem one is trying to address (1991). From this perspective, one has access to more existing evidence. Indeed, such an approach could include evidence from Bayesian reasoning and econometric approaches, as well as from historical and social forms of research that incorporate social and cultural considerations and frameworks rooted in perspectives such as critical social theory and postmodernism. Using Upsur's approach, a much broader evidentiary base becomes available, and one may then choose the type of evidence rather than the level of evidence required.

The second take-home message is that health researchers interested in questions best studied using qualitative research studies need to continue building vehicles that move their summarized or synthesized findings into use in health-care settings. On the surface, the ongoing question seems to be about how much evidence is needed before utilization can be considered, but we think the question of utilization is about much more than just the mere amount of evidence. Moving evidence into practice is hard work. Estabrooks (1991) notes that "enough" was known about scurvy 263 years before citrus was finally introduced on ships as a dietary supplement.

As the contributors of the handbook have shown, one of the key challenges associated with moving the evidence from qualitative research into practice is associated with accommodation of the larger complex macrosystem issues such as poverty, profit margins, and globalization, which are made explicit in qualitative research. A key part of this challenge is nagging doubts about the certainty of the evidence from qualitative studies. While meta-analysis has provided quantitative researchers with the tools for assessing certainty and even increasing effect size, the ontological and epistemological assumptions inherent in the research designs used in qualitative research make it essentially impossible to ever obtain certainty in the same way. As noted above, however, there is a growing body of literature about alternative approaches for increasing the confidence in findings from qualitative research by combining results in various ways. The narrative reviews presented in Part II of this handbook are one such approach. The chapters presented in Part III show that this approach has already demonstrated utility when solving problems in health-care settings.

As you read this book, we hope that you are challenged to think about the nature of evidence derived from qualitative research in new ways and to see the breadth it adds to the evidentiary base for solving complex problems in health-care systems. As the contributors to this handbook have shown, the evidence already available from qualitative studies is significant. We challenge you to add to this evidence where needed and to fill in the gaps where evidence is limited. We also challenge you to develop strategies that implement and evaluate the usefulness of this evidence in clinical practice, policy, and health-care system.

We welcome a wide, multidisciplinary readership of this handbook: physicians, nurses, psychologists, occupational therapists, vocational rehabilitation professionals, and other allied health professionals. In addition to health scientists and researchers, we invite all health-care stakeholders, including clinicians, program and best practice developers, policy and decision makers, and health-care and compensation system executives and management, to join us in integrating qualitative evidence into evidentiary guidance for building better patient-centered health care and for producing improved individual health, systemic, and economic outcomes. The impressive but undervalued body of knowledge generated from qualitative research is of critical importance in times of mounting health-care challenges and associated spiraling costs worldwide.

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Social Context of Health and Diversity Issues

2

Mohan Dutta

2.1 Diversity

I define diversity as a concept that is inclusive of all individuals within a society. Diversity captures the cultural differences within and between populations. In such a view of diversity, it is acknowledged that one size does not fit all, and therefore practices need to be adapted to cultural settings and characteristics of populations. The role of qualitative health research in the context of diversity is to discover the key characteristics of culture that need to be incorporated into health practices. Qualitative research offers insights into a diverse population through the presentation of cultural interpretations in context. The context emerges through in-depth interviews, focus groups, and ethnographies, thus pointing to the aspects of the culture that need to be taken into account in shaping health practices.

In addressing diversity, researchers must note that issues of diversity relate broadly to the social context of knowledge production, including what the research questions are, and how data are gathered and interpreted, and thus construct research approaches that take these issues into account. That research is inherently political related to the framework within which evidence is constituted and the agendas of the status quo. Questions of diversity thus also relate to broader questions of power and the ways in which power is intertwined with the representation of diversity.

For instance, an interviewer who asks African Americans in a low-income community about their consumption of fruits and vegetables must understand the cultural interpretations of fruit and vegetable consumption. These interpretations can then be incorporated into culturally sensitive communication interventions that promote fruit and vegetable consumption through culturally targeted messages. Asking broader questions of power in the context of fruit and vegetable consumption, in turn, would push the in-depth interview to engage with the broader structures within which meanings are interpreted and seek to examine the ways in which these structures emerge in the narratives of African Americans in a low-income community. Such attention to power and structure could guide researchers toward interrogating the structures of food distribution, the commoditization of fruits and vegetables, the lack of availability of affordable fruits and vegetables in low-income communities, the limited economic opportunities for African Americans, and the high density of fast-food restaurants in low-income African American communities. The parts of the context that are featured in qualitative research relate to

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the broader goals of the researchers, the relationship of the research process to the dominant structures of articulation, and the relationship of researchers with communities.

Research about diversity is guided by an emphasis on difference, understood through the expressions of structural context in the participants' articulations and the ways in which these expressions of health differ from the expressions in the mainstream. For instance, research on Native American experiences of health in the realm of diabetes offers an interpretive frame for understanding the clinical practices around diabetes in the context of the lived experiences of Native Americans (Struthers et al. 2003). In this way, difference becomes the key entry point for engaging in research and becomes the point of interest in developing guidelines for evidence-based practice (Meadows-Oliver 2009). Rather than write over this difference in order to generalize or co-opt this difference into a broader overarching framework, qualitative research offers guidance regarding the ways in which difference is in and of itself the precise framework for the delivery of care (Dutta 2008). The understanding and treatment of evidence needs to be juxtaposed in the backdrop of this difference. Similarly, with respect to the gendered organizing of health-care processes, qualitative research foregrounds the ways in which gendered assumptions guide evidence and, therefore, offer meaningful interpretive frames for considering gender when addressing health needs.

In the experiences of different races, the examination of health-care disparities is guided by the rich insights into dynamic and changing contexts gleaned from qualitative research. Postcolonial theorists in qualitative research note that qualitative research shapes postcolonial contexts and offers insights into which research questions are asked, how problems are configured, and the research methods that are developed. The cultural logics of neocolonial configurations are interrogated for the processes of disempowerment they perpetuate. For instance, qualitative researchers working in postcolonial contexts share ways in which mainstream understandings of health erase the participants' expressions of their own agency, treating participants as primitive individuals and treating culture as barrier to the promotion of effective health behaviors and practices (Chilisa 2005; Dutta 2008; Smith 1999). Ethnographies, in-depth interviews, and focus groups conducted in postcolonial contexts offer opportunities for disrupting the dominant frames in research and for interrogating the taken-for-granted assumptions that circulate in these frames. The presence of postcolonial voices in discursive spaces of knowledge production interrupts the overarching frameworks and interrogates the forms of marginalization that are paradoxically intertwined with these very frameworks.

Studies focused on diversity often highlight certain groups that are disenfranchised because of their difference from the mainstream or cultural differences that distinguish them as a population subgroup (Airhihenbuwa 1995; Airhihenbuwa and Obregon 2000; Dutta 2008). I am particularly concerned about structures with the social context that may constrain the health of disenfranchised groups (Basu and Dutta 2008, 2009; Dutta 2008). Structures of particular concern include health policies and programs as well as particular cultural characteristics of a subgroup (Airhihenbuwa 1995; Airhihenbuwa and Obregon 2000; Dutta 2008; Varjas et al. 2005). Culture here refers "to an organized body of rules concerning the ways in which individuals in a population should communicate with one another, think about themselves and their environments, and behave towards one another and towards objects in their environments" (LeVine 1973, p. 4). These rules are neither static nor monolithic, and each of us is part of many cultures. For example, one may be influenced by "rules" related to employment, his or her role within their family, ethnicity, and geographic region.

2.2 The Production of Knowledge About Diversity

Knowledge about diversity can be produced in many ways. The knowledge about diversity that is obtained through qualitative research is particularly valuable because the qualitative researcher is required to consider both the data and the social context from which the data are obtained. Context is constituted in the lived experiences, spaces of meaning making, and stories of life shared by community members as they negotiate the structures, including the structures of practice, within which they find themselves (Dutta 2008). As the researcher learns more about the context, new understanding and insights are gained. This new understanding shapes the ways the researcher asks questions, gathers and analyzes data, and uses the research results. The resulting data help the researcher understand the complex and dynamic nature of the contexts surrounding the data, understand the meaning of the data, and highlight implicit aspects of the context that may be contributing to disenfranchisement. Knowledge of these contexts may also help the researcher assess factors that could enhance the effectiveness of solutions implemented within these contexts that take diversity into account.

The relationship between context and qualitative research is central to the development of knowledge about health and diversity (Dutta and Basu 2007a, b; Basu and Dutta 2008). The availability of data about social contexts provides insight into the rich and dynamic web of meanings that surround health policies and programs (Doornbos et al. 2013; Dutta 2008; Nastasi and Schensul 2005; Nastasi et al. 2004; Varjas et al. 2005). The explicit examination of context therefore provides a framework of understanding meaning and stories that offer insights into the nature of practice, the gaps in practice, and elements of disenfranchisement that are built into the social context. Thus, these data help the researcher understand the complex and dynamic nature of the social context surrounding the data and highlight implicit aspects of the context that could be contributing to disenfranchisement.

The insights obtained through qualitative research about diversity are available because the data are obtained through engagement with community members in naturalistic settings (Lincoln and Guba 1985). For instance, researchers who use qualitative research approaches to understand multicultural and culturally sensitive health practices are able to learn about both the meaning of practices and the ways in which the practices relate to the diverse needs of community members (Dutta 2007; Nastasi and Schensul 2005; Nastasi et al. 2004; Varjas et al. 2005).

Qualitative research changes the power relationship between the participants and the researcher. Participants are typically configured as recipients of interventions and policies. Community-based approaches to qualitative research, however, offer participants the opportunity to shift this power relationship and become creators of interventions and policies (Wallerstein and Duran 2006). Similarly, a culture-centered approach to local participation foregrounds the theoretical insights that emerge through local participation (Basu and Dutta 2008, 2009; Dutta 2004a, b, 2007, 2008, 2011). The grounding of research in the hands of communities creates an entry point for the development of practice that is intrinsically intertwined with the needs and aspirations of communities and foregrounds the social contexts within which research is carried out. For example, the Navajo Nation Institutional Review Board developed sophisticated processes of evaluation for determining whether research with Navajo participants would be allowed. If so, researchers are invited to move into the very social contexts that they seek to describe and, in doing so, work through participatory processes that are rooted in the voices of communities (Wallerstein and Duran 2006).

Because qualitative research is focused on the voices of participants, it provides novel approaches for considering the effectiveness of policies, programs, and practices intended to benefit disenfranchised groups. By using qualitative research designs, the participants help to determine what counts as data, how the data are interpreted, and what the practical ramifications of the study will be. The culture-centered approach (CCA) foregrounds a framework based on listening to communities at the margins as a catalyst for structural transformation (Dutta 2008). Listening becomes a way of “talking back” to the structures inhabited by researchers and policy makers and for interrogating the ways in which these structures may perpetuate the inequities in all areas of life, including health. The new meanings that emerge may be used to interrogate barriers and reshape practice in ways that are inclusive of marginalized groups (Nastasi et al. 2004; Varjas et al. 2005). These new meanings may also be used to question the relationships between research and practice and the manner in which social context influences power structures that shape these relationships (Dutta 2004a, b, 2008; Dutta and Basu 2007a, b).

2.3 Power and Qualitative Research

As noted earlier, engaging with context draws attention to the structural frameworks within which research endeavors are measured and evaluated (Dutta and Basu 2013). Therefore, putting qualitative research in context also means that qualitative researchers turn the lens on the very structures of knowledge they inhabit, (auto)ethnographically examining these structures and the practices within these structures and also interrogating the very processes of evidence making and articulation of standards (see Alford 2000). To the extent that the context of the research process becomes centered in discussions of evidence, possibilities are created for community participation in working through the evidence in collaboration with researchers and practitioners. In this way, knowledge obtained through qualitative research shifts power relationships. Context also taps into the historical and geographical structures that privilege specific forms of knowledge, specific processes for making knowledge claims, and the specific forms of articulations that are acceptable (Dutta 2008).

2.3.1 The Politics of Qualitative Research

Who are the key stakeholders that participate in the evaluation, articulation, and interpretation of research results, and how are values tied to research situated within broader political structures? The answer to this question is complex. Morse (2006) notes that sometimes qualitative research is simply excluded from the agendas of funding agencies. The growth of the comparative effectiveness research movement around the world, however, shows more subtle political influences. Comparative effectiveness research is research that compares the benefits and harms of various approaches to the prevention, treatment, and monitoring of specific conditions or the delivery of health care, by synthesizing the results of all relevant studies on the topic of interest. Thus, the emphasis is at the population level, rather than at the level of the individual. While not specifically excluding qualitative research, the emphasis is clearly on the use of numeric data (Manchikanti et al. 2010; Meadows-Oliver 2009). One of the dangers of the comparative effectiveness research movement is the possibility that, because the voices of those from diverse communities are difficult to quantify, especially the voices of those communities at the margins of society, they will not be heard and therefore will not be considered in the development of the health-care agenda.

Attending to the politics of qualitative research is important because it foregrounds the political processes that make up the structures of evaluation and the corresponding structures used to develop policies. As a result, conversation turns to the location of research within political processes, and the traditional ideas about research being held at an objective distance from the political process are questioned. Now critical insights about the rubric of objectivity are clearer, and one may examine how such a rubric gets tied to the agendas of the power structures, such as private sector, large transnational corporations, and pharmaceutical lobbies (Dutta 2008). Understanding the politics of research also becomes an important organizing frame for identifying the political processes through which structural transformations may be sought, and complementary processes for dialogue and simultaneously exploring spaces of antagonism that include marginalized groups may be found.

2.3.2 Relationships in Qualitative Research

The political nature of qualitative research has implications for relationships within qualitative research. Qualitative researchers often work with both communities that are disenfranchised and structures in the mainstream in order to articulate entry points for change (Bungay 2013). Relationships between researchers and individuals from disenfranchised communities are unique because they are embedded in inequities of power and access to resources. Often the expectations that researchers bring to the table differ from the experiences and expectations of disenfranchised communities. Thus, it is important that these relationships are long term, starting long before the project and continuing long after its completion. Long-term relationships are needed in order to meaningfully identify the scope of problems to be addressed and to have the time required to collaboratively determine and then implement solutions that are evidence based, that are sustainable, and that will improve health practice. Time is also needed for qualitative researchers working with marginalized communities to negotiate the required relationships with the dominant structures they inhabit, such as institutional structures and expectations that are tied to these structures and the overarching attitude toward qualitative research within these dominant structures (Mauk 2008; Morse 2006).

2.3.3 What Counts as Evidence?

The political nature of qualitative research raises questions about the research questions that are asked, the research goals that are set up, and how these central features of a study fit the metrics for evaluating research that are often embedded within the dominant structures of knowledge production. When one chooses to conduct research with diverse communities, especially those from the margins of society, the research processes disrupt the normative Eurocentric assumptions that are built into research studies and into the broader academic understanding of what counts as evidence. When clinical data gathered through randomized control trials are considered to be the only framework from which to evaluate practice, the voices and ways of understanding communities at the margins are more likely to be excluded. For this reason, it is especially important to open up spaces for participation of disenfranchised communities in processes of establishing goals, parameters for measurement, and establishment of evaluative research design. In this way, the researcher is able to also open up the conversation about what counts as legitimate evidence from the standpoint of the community. For instance, when a community articulates the stories of heart attack experienced by community members as legitimate evidence, this becomes an entry point for acknowledging stories of heart health within the discursive space.

It is difficult to study questions of relevance to diversity in health care because the assumptions that guide the predominant research approach methods represent the biases of the status quo and devalue the voices of disenfranchised communities. Research approaches that question these assumptions open up spaces for other ways of knowing, for other ways of understanding and evaluating practice, and for adding these other ways of understanding and evaluation to a systematic set of criteria that engage the mainstream. This back-and-forth flow between the dominant structures in the mainstream and the spaces for articulating alternatives that are grounded in community experiences is vital to questions about evidence because they are both embedded in the community's lived experiences and are engaged with the expectations of the mainstream. For example, community-based focus groups for evaluating practice emerge as spaces for sharing community voices in conversation with each other, building on collective community responses, and working through differences that are articulated in the community. Such a method becomes open to understanding the different interpretations of practice and situating evidence within this diversity of different understandings, interpretations, and lived experiences.

What we see here is the central locus of lived experiences in understanding practice. Engaging in conversations about the nature of evidence offers a framework for democratizing knowledge and for resisting the disenfranchisement of diverse communities. Putting empiricism in context means that researchers work with communities in making sense of data, in interpreting data, and in connecting data to health practice that is rooted in social justice. A key part of this process is in building community capacities for participating in the research process for developing the evidence base. To the extent that diverse communities are able to participate in the discursive space in understanding evidence, in questioning it, and in attending to what is present and what is absent, opportunities are opened up for situating the evidence amid questions of diversity.

2.3.4 Evidence and Change

When working with evidence in partnership with diverse communities, evidence becomes connected to the politics of social change because the researcher works actively to funnel the research questions through the voices of community members' stories of their lived experiences. For instance, if African American community members were given opportunities to articulate their perceptions of connections between racism, stress, and heart health outcomes, the framework for evidence would also need to include issues important to them, such as racism and stress. The designs available to qualitative researchers are well suited for this process. New questions become possible, and these questions guide evidence-gathering processes that resituate the research process.

The broader framework of working toward building an evidence base also raises important questions of evidence gathering related to the structures and systems of health care, the structures and systems of health practices, and the outcomes that are associated with these structures and practices. For instance, guiding the framework for evidence-based practice toward questions of health-care systems, health-care costs, and the associated outcomes would mean that researchers would need to ask questions that fundamentally interrogate the capitalist framework of health care, the rising cost structure within this system, and the profit motives that fundamentally guide this system and then compare this system with other systems of health care.

2.3.5 Power, Evidence, and Health

Evidence-based practice in health-care settings is formulated under the assumption that the practice of health-care delivery can be shaped by the body of evidence that has been gathered by researchers. The impetus of evidence-based practice in health is driven by generalizability and the belief that generalizability is the cornerstone of scientific practice. When a limited view of what counts as evidence is held, the resulting practice ignores the central role of context and hence the fragmented, multiple, and often polymorphic layers of meaning related to health that diverse communities hold. The drive toward generalizability thus undermines the vital role of context as a guiding feature of practice and is antithetical to the notion of culturally sensitive practice. Moreover, from the framework of the culture-centered approach that notes the dynamic and emerging nature of culture, evidence-based practice approaches that attempt to take multiculturalism into account do so by incorporating culture as a variable, that is, measured by a fixed set of values, beliefs, and practices and treated as monolithic. This approach does not attend to the contradictory, competing, and often shifting nature cultures.

Qualitative researchers addressing health issues with diverse communities must make sure that community needs are introduced into the research frame and that community needs are articulated in the identification of problems for evidence gathering. In mobilizing for resources, qualitative researchers could work with community members to offer guidelines on key concepts to be mapped out and measured that take the lived experiences of community participants into account. In understanding the evidence and in connecting the evidence to practice, voices of community members could shape how evidence is incorporated into the realms of practice, foregrounding the local context within the realm of the evidence-practice linkage.

2.3.6 Qualitative Research in Neoliberal Contexts

Increasingly, as the global configurations of health have been constituted under the logic of the free market, large-scale inequalities in health outcomes have resulted from the growth-driven logic of development, simultaneously reducing public resources and minimizing state-driven welfare programs (Dutta 2011). Communities of color, communities in the global South, and poor communities have often been at the receiving end of neoliberal health policies that drive the hegemony of the market logic in the realm of health (Dutta 2008). Therefore, qualitative research plays a vital role in documenting the experiences of health at the global margins, documenting the ways in which poorer health outcomes have been produced as a result of the implementation of structural adjustment programs. Whereas large-scale quantitative data are unable to capture the struggles with poverty among the disenfranchised sectors, in-depth qualitative data can provide close insights into the lived experiences of the poor through thick description. Qualitative research, such as longitudinal in-depth interviews conducted over a sustained period of time, documents the contextual features of inequities and the ways in which these features are situated amid changing economic and political structures as nation states have liberalized. In documenting the lived experiences at the global margins amid the neoliberal shifts in global economics and politics, qualitative researchers could develop important alternate conceptual frameworks and evidence bases for interrogating the role of neoliberal policies in health and health care.

2.4 Using Qualitative Research About Diversity to Shape Health Practice

2.4.1 Qualitative Research as a Tool

Qualitative research can be used as a tool to shape practice by offering insights into the parameters of problems, scope of solutions, and the possible outcomes including practices (Hitchcock et al. 2005; Mills et al. 2005). Qualitative research also provides empirical evidence about the disenfranchisement of communities and sets the stage for evaluating the established sets of practices (Braithwaite et al. 2006). It is through qualitative research with marginalized groups that the researcher is able to obtain deep insights into both the inequities in health practices and the broader structures that constitute health (Doornbos et al. 2013). For instance, through an ethnographic study in which data were collected from five focus groups conducted with women from ethnically diverse and impoverished neighborhoods, Doornbos et al. (2013) and the focus group participants collaborated to articulate their important concerns about anxiety and depression. They offered insights into the opportunities for addressing the concerns, for mapping current resources, and for developing a framework for desired resources such as support groups, educational resources about anxiety/depression, and resources such as family/community activities, church involvement, and professional resources.

Highlighting the important role of context, the research on health inequities points toward an imbalance in the quality of care received by patients of different races in the United States (Kreps 2005). For example, in a study of various underserved groups including racial and ethnic minorities, the under- and uninsured, immigrants, homeless populations, ex-offenders, and incarcerated populations, Braithwaite and colleagues were able to identify gaps in services for underserved communities (2006). They also identified strategies for developing and improving health services, leveraging and building support for the health-care safety net, highlighting community needs and community-driven solutions, designing and implementing locally driven solutions, and building the evidence base to guide local, state, and national strategies. The impact of the community voice projects undertaken by Braithwaite and colleagues is evident in the model offered by the project for the federally funded Healthy Communities Access Program, the groundbreaking work with the community health workers program, and its advocacy role in bringing oral health, men's health, and prison health to the forefront of public health.

Historically, in evaluating policies and interventions, research has been understood primarily as a tool for quantifying outcomes (Hadorn et al. 1996). The ultimate expression of effective research in the context of practice has been the randomized control trial. Qualitative research, in comparison, offers thick descriptions that are rich accounts of the practices and events. Evaluators using both quantitative and qualitative approaches are able to build on the strengths of both types of designs. While researchers using quantitative data are able to provide numeric results often sought particularly in health-care system research, qualitative researchers are able to challenge the assumptions embedded in quantitative designs, add information about the social contexts through which quantitative data might be understood, and provide interpretive frames and meaning parameters to guide practice (Hitchcock et al. 2005; Mills et al. 2005).

The in-depth and open-ended data collection strategies found in qualitative designs provide a mechanism for showing the worldviews of disenfranchised communities. Such strategies place the perspective of disenfranchised communities within the research frame and point toward the limits of dominant configurations of practice. In my own work with disenfranchised indigenous communities of Santalis in Eastern India (Dutta 2004a, b), conversations with community members offered insights into the structural marginalization of Santalis and suggestions for developing health practices that addressed the basic needs of community members. The in-depth interviews also offered new conceptual parameters, such as corruption in the delivery of health care that provided directions for addressing the practice of health care for underserved communities in India. In this way, in-depth interviewing emerges as a guiding tool that foregrounds corruption in the health-care system as a vital element of health practice that needs to be addressed.

On a similar note, conducted focus groups and in-depth interviews in a community of poor and underserved Latinos and then led a community-based workshop among key stakeholders that identified mental health stigma, immigration-related stress, violence and alcoholism, and concerns about psychotropic medicines as the key elements of a mental health research agenda. Similarly, through in-depth interviews conducted with African American women residing in Chicago, offered insights into the processes of weathering experienced by African American women, narrativizing the stories of institutional racism and limited access to resources that in turn constituted in their relationship to heart disease. The twelve women who were interviewed by drew attention to the social context of heart disease, pointing toward the everyday experiences of racism, poor access to health, family disruptions, financial hardships, and environmental hazards as integral to the experiences of African American women with heart health. The stories shared by the women offered insight into the ways socially just practices could address the structural features of institutional racism and limited access to resources.

Finally, engaging communities at the margins in conversations through qualitative research counters the silencing of this population that is often built into the frameworks that dominate research (Basu and Dutta 2008, 2009). Specifically in the realm of issues of diversity where the concept of culture has often been treated as an exotic construct that acts as a barrier to the deployment of effective practice, conversations with community members become a way for inverting the logic of culture as pathology and for foregrounding the role of culture in the domain of science of practice. Foregrounding context in the research process shows the research process as a cultural artifact and leads to a closer interrogation of the assumptions and logic that make up the research process. For example, one may question the expectations that are tied to the design, deployment, evaluation, and publication of randomized controlled trials: how context emerges in the framework of randomized control trials, the implications of obtaining funding for randomized control trials from transnational corporations that manufacture the medications being evaluated in the trial, and how communities at the margins interpret these elements of context in their practices of health.

2.4.2 Qualitative Research as an Evaluative Mechanism

In a traditional sense, evidence-based practice in health settings has typically been associated with quantitative research and, more specifically, with randomized control trials (Meadows-Oliver 2009). The related outcomes of interest are based on an evaluation of the responses of a group of people who are given a new product, typically a medication, relative to those of a group of people who are not given the new product. The random selection of participants in the two groups is meant to remove bias from evaluation. Randomized control trials, however, are poorly equipped to offer explanations and insights into the results, an understanding of the patterns of observations, or an understanding of the barriers to practice. Qualitative research plays a key role in the context of randomized control trials by grounding the research in the voices of patients (Meadows-Oliver 2009). Specifically, qualitative research offers insights into the quantitative patterns of evidence that emerge. Here the role of qualitative research is complementary to quantitative research, adding insights to the quantitative data on effectiveness, providing additional information that helps us understand the quantitative data at hand as well as offering insights about culturally situated barriers to practice (Mills et al. 2005). In-depth conversations with participants offer additional insights into their lived experiences in the context of the practical solution, their experiences with the solution, and their in-depth views on the solution that was implemented. Through the interviews we come to understand the stories that circulate around the implemented solution. Now we not only have a picture of whether the solution works or not, but we also have a deeper understanding of how the solution is perceived, which parts of it work, which parts of it do not work, and the underlying reasons for why the solution does not work. In a nutshell, through qualitative research, one is able to obtain greater insights about the practice from the standpoint of the intended recipients.

In settings of diversity in health care, there are situations where qualitative research emerges as the principal method of evaluating practice because it opens up the ground for understanding the lived experiences of community members. Community voices engaged through qualitative research offer the framework for asking research questions, developing research design, setting up expectations, and establishing evaluative frameworks for measuring the practices in the backdrop of expectations. In the context of a community that has been historically disenfranchised, community members foreground the importance of their stories as legitimate axes for engaging with practice, and it is through these stories that alternative insights can be gleaned into existing practices, and new opportunities for offering health and health services can be explored. In such instances, quantitative research is rejected because it represents the status quo and fails to adequately include marginalized voices. Resisting the impetus of research that privileges numbers and undermines stories, community participants may tell stories that are locally grounded as legitimate frameworks for evidence. In addressing the question of quality of data in evaluating practice, Beck (2003) suggests the important role of meta-syntheses of qualitative studies. Meta-synthesis can play an important role in generating results useful for evidence-based practice by making the results generalizable to a more diverse population (Flemming 2007a, b). Whereas generalizability is often seen as central to guiding the development of evidence-based practice, its restrictive focus may exclude those in settings of diversity.

2.4.3 Qualitative Research as Advocacy

When it comes to questions of diversity in the realm of health, qualitative researchers are often working on processes that are shaped by the acknowledgment of fundamental differences in access to health-care resources. These inequities become the basis for research. Here, health research is driven by an advocacy agenda that seeks to disrupt these material differences and bring about structural transformation, as the research is materially situated amid the inequities that constitute the field and is constituted amid the structures of power that underlie the material inequities (Dutta 2008, 2011).

To be transformative, research has to be driven by a transformative agenda. The relationship with evidence-based practice is situated at the nexus of research and social change, working with research design, research instruments, and reporting tools in order to bring about changes in unequal social structures that result in inequities in health. This nexus becomes a point of departure from which researchers may question the very research design, research tools, and research frameworks they utilize in working with disenfranchised communities. The qualitative research paradigm accommodates a transformative agenda because the various designs included in this paradigm have philosophic underpinnings and data collection strategies one may use to uncover structural inequalities where they exist. For example, community voices can interrogate the fundamental question of what counts as evidence and what is considered as legitimate in their worldview (Braithwaite et al. 2006). Through the power of their stories, communities shape our understanding of evidence. Community voices further capture the inequities in the structures of accountability, insisting that research be accountable to the community and to the stories shared by community members. The evaluation of evidence-based practice within this framework links practice and structure by answering questions like "Did the solution being offered transform the structures of inequity?" Engaging structure in conversation practice is a new avenue for thinking about evidence because it uncovers the links between practice and structure and provides information about how they may be related. Research is thus a tool for advocacy that speaks with the community and addresses structures raised by the community that influence inequity. Each voice matters, and together these voices help to transform structures that are related to inequities in health.

2.4.4 Qualitative Research as a Vehicle for Transforming Structures That Constrain Health

Qualitative research offers a framework for investigating the way research gets defined and the issues of power that are tied to the framing of research questions and research design. In addressing practical problems of health and diversity, the qualitative design should be selected with the outcomes of the study in mind. In this sense then, the role of qualitative research is intrinsically tied to practical questions of social change, social justice, and structural transformation. In addressing issues of diversity through policies and programs, qualitative research can play an integral role in determining whether diverse voices are included, represented, and recognized. In asking questions of representation, qualitative research provides insights into the processes through which opportunities of representation are created and delves deeper into these processes through thick descriptions. For example, in-depth interviews conducted with the developers of an organizational equity program could shed light onto the processes through which the program is implemented, the effectiveness of the program in addressing issues of equity, and the challenges and barriers faced by the program during its implementation. In this case, setting up criteria such as representation, participation, and engagement of minority voices in the discursive space can work within the research design to offer evaluative insights regarding the program and could also work toward developing iterative cycles for improving practice. Most importantly, in the context of disenfranchised communities that are often left out of discursive spaces of research, policy making, and program development, qualitative research creates entry points for introducing new categories and frameworks that are rooted in the lived experiences of communities.

Yet another question to consider is the extent to which the voices of community members are represented in the development of criteria for assessing effectiveness. Having community voices recognized in discussions about research design is transformative because it challenges the structures that have implicitly excluded these voices in the past. Here, the context of disenfranchisement from processes of knowledge production is directly challenged through the participation of community members in shaping the research design, and thus the inequalities in production of knowledge are actively reworked through the participation of community members in research processes. Communities are empowered to participate in decision-making processes, in shaping what would count as evidence and how such evidence would be gathered, and in developing frameworks for gathering evidence, considering it, and shaping the nature of practice.

2.4.4.1 Transformational Designs

Qualitative researchers working in contexts of diversity in health settings have to consider the types of design that would create the most opportunity for the context to be visible in the qualitative work. The more open the design in the initial phase, the more sensitive it would be to the articulations of the community and to the emerging context. This is important because experiences of disenfranchisement often only come to light only through conversations with community members. In such instances, going into the community with a preconfigured design might be limiting, as the researcher may not fully understand relevant contextual features before entering the community. Power, reflecting the differentials in access to frameworks of knowledge production and decision-making, emerges in design through the conversations with community members. On the one hand, power shapes the relationships and the terrains of relationships within which the practice research is understood, implemented, and evaluated. On the other hand, research with diversity and health often seeks to express the linkages of power that constitute, marginalize, and erase experiences of health. This forms a cyclical relationship, as the study of the dynamics of power is itself constituted amid relationships of power. The tension between keeping an open framework and the assigned expectations of preconfigured rigor is difficult to manage and thus requires ongoing negotiation between the qualitative researchers and the disenfranchised community. Reflexivity becomes an important tool in engaging with questions of power and in studying the ways in which power emerges in qualitative work. Through the tool of reflexivity, researchers turn the lens on the institutional practices that dictate the parameters of design, thus being able to interrogate the key assumptions that are built into research design and the ways in which these assumptions shape, enable, and constrain the research process. It is at this intersection of understanding the research design process, the articulations of the dominant structures, and the expectations of marginalized communities that qualitative researchers can work toward challenging the unequal structures of power. The presence of marginalized communities as collaborators is a first step toward inverting the imbalance.

2.4.4.2 Transformational Design Collaborations

When working with issues pertaining to diversity, the relationship between the communities and researchers can be seen as one of collaboration, one that works through the many layers of power, access to resources, and understandings that communities and academics bring to the table. Working through collaboration also points researchers toward questioning the logics with which they design research processes. In our work with African American communities in Indiana on developing community-grounded capacities for engagement with comparative effectiveness research on heart disease, we have witnessed the many instances where the expectations of the academic partner have been out of touch with the articulations of community members. In such instances, working through a collaborative framework calls for continually responding to community articulations and jointly putting together design processes that are mutually agreed upon. In this sense, when academics share their understanding of research and evidence-gathering processes with communities, the process itself becomes open to conversations and inputs from multiple stakeholders. When community voices comment upon the research process, their articulations become valuable entry points for co-constructing the research process, working through the basics of design, setting up expectations, and then connecting the metrics of evaluating evidence to these expectations. In doing so, the framework of what counts as evidence is disrupted from the dominant structures in the mainstream. Further, the collaborative spaces that are created through academic-community partnerships also become entry points for engaging with the evidence base. For instance, clinical data gathered through randomized control trials or case studies can be introduced into these collaborations as topics for discussion, thus offering contextual data and creating the space for communities at the margins to offer contextual insights in understanding the clinical data.

2.5 Challenging Structures

Research on evidence-based practice is most relevant in the realm of diversity when it seeks to transform the structures that make up the fabric of health (see Basu and Dutta 2008; Bungay 2013). This sort of transformation calls for a fundamental rethinking of the practices of health, asking researchers and practitioners to interrogate the very frameworks through which they come to understand health practices (Dutta 2008; Ford and Yep 2003; Sharf and Kahler 1996). Take for instance, research on evidence-based practice of health campaigns targeting underserved communities encouraging them to eat five servings of fruits and vegetables discussed earlier. Such research is limited when it does not fundamentally address the structural issues that make up the unequal distribution of food resources in communities, the commoditization of food, and the large-scale inequities in access to food. To be transformative, evidence-based qualitative research would need to move toward working with community voices to highlight that which is present and to more critically interrogate that which is absent, thus foregrounding the structures that make up health.

Qualitative research plays a key role in not only foregrounding the stories that are presented through the interactions between the researcher and her/his participants, but also in asking questions of omission, in interrogating that which is absent, and in working with communities in articulating these erasures, foregrounding them in policy and program discourses and in working toward solutions that are constituted in these gaps. In asking these questions of omission, qualitative researchers are uniquely positioned to work with disenfranchised communities in pushing for new imaginations and for new ways of conceptualizing health practice, in engaging with dominant understandings of health, and in challenging the basic assumptions in these understandings. Unlike quantitative research that has to depend upon existing frameworks to test them, qualitative research offers an opportunity for forging new ground, for suggesting hitherto unimagined possibilities, and for suggesting the ways in which new practices can be created and/or existing practices can be reimagined.

In working with social contexts that document the everyday experiences of marginalization in diverse communities, qualitative research becomes activist in nature (Dutta 2008). The line between empirically driven research, structural transformation, and politics of change becomes blurred as researchers work within a broader framework of seeking to achieve social justice. Rather than erase their subjective positions as participants in the journey under the guise of objective distance, qualitative researchers find themselves in a position where documenting the social contexts of disenfranchisement also comes with the moral imperative to work toward changing the structural oppressions that produce the various forms of disenfranchisement. The role of research then becomes not only one of documenting the inequities and examining the ways in which these inequities configure in health practices, but also in working toward changing the very social contexts within which the research endeavor is located. Through a wide variety of strategies that range from dialogues with the dominant structures to participation in antagonistic processes that directly interrogate the structures, the ethical responsibility of the qualitative researcher becomes intertwined with the goals of structural transformation in ensuring greater access to health and health care.

2.6 Conclusion

This chapter documents the cyclical relationship of context and research. At once, context is embodied in research as the framework that defines the realm of acceptability, the organizing of the research methods, and the ways in which methods are evaluated. Simultaneously, context emerges in the voices and stories shared by researchers. In working with contexts of marginalization in diverse cultural settings, qualitative researchers grapple with the ways in which they work with evidence to create transformative opportunities. Recognizing the role of privilege in constituting the framework of research, qualitative researchers explore the ways in which this privilege can be simultaneously interrogated and catalyzed in building the health capabilities of diverse communities.

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3 Examining Qualitative Alternatives to Categorical Representation: The Case of Culture and Health

M. Judith Lynam

3.1 Background

The interest in understanding culture and intercultural relationships is particularly salient in societies such as Canada because historically its population has grown and diversified through immigration. As such, in Canada as elsewhere, culture has been a substantive focus of research in many disciplines including the social sciences, education, and health. Qualitative research and the theorizing that has arisen from it have made significant contributions to the ongoing dialogue on the nature or meaning of "culture" and how it shapes and is shaped by a number of social forces (Anderson et al. 2007; Bhabha 1994; Bourdieu 1987, 1990a, 1994; Chen and Morley 1996; Giddens 1997; Lynam 2007).

Qualitative methods are well suited to understanding culture and cultural influences on behaviors or practices in many contexts in part because qualitative researchers are not limited to the use of tools validated for different groups and languages and because the inductive nature of the data gathering and analysis process allows the researcher to not simply confirm the existence, prevalence, or incidence of predetermined categories, thus providing an opportunity to question or reframe concepts. Qualitative research methods have not only offered a *how* to researchers but have also generated insights to refine and extend theorizing about culture and cultural influences. It is the richness of this duality of method and knowledge development that qualitative research offers to researchers seeking to understand the complexity of culture and the myriad of ways it influences our day-to-day lives.

A concurrent concern for qualitative researchers in recent years has been how our analyses are positioned in the broader discourses on the nature of evidence, or evidence-based practice. In the last decade, clinicians and decision-makers have been challenged to enact evidence-based practice and evidence-based decision-making, which has also underscored the importance of research to practice. However, this trend has also prompted considerable debate about the nature of evidence. As Killoran and Kelly (2010) have observed in their analysis of the discourse on evidence-informed policy-making in the UK,

> Development of the evidence base in public health has been both hindered and promoted by the parallel rise to prominence of evidence-based medicine. On the one hand, evidence-based medicine has established the value of evidence in the minds of many practitioners and managers […]. On the other hand, the perceived dominance of particular research designs, particularly the randomized controlled trial, in evidence-based medicine, may have focused attention towards public health research

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> on the proximal rather than the distal causes of public health problems.
> (Killoran and Kelly 2010, p. 18)

These authors' analyses of the complexities of the policy-making process underscore the need to understand and consider context in which decisions are being made while also illustrating the range and nature of evidence that may be drawn upon to inform decisions. They propose "understanding the influence of different circumstances on effectiveness implies comparative research across a range of settings as well as the need to employ qualitative and quantitative research methods" (p. 19). Their stance is in keeping with my view that insights generated through qualitative analyses—particularly qualitative analyses that move beyond description—can extend or enrich understandings and produce evidence that has the potential to make significant and unique contributions to practice and policy-making. In what follows, I draw upon my own program of research in health as a point from which to illustrate ways qualitative methods have contributed to our understanding of culture. I will illustrate some of the ways qualitative methods can be used to address issues that have arisen as researchers have sought to consider culture as a variable in research and issues that have arisen as practitioners have sought to act on research insights related to the conceptions of culture.

To achieve these two aims, I offer a brief overview of the ways in which qualitative research has shaped our understandings of cultural influences on health and then consider some of the problems, particularly the problems associated with categorization and representation that have arisen as culture has been taken up in research and practice. I follow this with examples of ways in which qualitative methods are used to minimize or address the identified issues. In the process, I illustrate ways qualitative analyses contribute to knowledge development and produce evidence or insights to inform the decision- and policy-making processes.

3.2 Conceptualizing Culture and Health

In the past several decades, qualitative research has made significant contributions to understanding culture as an influence on health and drawn attention to culture as a consideration for how health services or health care may most effectively be delivered. Kleinman and colleagues' (Chrisman and Kleinman 1983; Eisenberg and Kleinman 1980; Kleinman et al. 1978) analyses have been informed by, and have informed, social science theorizing. Their research and the conceptualizations developed from it have been influential in expanding our understandings of health and health behaviors to include the recognition of such cultural influences as knowledge, history, and traditions as well as the organizational features of society that sustain cultural practices. These scholars' work has also challenged us to extend our thinking about the culture concept beyond geographical and political boundaries. For example, their analyses of medical practice made visible the ways the premises of biomedicine shapes how physicians and other health professionals view and approach professional practice, and perhaps more importantly, their analyses sought to broaden the theoretical underpinnings of health professional practice beyond biomedicine by focusing attention on the relevance of the social sciences to medicine (Eisenberg and Kleinman 1980). Kleinman's explanatory model (Kleinman et al. 1978) concept offers an alternative to the "categorical representation" of culture and has been drawn upon by scholars to illustrate why patients and professionals might understand, explain, or manage their health condition in different ways. These insights have provided the conceptual foundation for the development of educational and practice resources to guide professional engagement with patients (Waxler-Morrison et al. 1990; Waxler-Morrison and Anderson 2005). Such resources have been influential in refining professionals' understandings of the health professional culture and understandings of patient populations.

However since the 1980s a number of scholars in Canada's multicultural context, as elsewhere, began to question the ways in which the concept of culture was being drawn upon by researchers and practitioners. The questioning was prompted by a number of observations including the following: in many contexts the way the concept of culture is understood and has been taken up in research and practice tends to represent the more narrow view of culture as beliefs and values; many studies, in the ways they are designed or presented, reduce the concept to a single variable or descriptor, thus stripping away context; many analyses do not consider the assumptions inherent in the categories used to represent culture or cultural positions. Such categorizations or representations may not only infer that all people who share particular characteristics share the same viewpoints and traditions but also that they may conflate culture with such categories as ethnicity, geography, color, or 'race'. A central concern is that of categorical representation associated with such analyses. Such issues need to be considered by researchers working in qualitative and quantitative methodological traditions.

Considerable scholarship has been devoted to explicating and examining the issues identified. It is beyond the scope of this chapter to provide a comprehensive review of this work here. Instead, in what follows, I will draw upon the work of scholars from a number of disciplines to illustrate the problems associated with categorical representation. I then propose a number of ways qualitative research can be undertaken to provide alternatives to categorical representation.

3.3 The Problem of Categorical Representation

While there are many different ways individuals or groups may be categorized or represented, I will use the substantive focus on cultural categorization or representation as my point of entry to this examination. My interest in this topic has evolved out of a dual interest in understanding cultural influences on health and exploring this substantive focus using qualitative methodologies. In my case, as I have built my program of research, these dual interests have informed one another, and over time, new insights have prompted a shift in my conceptualization and theorization of cultural influences on health. This research and my reflections on it have informed the refinement of the qualitative approaches and analytic strategies I use. My research interests arise out of a spirit of inquiry and an interest in generating knowledge that may ultimately influence how we—researchers, health professionals, communities, and policy-makers—take action to address inequities in health.

Why, then, have I come to the view that categorical representation is potentially problematic? The conceptualization of culture as an objective category has received considerable attention and critique. In some of our earlier work, we drew attention to one of the issues inherent in categorization, "rather than being static and neutral, [culture] is continuously being negotiated and re-defined within different contexts" (Lynam et al. 2007, p. 24). The dynamic nature of culture is in opposition to the process of categorization because the latter is, by definition, static. Thus, categorical representations cannot explicate contextual influences or capture the dynamic nature of the concept and its meaning to people.

The importance of context is underscored by many scholars. For example, Anderson (2004) and colleagues (Anderson and Reimer Kirkham 1998) observe interpersonal relations and the traditions or conventions that shape them to be historically constituted. Their analyses guide us to consider the ways colonial relations and racial hierarchies shape how we understand culture and its role in society. Similarly Culley (1996), writing in the UK context, notes that the emphasis on culture (typically understood as beliefs and values) as the explanation for variations in individual or population health profiles:

> [….] plays down or ignores the importance of power, inequality and racism as embedded in structures or institutions—factors which fundamentally

> affect the health of minority ethnic groups and their access to good quality health care.
> (Culley 1996, p. 566)

These observations recognize contextual influences on what we experience in different social contexts and draw attention to some of the consequences of categorical representation.

Browne (2005) extends this commentary on the use of culture as an explanatory variable and draws attention to the implicit assumptions inherent in such forms of categorization. Here she not only notes that culture or particular cultural features are equated with social problems but also contends that implicit in this practice is the notion of culture as characterizing intrinsic attributes: “equating social problems with cultural characteristics is not uncommon in health-care discourses… [C]ulture is often given as the primary explanation for why certain people or groups experience various health, social or economic problems” (p. 75). These analyses focus attention on why cultural categorization and representation can be problematic.

Kirkham and colleagues (2002) focus attention on methodological considerations in critical scholarship. They draw upon Pfeffer’s (1998) work and note that the categorization of individuals into groups creates the problem of essentialism. They propose that analytic processes and associated discourses that fix people into immutable cultural categories do not take into account the “dynamic and shifting nature of people’s identities which intersect with class, ethnicity, gender, religion and many more cultural configurations” (Kirkham et al. 2002, p. 227; Pfeffer 1998, p. 1383). Such categorizations and the assumptions that underpin them can lead to erroneous conclusions such as those that place the blame of poorer health or socioeconomic status on ethnic minority groups’ biological characteristics or sociocultural behaviors. Such an approach conveniently avoids and thus “denies the significance of the political and structural aspects of society and ultimately makes culture itself problematic” (Culley 1996, p. 566).

In examining or seeking to explicate contextual influences, I have found drawing upon critical theoretical perspectives useful. For example, Bourdieu’s (1990a, 1994, 2001) theoretical stance and empirical work illustrates the implicit value of particular categories and makes manifest the processes that contribute to sustaining their meaning. His conceptualization of the social processes that construct notions of what is valued offers guidance on what is potentially problematic with categorical representation. His work offers insight into how particular social traditions, practices, and representations shape and reinforce societal conceptions through discourse and institutional practices. As his analyses illustrate, such conceptions inform prevailing conceptions of “good” art, “high” or “low” culture, who or what work, and/or what social roles hold social value. I have found that such theoretical tools can prompt us to critically reflect upon categorical representations and to consider them within context.

The processes of representation and categorization are informed by tacit, and therefore largely unquestioned, assumptions about individuals and groups. As Bourdieu (1990a, b, 1994, 1998, 2001; Bourdieu et al. 1999) has observed, organizations, institutions, and societies rely upon such taken for granted representations and the associated rules, conventions, and practices that sustain them. In my work it is particularly important to illustrate the ways such organizational structures and associated practices maintain the status quo because of the tendencies that privilege some over others. Bourdieu’s analyses, like the work of many scholars working in a critical tradition, illustrate the types of policies and practices and the discourses associated with them that locate particular groups on the social margins and, in doing so, offer another perspective on observed patterns or practices. In addition, some of his analyses have drawn attention to the potentially toxic impact of such implicit practices, and he observes that individuals can become complicit or accepting of the ways they are represented and thus be unaware of their privilege or potentially contribute to their own oppression, “[w]hen marginalization becomes part of the order of things, it deprives one even of the consciousness of exclusion” (Bourdieu et al. 1999, p. 153). Thus, research that enables the critical examination of processes of categorization and their consequences can generate understandings that may be drawn upon to shift or disrupt the status quo.

Similarly, critical feminist scholars have illustrated the tacit and manifest assumptions that operate to contribute to the differential social location of women in societies. Critical feminist perspectives guide us to explore the conditions and practices that are implicit in gender categorizations and to examine the ways such categorical representations are maintained or disrupted. Moreover, some scholars contend that when the concept of culture is constructed using discourses of difference, such analyses are implicitly privileging the western worldview and may contribute to "othering" by reinscribing or reinforcing the social organizational practices that structure relational hierarchies (Bhabha 1994).

While I seek to reduce my reliance on categories, and the harms associated with their use, as a researcher I find I must continually reflect upon how my work is framed and how it is understood. For example, ethnicity is a category frequently used by researchers. In health-care contexts it has been noted that "ethnicity tends to be conceptualized very narrowly, and is often used as synonymous with 'race'" (Drevdahl et al. 2006; Ford and Harawa 2010; Ford and Kelly 2005; Varcoe et al. 2009). Thus, in my work I try and contextualize descriptions of populations. Where possible, one way of doing this is to shift the terms employed in order to open up space to present the issues of interest. Recognizing that it too is a category, my analyses have typically used the descriptor of "immigrant"—as opposed to "ethnicity"—to shift the focus away from a culturalist emphasis on the beliefs and values of particular ethnocultural groups. My intention in using this phrasing is to highlight the contextual (e.g., legal rights, employment opportunities or constraints, and health service access) and social consequences (e.g., social isolation, language barriers) associated with migration that can have an impact on health. However, I have also learned that, while discourses of categorization about immigrants may be pervasive and do influence individuals' experiences, their impact is not always evenly felt. Some immigrants, even those who share a similar ethnocultural background, may have significantly different resources to draw upon to protect themselves from adversity, such as diverse community networks, better education, superior English language skills, or more material resources. Such observations have reinforced the need to be attentive to the ways research analyses are undertaken and outcomes are presented.

In addition to capturing data in categories, we must attend to the ways in which we draw upon such categorical representations. For example, a prevailing discourse in health relates to the "social determinants of health." This phrasing implies causality when the majority of the researches are informing it is derived by correlating particular health or illness profiles with a variety of social and environmental conditions such as income, ethnicity, level of education, profiles of housing, and food security. While there may be strong correlations, as Killoran and Kelly (2010) have cautioned, the etiology of the effect is not always evident from such studies. Nonetheless, the use of the terminology "determinants of health" represents the associations between categorical representations of particular groups of people and poor health in the language of causality. On the other hand, more contextual analyses can and have prompted researchers to reflect upon the causal pathways decontextualized analyses can imply. More contextual analyses have the potential to consider multiple influences and, for applied researchers, to consider the points of engagement (e.g., at the point of care, in framing policy) to redirect such trajectories. On these points Williams (1989) had the following observations:

> Although the step forward taken by ethnicity researchers was to examine culture from the immigrant's point of view and in a positive light […] and to establish the reality of a multi-racial society, nevertheless, looking at "minority-majority" relationships in a cultural framework excludes vital elements in the relation of "race" to class and power, and institutionalized racism. This means, however sympathetic the cultural appreciation it can still skew the analysis and "blame the victim." (Williams 1989, p. 92)

Part of the allure of categorical representation is that it can be readily quantified or reproduced as "facts" which may, albeit unintentionally, lay a foundation for stereotypical claims. Concerns about the issues associated with representation are not only voiced by scholars: Varcoe and colleagues (2009) critically examined the processes that underpin the construction of categories and undertook research that sought perspectives on the processes of collecting ethnicity data in a clinical context. Their work gives voice to the types of concerns such forms of representation raise for patients and professionals.

The harms these study participants identified included being judged on the basis of assumptions and stereotypes and the possibility of receiving poorer care based on such judgments. Participants expressed their concerns in relation to groups they thought are likely to be vulnerable to the effects of inequities and racialization, such as Aboriginal people and visible minorities. Many were concerned that ethnicity data could influence health-care staff to reinforce stereotypes that link certain health behaviors to particular groups (Varcoe et al. 2009, p. 1663). As these authors note, there are concerns about the potential consequences of categorical representation as well as the processes by which such data are gathered.

Many research processes can, through data gathering processes, require individuals to self-categorize. What is not always evident is that such processes may close off opportunities to contextualize oneself. Through self-categorization the participant may unwittingly surrender his or her opportunity to examine or reflect upon the assumptions that are implicitly and explicitly associated with the category. Moreover, depending upon the nature of the analysis produced from such data, the categorical representation may essentialize or strip away context and, in doing so, assign or confer identity. It is therefore important, when we present our study, when we invite participation, and when we undertake our analyses, that we work to anticipate and consider how our own assumptions are operating to create opportunities for dialogue.

Although I have focused particular attention on categorical representation as a product of research, as the preceding comments suggest, such representations are also part of popular day-to-day discourses. Formal and informal day-to-day discourses are "structuring devices, and as such shape and frame interactions" (Lynam 2006; Traynor 2004). Discourses are not neutral; thus, representation holds meaning and can create conditions that foster privilege or disadvantage. For example, racialization on the basis of categorical representations implicitly and explicitly confers meaning and can contribute to marginalization. Categorical representations, the assumptions that underpin them, and the impact they have on social interactions merit critical appraisal (Anderson 2004; Varcoe et al. 2009). Qualitative methods offer such analytic tools to undertake such work not only to offer alternatives to representation in how research is presented but also because such analyses may be drawn upon to challenge or disrupt prevailing and problematic discourses.

In categorical analyses, the researcher may present individuals in relation to particular attributes or features and/or presumed affiliation with a group which can have the effect of masking individuals' personhood and in some analyses usurp or mask the individuals' agency. For example, in research we are engaged in with families living in the inner city (Lynam et al. 2010b), parents spoke of the harms of "judgements associated with particular categories of representation" and spoke of the consequences that can accrue when they are "prejudged" and have lost the capacity to give "voice" to their own story or situation.

> Parent: "I don't want to be pre-judged."
> Researcher: "Can you talk a bit more about that?"
> Parent: "Well I—I lived on the streets for 18 years—and I remember just going and talking to the social worker and she's all dressed up nice and nice rings and it was just like totally like she was from another world and so, yeah, so I try and I don't know."
> Researcher: "So you couldn't relate?"
> Parent: "No."
> Researcher: "And you felt that she was judging you?"
> Parent: "Yeah, and for a mum to go and ask for help anywhere is tough … so [if] somebody's looking down her nose at you—I'm out of here." (Parent focus group)
> (Lynam et al. 2010b, p. 338)

In this quote the parent speaking helps us to understand the complexities of help seeking. It also illustrates ways categorical representation can operate; here the mother perceives herself to be "pre-judged." But in approaching the encounter with a social worker, who is the point of connection with an institution with a particularly powerful and potentially very threatening mandate, the parent also looks for clues that might signal there are potential points of understanding. Here, "dressed up nice and nice rings" underscores this parent's marginal position and signals to this parent the professional was from "another world."

As the preceding review suggests, scholars working within a number of scholarly traditions remind us that categorical representation can reduce or constrain our ability to understand contextual influences which can have a number of unintended consequences for individuals and groups. As we move forward, it is important for us to recognize that categories themselves are social constructions.

3.4 Enacting Qualitative Methodological Approaches: Creating Alternatives to Representation and Categorization

In this section of the chapter, I seek to answer the question: In what ways can qualitative approaches and analyses offer alternatives to categorical representation? In responding to this question I hope to demonstrate that qualitative research can offer richer, more nuanced, contextual and meaningful analyses to inform knowledge development while also allaying the potentially negative consequences of categorical representation. I also hope to show that my interest in this objective influences the theoretical stance I have adopted and that this theoretical stance has shaped how I have designed my qualitative studies and interpreted the results.

As noted in the preceding section, there are a number of consequences to categorical representation. Here I draw upon my own program of research to share insights on ways that qualitative research can contribute to knowledge development while also avoiding these consequences. The examples are organized to follow the research process, from conceptualization to presentation of the analysis. There is, however, overlap between sections that reflects the iterative processes that characterize qualitative research. I begin by introducing the central premises of the theoretical stance and general aims of my research program. I then draw upon this stance to illustrate how tendencies to categorical representation can be countered.

Theoretical stance: In my case, my research is informed by critical theoretical perspectives (Anderson et al. 2007; Lynam 2009, 2010; Lynam et al. 2007, 2012a, b). This theoretical stance not only informs the ways research is designed and the analysis is undertaken but also aligns with the goals of my scholarship which, broadly framed, seeks to understand and address inequities in health (Lynam 2005). Critical theoretical perspectives are characterized by particular premises that focus attention not only on the research aims but also on the relationship of study participants to the research.

In what follows, I focus attention on those premises I believe are particularly relevant when seeking to counter the negative consequences of categorical representation. The premises include voice, agency, person, presentation of analyses that focus on explicating concepts, context (including making visible implicit and explicit assumptions that are operating), and processes (as alternatives to "dichotomous categories") in how the study is designed and the analysis is undertaken and presented (Anderson 2004; Bhopal 2001; Drevdahl et al. 2006; Ford and Harawa 2010; Ford and Airhihenbuwa 2010a, b; Gerrish 2000; Olesen 2005).

Like other scholars whose research is informed by a critical stance, my program has a number of goals that align with these commitments to voice, agency, and person. I have elected to focus on these particular goals for, in achieving them, research may address or avoid many of the negative consequences of categorical representation. One goal is to introduce the viewpoints or perspectives of those on the social margins. The intention is to include people whose viewpoints are not reflected in, or who are the object of, prevailing discourses or representations. In many cases the persons of interest are people broader discourses may have discredited (Fiske and Browne 2006; Tang and Browne 2008). Using a critical stance to understand the viewpoint of people on the social margins necessitates that the analysis considers how formal and informal power is manifested and drawn upon (Browne et al. 2000, 2011; Ford and Airhihenbuwa 2010a, b). A second goal is to make manifest the assumptions that underpin organizational and institutional processes and practices, including categorical representation (Anderson and Reimer Kirkham 1998; Bourdieu 2001; Bradby 2012; Drevdahl et al. 2006; Lofters et al. 2011; Varcoe et al. 2009) and trace the range and nature of their impact. This form of analysis may enable us to draw upon the data to introduce alternative viewpoints or perspectives and, in doing so, begin to disrupt, broaden, call into question, or prompt reflection on the prevailing viewpoints, including how particular groups are represented (Lynam and Cowley 2007; Perry et al. 2006). A third goal is to generate analyses that may foster "dialogic engagement" to effect a change in the status quo (Anderson et al. 2007; Lynam 2009). *Methodological techniques* for upholding these commitments and achieving these goals as research include the use of reflexivity and critical reflection.

3.5 Critical Reflection and Reflexivity: Analytic Tools and Resources

The researcher plays an integral role, as an instrument, in the qualitative research process. Thus, there is no standard way to enact qualitative methods. As has been clearly articulated by many scholars, it is essential we explicate the premises of our practice and illustrate how we have proceeded to undertake our work in order to illustrate how we have upheld commitments to integrity. As many authors have noted, key considerations in enacting qualitative methods, particularly qualitative methods informed by critical theoretical perspectives, are the processes of *reflexivity* and *critical reflection* in framing the question as well as in gathering and analyzing data (Anderson et al. 2010; Khan et al. 2007; Olesen 2005). While the two concepts are related, I distinguish between them in that reflexivity draws upon my own professional and experiential knowledge domains and the assumptions inherent in them, whereas critical reflection extends this focus to include the examination and explication of assumptions that underpin other conceptual and organizational premises and practices. In what follows I illustrate how these two strategies inform the research process.

As researchers our viewpoints become integral to and resources for data gathering (Olesen 2005). She also cautions, however, that "researcher reflexivity needs to be tempered with acute awareness as to the contributions of hidden or unrecognized elements in the researchers' background" (p. 251). In my work, I am acutely aware that my gender, my professional background, my critique of the limits of biomedicine, my knowledge of social theory, and my commitment to social justice create the foundation on which I have framed my research questions and my interest in broadening discourses on health. At the same time, through my research, I have become increasingly aware of the limits of my knowledge of concepts salient to this program of research. Such concepts include, but are not limited to, oppression, racializing processes and practices, and social and material disadvantage.

I have come to understand, however, that my *capacity for reflexivity* is enhanced when research data "confronts" me with my own privilege or the limits of my knowledge, such as my profession and my stature in the academy. For example, I am knowledgeable of how health systems function and can engage clinicians in a dialogue about symptoms, diagnosis, and treatments. I am aware of my rights when accessing health care and/or health information. My professional and personal knowledge has generally enabled me to "activate" the Canadian health-care system and I have knowledge that allows me to make sense of the system. Thus, in a research interview when I hear about problems of health services access, learn that access is constrained not only by what a particular clinician may do, and appreciate the legacy that individuals' experiences have had in their encounters with clinicians, I begin to reexamine my assumptions and contrast my knowledge of how systems operate with others' experiences, in order to enrich the dialogue and discourses on "access." When my own assumptions, viewpoint, or knowledge are "confronted" by apparent contradictions, *reflexivity and critical reflection become analytic tools*.

Similarly, when engaging in dialogue with the community in order to lay the foundation for a community-based research study, I found I had to "resist" defending the system on the basis of what I understood, assumed, and believed. Rather, using critical reflection, I began to explore the apparent contradictions between my own experience and the experiences of community members that helped to make visible the source and nature of my assumptions—institutional, professional, or middle class—and then to trace how they operate to influence access to, and the responsiveness of, care. In undertaking analyses we draw upon data to ask questions of our own understandings. How does this information prompt me to rethink my initial preconceptions? Such questioning may take place at the outset of a study when we are articulating the study purpose or aims and continues over the course of the research. In this case, this reflection began to highlight the extent to which the "systems" and the assumptions that underpin them aligned with my own viewpoints while illustrating the disjuncture with the experiences of many community members. As a researcher then, in this case I am charged with drawing upon this data to conceptually make sense of the range of potentially conflicting viewpoints and drawing upon these perspectives to address the question of access.

Reflexivity is related to, but differs from, critical reflection as an analytic strategy. As noted above, one goal for knowledge development in the critical tradition is to trace the ways assumptions operate. In this work the interest is not only in explicitly stated assumptions but also in tacitly understood assumptions. The latter can be very difficult to apprehend and thus present analytic challenges. Critical reflection, on representations, on typical patterns and practices, and on the conditions that influence them, is aided when the literature reviewed or the data gathered points to or illustrates disjunctures between what is "officially" stated (e.g., in policy or procedures) and what is actually practiced, experienced, or manifested in day-to-day discourses. These disjunctures can offer the starting point for critical reflection on the topic or issue and provide an avenue for further exploration and dialogue.

Similarly, gathering data, by conducting interviews with individuals or in a group context and/or recording field notes, necessitates not only reflection on the part of the researchers but also recognition of our own *reflexive engagement* with the data gathering and analysis processes. For example, at the outset of a current study, I was aware of the literature on health service access and the tenets or premises of our universal system of health services and, in consultation, we identified that the lack of access contributed to the poor health profiles of children in the neighborhood of interest. Initially, it seemed reasonable that access could be achieved by addressing structural issues such as scheduling and location of clinics. However, in our initial community consultations, these premises were challenged. We learned, for example, that community members' knowledge of how health services operate interfered with their abilities to access services. We learned in our data gathering that the structural organization of services and the "rules" that governed access to different services had no logical foundation for many participants.

Critical reflection on the points of disjuncture identified between the premises of policies or programs and participants' experiences enabled us to begin to apprehend the assumptions informing systems design. Thus, in one study, the assumptions that largely reflected professional viewpoints and not those of community members, and the gap(s) in understandings between the different constituent groups, contribute to challenges of access. As I will illustrate more in what follows, this type of critical reflection not only informed the design of the research but also underscored the need for points of dialogue between different constituent components of the system. Ultimately, these insights informed the creation of new structural arrangements made to foster ongoing engagement of the community in the design and delivery of an innovative, more accessible, model of health service delivery.

The analytic strategies and the goals of the analysis enabled us to focus attention on processes and key premises that underpin the system design. The analyses that result also enable us to illustrate the ways in which systems shape interactions. This type of analysis offers an alternative to categorical representations that could blame professionals or parents for problems being faced. Here, the focus shifts to understanding the "roots" of the issues and engaging constituent groups in dialogue to improve understandings and potentially explore solutions. In what follows I illustrate ways these techniques of reflection and reflexivity can be drawn upon to inform qualitative research practice from conceptualization to knowledge translation.

3.5.1 Reflection and Reflexivity: Formulating the Research Aims and Focus

One of the first points in the process where my research, like research of other scholars, has the opportunity to shift the dialogue or disrupt the discourse on culture as a "risk factor" for poor health is in the *framing of the research question*. Although in many of the studies I have been engaged with we were working with, and within, ethnoculturally diverse communities, we sought to identify conditions, practices, and processes that influenced the experiences of immigrant people. Instead of examining culture as an explanatory variable for poor health, which often essentializes the person as the problem, our work examined relational influences on health. The reflective analytic process begins when the research question is posed. The researcher begins to "ask questions of" what is being observed, presented as, or understood to be, the problem. Here, reflexivity aids the framing of the question and the identification of the target population for the study.

Our social pediatrics research was prompted by the concern to generate understandings that could potentially change the patterns of poor health in an inner city community. In framing the research, we drew upon the statistical profiles describing the characteristics of the neighborhood and profiles of disadvantage in the community. We then set out to understand the "roots" of the poor health and social profiles in order to begin explicating the potential ways health services could be modified to address the identified conditions.

As researchers, we ask ourselves whose viewpoints we are interested in and why? The answer to such questions would be informed by our understanding of the problem and our theoretical stance. When working within the critical traditions, one goal is to recognize the conditions that privilege different perspectives and "write in" the viewpoints of individuals or groups who are "outside" because of their social location. In health care this might include a range of perspectives such as complementing the views of professionals with the views of patients; seeking the viewpoint of children (not only their parents or other adults), including people typically excluded because of literacy, education, or language; and actively recruiting people who are not part of typical networks of care, for example, those without ongoing access to care, transient populations, or people living in poverty. This approach recognizes different forms of expertise and seeks to create a mechanism for introducing such expertise into broader discourses (Lynam et al. 2012a, b).

For example, in one study I was interested in having a better understanding of the potentially modifiable conditions that were associated with the trend toward poor health profiles of new immigrants documented in population analyses (Beiser et al. 2002; Raphael 2007). In this study of immigrant mothers and their daughters in two countries, data that explored the nature of their health challenges and the range and nature of influences on help-seeking practices was gathered. As poverty and disadvantage featured prominently in the participants' accounts, I considered their experiences in relation to health inequalities research that had established links between poverty and poor health. My own reading, and others' analysis of this body of work, showed that, although the first level of analysis demonstrated relationships between poverty and poor health, more *critical analyses* made visible the conditions associated with poverty that were both pernicious and protective (Lynam 2005; MacIntyre 1997). Reading reports of the categorical analyses in light of analyses being produced by critical theorists prompted me to ask: *Why are visible minorities, as they are referred to in the UK, overrepresented among the poor, and is there a similar pattern in Canada?* In this case the "why" meant seeking to understand what conditions are operating to contribute to this documented pattern.

In this study, the theoretical stance I was drawing upon focused attention on the local experiences of women but also directed me to examine the broader organizational policies and practices, including discourses, that structured or shaped these experiences. As such, the question that emerged in the analysis prompted further exploration in data gathering and focused attention in the analysis to *processes of social location*. These steps in the analytic process specifically drew attention to the problem of "categorization" and representation as informing day-to-day discourses. The processes that are associated with being categorized are reflected in these women's comments:

> For two reasons I'm doing it or I've been trying to achieve […] as a woman, um, in any society women are always, you know, kind of like second citizen, um, but the other one was because you—a woman from ethnicity minority—have it worse, I think people don't give you credit […] and it's a shame, it is a shame really, because that's the way people perceive other people. But, if you, you know, are white and well dressed right away they think, you know, she's educated.
> (Lynam and Cowley 2007, p. 142)

Another study participant's account illustrated how particular categorical assumptions operated in her experience. "When people look at me they see me as a Black person and then make assumptions—that I am not English, not educated" (Lynam and Cowley 2007, p. 141).

As these quotes from study participants suggest, day-to-day discourses were influential in shaping the study participants' experiences. Again, taking direction from the theoretical stance, the analysis proceeded to consider both the implicit and explicit assumptions informing such discourses. In this way the analysis moved beyond description to identify systemic processes operating to shape experiences. In the analysis of data in this study, we focused on:

1. Understanding the *contextual influences* in order to consider behaviors or understandings in relation to typical representations
2. *Explicating the processes*, in this case the marginalizing processes and practices that for many are not visible yet operate to influence particular practices, behaviors, or understandings (Lynam and Cowley 2007)

In producing the analysis, we hoped to gain insight into potential points of engagement for effecting change. Such domains of change could include how individuals might interact with one another and changes in the ways policies are framed and presented in formal discourse. This type of analysis differs from categorical representation, in that it foregrounds "voice" and context and it potentially creates points of connection that may be drawn upon to inform dialogue.

Similarly, in our current research, we sought to understand the conditions that contributed to poor health and developmental profiles of children living in the inner city, many of whom are also described as Aboriginal, Chinese, or immigrants (Lynam et al. 2008/2011, 2010a, b, 2011, 2012a, b, 2014; Wong et al. 2012). Studies undertaken by other scholars, particularly population analyses, had drawn attention to poor health and developmental profiles of children and families in the neighborhood, and broader literature- and population-based studies drew attention to conditions that contribute to inequities in health and their consequences.

In framing the research question, we sought to generate insights to inform approaches to address inequities in health, with a particular focus on inequities in child health and development. As there is considerable evidence to show the range and nature of professional and community-based interventions and resources that are effective in fostering child health and development, our studies were designed to focus attention on *issues of access* to the full range of such resources. We anticipated that this focus would enable us to engage with children and families and generate understandings that could shift processes or modify practices to positively influence the accessibility to, and responsiveness of, care. In framing the study in this way, we were also responding to what the community had identified as a priority—system responsiveness. On reflection, this framing also enabled us to mobilize the interest and engagement of community members and clinicians, as it was a concern that was shared. Our theoretical stance challenged us to engage with and learn from the community and to draw upon and incorporate community expertise, giving it voice as systems were "reformed."

As we undertook initial consultations to understand the range and nature of challenges the children and families were facing, we also learned about structural and social barriers that influenced access to service, both of which had consequences for these children's health and development. As noted above, one of my initial assumptions was about what health-care access meant in a society and neighborhood with a universal health-care system. On the one hand, we assumed that the system "worked" as we were aware of a number of programs in place to support children and families. But in our interviews, we came to understand the constraints on access that were out of the control of the families, and we learned that the professionals engaged with such programs not only faced their own constraints in practice but also were often unaware of the structural constraints for families. But, perhaps more importantly, in addition to gaining insight on structural barriers, we gained an appreciation of the social barriers to health service access.

In listening to parents who spoke with us in our data gathering sessions, we also learned about the nature of social constraints on access that arose from past experiences and from being "represented" in particular ways, and we learned about the ways historically constituted understandings and representations continued to frame interactions. Parents offered many examples of ways they felt they were being "prejudged" which made them wary of engaging with formal health services. One parent describes how her dilemma plays out:

> [Here] comes that mum that thinks her kids are sick all the time. Because you worry […] like when I first got my boys, custody of my boys and then of my girl, *I wanted to do everything right* and my husband, he was always (commenting), 'all they had to do was sneeze and we're off to the doctor's, right?'. And then my friend was, *'jeez be careful, because they might take them away'* because they might think that you're not capable or whatever. (Parent Small Group)
> (Lynam et al. 2010b, p. 339)

So here we begin to see that access extends beyond scheduling of clinics, it is also bound up in the experiences people have had, and anticipate they may have, with service delivery systems and their vulnerabilities in dealing with such systems. In this quote, the power of the health professional is evident, as is the parent's desire to do the right thing. In this case the mother engaged with the clinician; in other parents' cases, they avoided the clinicians because of their fears. In each case the parents are challenging the ways they have been represented.

Similarly, a health professional commented on the vulnerabilities of parents who interact within a system where they feel they must confront stereotypes about poverty or the abilities of single parents, especially when they are parents of children with developmental challenges who are in childcare settings with typical children. In the following data excerpt, a professional comments on challenges parents face and underscores the ways unchallenged assumptions shape interactions. Here, a professional observes that while service providers may be skillful in working with children:

> Very few people are effective in working with the parents. And very few people make an effort to ensure that the parents aren't marginalized or excluded by the rest of the parents… In other words if their life isn't hell because they have a special needs child and people think that it's

> because they always come late [to the day care] or… because the kid doesn't have the right snack… Or because who knows what?
> (Lynam et al. 2008/2013)

The judgments here—about poverty and parents' comparisons to their own abilities to get to day care on time—also implicitly question the parents' abilities or capacity to parent. As the preceding quote implies, such situations, and judgments about them, are further compounded by assumptions about the parent's responsibilities for a child's abilities or lack thereof. Such observations erode not only the parents' ability to develop supportive relationships with other parents but also can marginalize their child by limiting the child's access to friendship groups. Parents living in poverty or with a child with a developmental or health "difference" are very aware of such differences and may, because of previous experiences of having to account for themselves or to challenge preconceptions, be tentative in their engagements. So, the "prejudgment" potentially shapes the health-care encounters on both sides.

The questions of interest in my research and the concern to generate contextual understandings necessitate that attention is paid not only to experience but also to the organizational influences on such experiences in the analysis. The theoretical stance informing my work underscores the need to consider different forms of power (e.g., institutional authority, interpersonal credibility, knowledge, different forms of social and material capital) and to consider how power is deployed to create, sustain, and/or disrupt prevailing "narratives" or social constructions. The theoretical framing recognizes the need to consider multiple viewpoints and seeks to trace the impact of different conditions on understandings and actions of participants, thus enabling the analyst to locate experiences in context.

3.5.2 Reflection and Reflexivity: Tools to Aid Analysis

In considering alternatives to categorical representation, I have proposed that the aims of analysis can include the production of contextual and/or critical analyses of processes and practices. In producing *contextual analyses*, the researcher seeks to consider multiple viewpoints on a particular problem or issue in order to identify points of disjuncture between typical or prevailing understandings and the point of view of people whose experience may be "outside" of the "typical" experience. The researcher also seeks to ask such questions of the data as: How was the "typical" understanding produced? Why is there a disjuncture in views, and on what points do the perspectives vary? And why, despite the disjuncture in views, does a particular view or representation continue to prevail? Such questioning helps the researcher begin to unpack the conditions and the institutional or organizational processes and practices that are operating.

Critical analyses may build from a contextual analysis and proceed to examine the ways structures—including discourses, policies, procedures, and the implicit and explicit assumptions that underpin them—operate and with what effect. Complementing typical qualitative interview data with documentary evidence can also enable the researcher to illustrate contextual influences, such as ways policy or popular discourses operate to shape, reinforce, or reinscribe individuals' viewpoints and experiences. Drawing upon such forms of data can helpfully move the dialogue on issues beyond the personal stories to draw attention to the systemic features that may offer opportunities to be points for change.

There are a number of ways in which the researcher may construct the analyses of qualitative data while also offering alternatives to categorical representation. These different types of analyses include:

1. Focusing on processes that generate categories (Varcoe et al. 2009) and in doing so making the tacit and explicit assumptions inherent in the concept(s) visible.
2. Focusing the analysis on the identification of core concepts and explicating the *processes* of influence. This is a strategy that is particularly important for those of us who are seeking to generate understandings and identify points of engagement to effect change (Lynam et al. 2010b).

3. Explicating the contextual influences on observed or described patterns of behavior (Lynam 2010) which can produce another "read" of the situation.
4. Including the prevailing or prominent examples the data produces but also incorporating the contrasting or "dissenting" cases into the analysis order to make visible the conditions, actions, or perspectives that contribute to the variations seen (e.g., social location, agency, resilience, engagement, resisting racialization and marginalization, etc.) (Lynam 2010; Lynam and Cowley 2007; Lynam et al. 2010b).

In *presenting the analysis*, the researcher may actively seek to reconcile categorical understandings and/or dichotomous presentations of facts produced through other methods by proposing a broader conceptualization or an alternative explanation. The choice of language and phrasing foregrounds context and "action" processes. The intention is to identify core concepts and processes that are operating and to illustrate the conditions that magnify or attenuate their impact. Such phrasing reminds us of our commitment to voice, agency, and person. Thus, in rendering accounts, we seek to locate the participants' experiences in context while also accounting for the variabilities of such experiences. In doing so, we may recognize and affirm the challenges individuals or professionals face but also provide a window into the possibilities for effecting change.

In my case, qualitative methods offered an opportunity to provide a more critical or more nuanced understanding of barriers to health service access and to use these insights to inform the development of a model to foster access and responsiveness. As I employ critical analytic approaches, I often place terms in parentheses to remind the reader that one goal of the analysis is to be open to revisiting or refining the meanings of terms (and categories) we use and, in the process, to consider the (tacit and manifest) assumptions inherent in the term or concept from different viewpoints.

In the following data excerpt, the researcher is exploring the clinician's perspective on the conditions that contribute to youth being "at risk." In the exploration the clinician offers an example of a clinical dilemma that arises in part because of the need to categorize behavior. In the example the clinician compares one set of behaviors that can be classified and categorized with another that does not neatly fall into a health diagnosis and/or a problem that can be readily resolved by a teen's compliance with a social service recommendation. In this case the clinician observes that "we"—the system and the professionals working within it—are absolving ourselves of our social responsibilities.

> Exactly, like when we have a kid with an eating disorder who's fourteen if they're starving themselves we're [meaning clinical team] going to certify them and take them against their will. But if we have a 14 year old who's dealing drugs and getting attacked with knives getting in knife fights who could definitely get killed by that behaviour we're not, we're letting them go, we're letting them make their own decision and assuming they have the capacity to do that when I'm not so convinced they do. Or a 14 year old who's coming in drunk and may have been raped doesn't even remember and we're assuming that they had the capacity to make the decision to leave the ER on their own. And I'm not convinced that they have that capacity and so it's a real ethical struggle for me because I also support youth developing autonomy.
> (Lynam et al. 2008/2013)

This form of reflective data gathering process enables the analysis to go beyond describing the prevalence of a problem or to describe a practice, by considering the tacit and manifest assumptions inherent in taken for granted practices related to consent. As the continuation of the research interview illustrates, in this case, the ethical issues related to such practices are put on the table for discussion.

In the context of the critical tradition, in addition to prompting reflection on the assumptions inherent in a term or concept, *an additional analytic intention is to illustrate how these meanings, practices, or ideas are reflected in, or shaped by, structural arrangements and similarly to consider how they (as concepts or discourses) structure or influence interactions*. As concepts are shaped by, and shape, context, one goal of the analysis is to generate insights to prompt reflection, to question assumptions, and, in our case, to consider conditions that influence possibilities for change. Presenting the analysis in these ways can offer a different "reading" of a recognizable scenario but a reading that reconciles or integrates different viewpoints. This approach aligns with good qualitative analytic practices by providing the audit or decision trail that has informed the analysis.

Representation without critical reflection can lead us to make inferences that are not well founded. Categorical representation can reinforce taken for granted assumptions (about particular ethnocultural groups, about women, about people with particular illness of a particular age or set of abilities) with such associated effects as masking personhood or silencing viewpoints. Similarly, discourses of representation can undermine dialogue or engagement if they prompt individuals to become defensive or "resist" the ways in which they are being represented.

By contrast, focusing on *explicating processes* and illustrating ways particular conditions operate to shape experience or "produce" particular outcomes can offer a more nuanced and contextual understanding of what has been documented by scholars engaged in different models of research. Given my goal to generate insights to address inequities in health, understanding points where change may be introduced to shift trajectories may ultimately be helpful. In either case, both in theory (Anderson et al. 2007; Lynam 2009) and in my experience, the introduction of alternative points of view and the focus on process can open up space for dialogue.

3.5.3 Reflexivity and Knowledge Translation

The social pediatrics research program has involved a research team that brings varied interests, abilities, and viewpoints to the table (Lynam et al. 2008/2011). This has made the research very complex, but it has also created opportunities for the research products to be highly relevant to multiple jurisdictions. Reflexivity operates at the level of the team in that, through ongoing dialogue and engagement, each team member's orientation and expertise becomes more visible to the other team members. Reflexivity enhanced awareness of my own stance and prompted me to seek out and reflect upon others' knowledge and perspectives, which, in turn, we have sought to incorporate into different presentations of the analyses. In addition, engagement with these team members has enabled me to build knowledge and perspectives to become a "bridge" for orienting research outcomes for different audiences and for different purposes.

For example, an initial paper sought to make visible the *processes and practices* that influenced poor health outcomes, with a focus on the (implicitly understood) roles and commitments of formal health service sector. Here, a number of representations of the target community were challenged and "new" explanations were offered (Lynam et al. 2010b).

Similarly, in an effort to engage with "decision-makers" and to explicate the model in language that would be understood within the health service sector, we articulated the premises of the practice, as we had come to understand it from the literature and from the research evidence we had gathered and developed a "logic model" to guide dialogue. The logic model was subsequently refined as new analyses were produced. But, in presenting the logic model, we focused on processes of influence and practices of engagement, rather than on more categorical exemplars (Lynam et al. 2011).

On reflection, however, we realized that the focus of knowledge translation had largely been on professional practices for professional audiences. And, despite introducing "voice" and viewpoints of our participants, the analysis had not explicated in the same depth and detail the significant role of the community (our community partners) in complementing the contributions of the professional team members. In response to this awareness, we shifted the analytic focus to consider community-based strategies of engagement that were foundational to the conceptualization of the practice model but less visible to the professionals. In the following quotes, parents describe the ways the community has worked with them to create strategies for inclusion of their children, who they are aware need support to manage their behavior, and to assist them in their parenting roles.

> They teach the other children how to recognize my son's behaviours so that they can back away as quickly as possible for their safety and for my son's safety. They understand that my son has no control… But the [community centre] has worked… to include him, and not only to include him but to include everybody else around him and educate them.
> (Lynam et al. 2012a, b, p. 101)

The following quote illustrates the ways she and other parents were included:

> We did the circle and we did another project where [parents]… attended a preschool. They went on outings with families, they built relationships, they got to know the kids, they got to know what kinds of resources were available in the community and experienced 2 months of really, really good direct, hands-on experience… The hands-on really made a big difference.
> (Lynam et al. 2012a, b, p. 99)

Reflection and inclusion of data from different viewpoints not only helped us to explicate the approaches taken by professionals but also assisted us to consider the ways the professionals' engagement is extended and supported by community-level practices which, in this case, served to further the aims of the clinical initiative. The analysis also enabled us to make visible conditions that characterized the community environment, conditions that also illustrate what many professionals would take for granted—that children would "always" have opportunities for inclusion or that parents have the opportunities to engage in recreation and play with their own children in their neighborhood. The project, and the publications on it, introduced new discourses on Learning Circles not only into day-to-day dialogue in the community but also into discourses of professional practice. Subsequent data gathering has provided examples of ways the introduction of these new discourses and associated practices has helped to begin to shift the largely negative representations of Aboriginal people.

As the Research Lead examining this model of clinical practice, I have also gained insight into the nature and contributions of interdisciplinary and intersectoral partnerships. As noted above, a consequence of categorical representation is that it can lead to dichotomous thinking. I think the qualitative approaches employed in this research and the analytic strategies used have the potential to reduce the tendencies toward dichotomous "blaming" of organizations, professionals, or families for lack of responsiveness. In addition, the organizational structures created within the project have created avenues for dialogue and ongoing engagement.

On many occasions, I have asked myself why the insights from this particular study have sparked dialogue and engagement in so many different contexts. In part, there is no doubt that these expressions of interest relate to the partnerships formed to enact the project and the research on it. But, over the course of my career, I have frequently seen qualitative analyses be "dismissed" or represented as preliminary analyses or insights, even though they may offer an in-depth and thoughtful analysis of a particular issue or groups' perspectives. These reflections and my current experiences prompt me to consider that it is possible that the readers or consumers of the research (e.g., a professional, educational, or practice setting) may not know how to effectively engage with, or draw upon, the insights because they have not been contextualized. Or conversely, if the target audience does not "see" that the insights relate to their own circumstances, they may be dismissed. The interdisciplinary and intersectoral nature of the research has assisted me in gaining new insights into the mandate, goals, and assumptions that underpin the social organization of practice in different jurisdictions. I also have a better insight into the ways our own social location within a system or society shapes and contributes to the creation of disjunctures in understanding the challenges children and families face accessing care. With my own expanded knowledge, and the insights of other research team members, we are better positioned to illustrate how different sectors and systems operate and to illustrate how "silos" of practice influence the capacity of the system and its practitioners to work effectively.

My capacity as a researcher has been challenged and enriched through the partnerships developed to examine the questions of interest, and thus, I would be remiss in not acknowledging the ongoing engagement of my research, clinical, and community partners in this work.[1] Access to these differing viewpoints complemented my own experiential and professional knowledge and helped us to create *bridges to other domains of expertise and forums for decision-making.* This *bridging* has also assisted us to create points of engagement for dialogue into how the analyses were presented. Our knowledge translation strategy has been informed through ongoing engagement of the different partners, perspectives, and jurisdictions. There would be no research insights if there had not been ongoing commitment to, and engagement with, the research by multiple team members. The practice mode and the model of ongoing research engagement evolved out of reflexive engagement.

3.6 Summary

Qualitative research offers a rich palate of methodological and analytic strategies for knowledge development. Here I have sought to share ways qualitative research may offer alternatives to categorical representation. Our ongoing challenge is to be open to hearing different perspectives and sharing insights to foster ongoing dialogue. I contend that over the course of our studies, it is incumbent upon us to continue to ask: Who benefits? Whose interests are being served and/or how might insights be drawn upon to benefit institutions and the groups they serve? Whose viewpoints are being eclipsed or masked? Our work is enriched when we build upon the work of other scholars and invite dialogue with, and critical reflections of, such scholars of our own work. We must be open to hearing other perspectives on the conceptualizations offered. In these ways, we shift from completing a study to developing programs of research and contributing to knowledge development.

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4

Contextual Action Theory: An Integrative Framework for Qualitative Health Research

Richard A. Young, Ladislav Valach, and Ada K. Law

4.1 Introduction

In this chapter, we present an approach or paradigm in which health, health interventions, and health promotion can be understood, studied, developed, and evaluated. Our intention is to point a direction to addressing questions about health-related processes as goal directed. We suggest that this approach is integrative. Since health and health research are complex and multilayered phenomena, simple and single research studies can be highly informative, but they often fail to address the bigger picture of health and its interdisciplinary nature. Indeed, the meanings attributed to *health* are themselves varied and reflect the complexity of the domain. For example, the World Health Organization's (WHO) 1946 definition of health is "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO 1946 p. 1). This definition has not been amended since and has been criticized for its lack of new understandings of disease at the molecular, individual, and societal levels (*The Lancet*2009). Huber and colleagues (2011) take up the challenge of defining health in a more dynamic fashion by relying on the approaches articulated in the Ottawa Charter (World Health Organization 1986) and the Dutch Conference (Health Council of the Netherlands 2010). The emerging preferred understanding of health, writ broadly, is "the ability to adapt and to self-manage." This definition implicitly combines natural scientific views of physiological processes of adaptation with the intentional view of self-management. Of course, this broad definition has been operationalized to permit the quantitative measurement of variables. At the same time, it invites the consideration of an integrative framework for understanding and evaluating these complex processes. While it is important to know specific factors related to, for example, myocardial infarction or posttraumatic stress disorder in order to explain and treat these conditions, it is also necessary to acknowledge the power and agency of individuals in maintaining and enhancing their own health across the life span. This perspective calls for attention to both the processes and outcomes of health research.

Basing decisions and intervention procedures on evidence has become an established standard

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in many institutionalized areas of our lives, such as medical practice and health research (Sackett 1995; Sackett and Rosenberg 1995; Sackett et al. 1996, 2000), education (Thomas and Pring 2004), psychotherapy (Goodheart et al. 2006), mental health (Norcross et al. 2006), law (Shajnfeld and Krueger 2006; Young 2010), organizational development (Locke 2009), finance, business, and management (Walshe and Rundall 2001; Rousseau 2012). With the exception of the law profession, the randomized controlled trial (RCT) has evolved as the gold standard for most disciplines including medicine, education, and psychotherapy (Cochrane 1972). In the last 20 years, however, there have been earnest discussions in the academic world about the value of relying entirely on quantitative evidence (e.g., Madjar and Walton 2001) when investigating a behavioral phenomenon. As a result, the social sciences have witnessed a vigorous development of qualitative evidence (Denzin and Giardina 2008; Morse et al. 2001). This burgeoning development has been driven by two claims about evidence in general. First, the knowledge used in evidence-based practice needs to be contextualized. Second, the success of evidence-based practice depends not only on technical knowledge but also on the dynamics of human care, such as the quality of provider–client interaction. McLeod (1997) proposed that extensive narratives and understandings in the form of phenomenological qualitative research might fill this gap. We agree that this type of qualitative evidence provides valuable insight into the experience and perceptions of individuals. We believe, however, that still more can be done. Specifically, research that addresses aspects in addition to narrated experiences might add yet another layer of understanding to human phenomena. In this chapter, we describe a way to connect these diverging requirements conceptually.

The characteristics and merits of quantitative evidence as compared to qualitative evidence have been widely discussed in academia, with resulting conclusions suggesting that both types have contributing and inhibiting consequences. Many researchers working with qualitative methodology, however, are not content with contrasting quantitative and qualitative research (Swanson 2001), as the distinction between the two is sometimes obscure or nonexistent. Unfortunately, partly due to this spurious separation, qualitative research is often left out of consideration of evidence-based methods. To conceptualize qualitative research as separate and different from quantitative and efficacy research may be counterproductive to the advancement of health research. Rather, it may be more fruitful to consider ways to incorporate qualitative research into evidence-based practice and to complement it with quantitative evidence. Thus, it is not a question of whether we use numbers, but rather how we consider human behavior in meaningful terms.

To respond to the call for the inclusion of qualitative phenomena in evidence and to overcome the dichotomy between qualitative and quantitative research, we propose contextual action theory (Valach et al. 2002c). The purpose of this chapter is to describe how contextual action theory informs this debate, to discuss the possible use of this perspective to develop evidence for health processes, and to situate the evidence-based movement in a paradigm in which qualitative phenomena are considered. Before articulating contextual action theory as an integrative framework for qualitative health research, we set the stage by addressing preliminary notions of action and health, qualitative and quantitative research, and the ontology and epistemology of action.

4.2 Action in Life and Science

Action is a term commonly used to describe many aspects of human life. It refers to what people do individually and together. In common usage, *action* differs from *behavior* by including the notion of "toward a goal," that is, it encompasses cognitive and emotional processes as well as social meaning. The definition of health identified earlier, that is, "the ability to adapt and to self-manage," implicitly includes lay understandings of action and goal. Human action is pervasive in life, and by extension in health, from getting up in the morning to maintaining long-term friendships. Individuals are clearly involved in action in their daily lives. Action is also present in a variety of complex manifestations in social and institutional phenomena from operating a national healthcare system to training midwives.

Action has received increased attention in health research in the past two to three decades. For example, a simple search for the terms *action* and *health* in journal article abstracts using the search engine PsycINFO in early November 2013 generated 976 publications for the 2012 publication year and 90 for the 1992 publication year, representing an increase of more than 1000 % over two decades. At the same time, very few of these publications are grounded conceptually in an action perspective, and even fewer use goal-directed action as research paradigm and methodology.

4.2.1 Qualitative and Quantitative Inquiry

Madjar and Walton (2001) maintain that "… the application of any evidence requires clinical experience, wisdom, care, understanding" (p. 37). We propose that clinical experience, wisdom, care, and understanding can find their ways into the application of evidence when we regard human action as goal directed. However, a critical and contextualized view of evidence has not always been present in quantitative health research. Rather, traditional quantitative research has tended to focus on the generation of evidence and less so on its application. When the meaningful understanding of the social and personal order is hidden in the research procedure, the application of evidence becomes more challenging and contributes to the research–practice divide in many health disciplines. Traditional research procedures in quantitative studies often prescribe that participants are controlled for personally and socially meaningful features, such as age, gender, education, class, ethnicity, and so forth. In turn, traditional research methods do not well represent the social world they intend to study, as this social world is considered independent of and different from everyday thinking. In addition, statistical understandings of causality have little to do with its philosophical understanding (Danks and Eberhardt 2009; Nisbet et al. 2009; Schlosser 2012), although it is not common for researchers to reflect this fact in their research. For example, in a study using traditional methods, Neblett and colleagues reported that racial identity mediates the association between ethnic–racial socialization and depressive symptoms among African-American college students from a predominantly white southeastern university in the United States (Neblett et al. 2013). Generalization of their findings are limited because of the context, age of students, time frame of behaviors in question, and the understanding of racial socialization as a long-term process, among other factors. In contrast, qualitatively oriented research is generally known for its capacity to attend to characteristics such as clinical experience, wisdom, care, and understanding. This is particularly the case when we can both conceptualize and assess such characteristics in the research.

4.2.2 Ontology and Epistemology of Action

Some researchers in qualitative health research suggest a pragmatist philosophy as a suitable ground for qualitative evidence (Kuzel and Engel 2001), some propose critical realism (Maxwell 2008), many assume a constructionist research paradigm (Bourdieu et al. 1991), and other paradigms are also invoked. The ontology and epistemology of action include important premises of pragmatism, critical realism, constructionism, relationalism, and the principle of enaction (Stewart et al. 2010). However, there are also aspects of the conceptualization of action that suggest unique aspects of its ontology and epistemology.

Action is the key element of our existence (Sartre 1957). We assume that our daily activities and behavior consist of actions (Vallacher and Wegner 1987). We develop through action (Brandtstädter and Lerner 1999), our brain develops by action toward the environment (Fuchs 2008), and our ontogenesis and phylogenesis are proceeded by our actions (Gallese et al. 2009). Action is the building block in our understanding of self and others in the world (Tomasello et al. 2005). For example, we may think about a physician as someone who *applies* medical knowledge and *treats* illnesses. One may also assume that the social world is constructed through action (Berger and Luckmann 1966).

An epistemology based on action focuses more broadly on action as the basis for knowledge construction than some other epistemologies (Frisna 2002). However, our view is not a radical methodological constructivism. It emphasizes goals rather than causes to explain human events and phenomena. Causes are here understood as more connected to the scientific (classical mechanics) explanation rather than as central to the motivational process. Any generation of evidence, particularly evidence of health- and treatment-related processes, can be seen as based on action-driven inquiry which, in turn, calls for a closer scrutiny of how action is conceptualized. Action driven does not mean exclusively outcome driven. Although goals are orientations toward future states and processes, action contains more than a goal. It includes ongoing processes in the here and now. As an illustration of the integration of goals and processes in action, consider the example of paramedics attending to a patient following a motor vehicle accident. This action entails the goal of taking an injured person to the hospital. This goal implies a whole hierarchy of functional steps, knowledge, and skills in paramedic procedures and the human anatomy, as well as detailed socially meaningful prescriptions on what step takes priority and why. The actions might include ensuring that the victim is breathing adequately, assessing his or her neurological state, reassuring the victim, and so forth, all of which are done with the mindfulness of being efficient. Thus, at any moment, this action sequence requires the paramedic's presence, steering processes, control, regulation, monitoring, energizing, communication with the team of paramedics, and so forth. This example illustrates that simply identifying the goal of an action is too narrow an understanding.

4.3 Contextual Action Theory

Contextual action theory is about individual and joint goal-directed short-term actions, midterm projects, and long-term careers.[1] Actions are units of behavior for which a goal is assumed, attributed, or experienced (for a more extensive discussion of this theory, see Valach et al. 2002c; Young et al. 2011b). Projects are comprised of a series of actions over a midterm length of time constructed to have a common goal. Careers are series of projects over a long period of time that have a common goal. Actions may be embedded in projects, which, in turn, can be part of a more extensive career. For the sake of illustration, a simple example of a health-related action, project, and career may suffice. The action of exercising with a partner may contribute with other actions to a weight loss project, which, together with other projects over a lifetime, constitute a fitness career. Equally, the action of exercising contributes to a relationship project and a relationship career as well as to an identity project and an identity career.

Action, projects, and careers are contextual processes, not only in the sense that they are embedded in contexts and create relational systems but also that their meanings change with changing contexts. Thus, action, projects, and careers are contextual and relational phenomena. That is, they are phenomena involving the relating of person and environment. They contain processes that are simultaneously manifest and observable, subjective and experiential, and social and shared.

The definition of health identified above as "the ability to adapt and to self-manage" suggests that human action is central to health and by extension to health promotion and health research. These constructs represent actions that are intentional, goal directed, and joint, that is, the actions involve more than the individual person. While health is a construct that represents

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[1] The terms "project" and "career" are not used in their everyday colloquial meanings. Their specific meanings in contextual action theory are described in this the text.

complex personal, institutional, and societal phenomena, its achievement and maintenance depend on joint human goal-directed actions, projects, and careers.

4.3.1 Accessing Goal-Directed Action for Health Research and Clinical Purposes

Our approach (Young and Collin 2004; Young et al. 2002) regards goal-directed action as multileveled and multifaceted. These facets include the manifest processes or observable behavior, the actor's internal and subjective experiencing that guides and steers the action, and the social meaning attributed to the action by the actor and others. These facets of action are conceptualized with the assumption that actions comprise not just what we see on the surface, but also the internal processes that steer behavior and the social forces that motivate thoughts and behavior.

Contextual action theory considers goal-directed action at three different levels. The first, or top, level has to do with meaningful processes, in other words, the goals of action. The second or middle level addresses how the order of tasks functions to accomplish the task. Finally, the third level is comprised of specific action elements that can be observed and measured in structural and physical terms. To illustrate these levels of action, consider a person sharing a cancer diagnosis with her spouse: verbal and nonverbal behaviors are used in the context of resources, skills, and habits that both the person and spouse have, for example, time availability (the person decided that she wanted her husband's attention for at least an hour), and the context for what the person considered the seriousness of the conversation—a walk in the park seemed conducive to this kind of conversation (the lowest level); the conversation is guided by both participants' thoughts and feelings as they engage in the conversation (the middle level) and is understood at the meaning level as being "about something" by those involved and others in similar communication or cultural communities (the top level).

One way to enhance the meaningfulness of health evidence, and thereby the applicability and effectiveness of evidence-based practice, is to utilize a method such as the one described above to generate multileveled evidence about human action. Without paying attention to the social context and the complexity of human action and simply focusing on just one of the several dimensions, researchers run the risk of generating evidence that has limited value and applicability.

In the research method developed to access action, we gather data from these three perspectives (Young et al. 2005a, b). Firstly, we use systematic observation for the manifest processes, frequently gathered through a video recording of the action. Secondly, we gather the actors' subjective processing of the action through the self-confrontation interview, that is, the recall of thoughts, emotions, and sensations based on viewing a video playback of the action to access subjective experience (Valach et al. 2002a, b, c). Finally, we use naïve observation by the actors and researchers to determine social meaning, that is, "what this action is about in its everyday sense." These methods are used to complement each other, as they refer to different facets of the action. They are not used to triangulate the data for purposes of validity, but rather to provide a comprehensive understanding of the action. In addition, the systematic observation system contains socially meaningful observation categories, functional categories, and physically and structurally formulated categories. These are designed to describe the different levels of the systemic processes of action, projects, and careers (Young et al. 2005b).

For example, in describing the action of a paramedic attending an accident scene, we need a commonsense meaningful term for segmenting the behavior out of the longer stream of behavior that is part of the action "saving the victim." The antecedent and subsequent actions can be labeled such as "taking a dispatch call," before the helping action and "walking out of the emergency ward" after "helping the victim." Once we segmented the stream of behavior into actions using socially meaningful observational categories, we can then observe and categorize the processes undertaken in the service of the assumed goal (saving the injured person) with categories designed to capture function (that is, its function, not the movement or utterance). One action can contain a number of functional units, which often are organized in a hierarchical system (stabilizing a victim's condition contains the processes of taking his or her pulse, watching and feeling the victim's breath, and deciding if cardiac pulmonary resuscitation is necessary). Finally, each of the described functions is specified in time, that is, duration, in physical space categories, in movements, in behavioral terms, and in linguistic terms. This is the observation at the lowest level of action organization.

4.3.2 Actions Are Systems

Contextual action theory maintains that the unit of analysis is an action. As action is multileveled and hierarchically and sequentially organized and not a single variable, it can be further specified, described, and measured within the system in which it occurs. The three hierarchical levels representing how action is organized, that is, goals, functional steps, and elements, are described above. Meaningful observational categories are used for identifying goals. Functional categories are used to distinguish the sequential order of action steps, including cognitive–emotional processes. Finally, physically and structurally defined units are used to code the action elements.

Consider a procedure a nurse or rehabilitation professional performs. It has a goal, and there are certain steps which have to be executed in a certain order, accompanied by certain thoughts and feelings. The steps have a prescribed time. There are defined physical objects to include and a guide on how movements and positions should be performed. The same system is used when observing and describing target actions, as well as formulating a standard operating procedure. The procedure described above is also used when studying joint projects and actions of a more narrative and communicative nature. In contrast, standard operating procedures are often based on a different conceptualization, that is, one in which goal-directed action is not central and in which subjective and social meaning and processes are obsolete.

4.3.3 Data Analysis

In using contextual action theory as a research paradigm and specifically the action–project method (Young et al. 2005b), each of the levels or systems—that is, the behavioral or physical level, the functional level, and the meaning level—is accessed in a manner described in the example above. Furthermore, each requires a different procedure to determine trustworthiness, or, in more standard language, different means are used to establish their validity and reliability.

Firstly, the physical and structural categories, which include observable behaviors, reported behaviors, and utterances, can be measured and quantified and thus are best evaluated using classical reliability criteria. For this type of data, the more precise the measurement is, the more trustworthy it is. For example, a researcher employing the action–project method may code specific behaviors such as "client asks the physician a question" or "stretches one's arm muscles." When these elements are coded with high interrater reliability, the data is believed to be trustworthy. In suggesting this type of reliability, we are not proposing a mixed method approach, but rather a qualitative approach that includes the reliable measurement of naturalistically observed behaviors at the appropriate level of the action.

Secondly, a different trustworthiness procedure is involved when determining the validity and reliability of the functional categories, which is based on the consensus of observers, specifically that of the researchers. It is based on the researchers' cultural understandings. It does not rely on numerical precision but on a consensus-making process among the observers. For example, a researcher may infer a functional step of "learning about cancer" amid a set of observed behaviors such as questioning the physician and reading a pamphlet. When there is adequate consensus among researchers about the presence of this functional step, this data is judged to be trustworthy.

Finally, the meaningful categories, at the highest and most abstract level of the action system, require social and cultural insight that are context dependent and based on conventions, as is the case in much qualitative research. Assuring the trustworthiness of socially meaningful observational categories means that a label such as "educating self about managing cancer" makes sense in the target communication community and that the majority of its members would ascribe this meaning to the behavior in question.

In data analysis using the action–project method, systematic observation and coding of the ongoing action proceed from both top-down and bottom-up, that is, from the meaning level to the functional level to the level of elements and vice versa. It follows the general principles of how an action is understood. People in general can grasp an action in its meaningful "gestalt," that is, "they get it." However, when it is difficult to understand the action for whatever reason, people start posing hypotheses about the meaning of the observed behavior. These hypotheses are supported or rejected by paying attention to behavioral details and trying to guess the meaning of the behavior. This can be understood as the bottom-up process. Observation of functional categories implies that the target processes are coded by their function in regard to the defined goal at the higher level. Thus, the same behavioral process may be labeled differently according to its function in different goal contexts. Even the physical description of the microprocesses, movements, and behavioral features makes sense only within the meaningful unit, which is segmented out of the stream of behavior by the assumption of a goal. Thus, physically defined units, coded independently and outside of their action context, do not lead to identifying meaningful, everyday relevant units. The observation procedure provides a description of the ongoing systemic processes within the levels of action, project, and career. For example, the systemic process of maintaining one's health over a long number of years can be described by the projects the person is engaged in, the actions the person performed, and the action steps used. The structural features of these actions, such as how many cigarettes were smoked, how much time the person spent exercising, and so forth, can also characterize this systemic process.

The action–project method also aims to gather data that is naturalistic and comprehensive. Rather than choosing only the bits of data that seem relevant to the research question at hand, this method takes in every piece of data, be it a respondent's facial expression or a description about health beliefs (Young et al. 2001a), that belongs to the meaningful unit of analysis. This approach to data analysis does not emphasize causal mechanisms and measurement principles of incremental, internal, and criterion validity, which are key aspects of the most classic quantitative studies.

In using action as the unit of analysis, we rely on several criteria: one for defining the goal that segments the action from the stream of behavior, another for describing the functional action steps, and a third for describing the action elements in structural and metric terms. This procedure and the principal on which contextual action research are based are the opposite of those found in conventional behavioral research. Many researchers, when choosing a unit of analysis, shy away from social criteria as these are often less readily defined in structural, physical terms. In addition, the mechanistic postulate that a unit of analysis should be defined only by one term exclusively to achieve clarity thwarts the identification of the unit of analysis as a systemically conceived unit, that is, an action.

4.3.4 What Processes Can Be Studied Using Contextual Action Theory?

Contextual action theory leads to studying health actions, projects, and careers (Young et al. 2005a, b). Researchers using this approach assume that these actions, projects, and careers can be studied in their everyday action context, without having to be reduced to numerical or variable form. They also assume that actions are more complex than just the execution of preformulated cognitive sets. These researchers study ongoing actions by collecting data on manifest processes, subjective experience, and social meaning. Specifically, they use systematic observation, the self-confrontation interview, and naïve observation. Ongoing actions are video recorded, not just retrospectively reported on. Equally, the researchers do not assume that cognitive and emotional processes are available to be reported as isolated units but that these are contextual–relational processes whose validity is ascertained only when studied in context. The action–project method does not answer all possible research questions. But it does help us to define the actions, projects, and careers we can study (Young et al. 2000, 2001a, b).

As we have argued above, it is our contention that nearly all health phenomena involve some form of goal-directed behavior of individuals and healthcare providers. A research method that is longitudinal, context focused, and multi-perspectival while at the same time focuses on the underlying goals and meanings of human action would likely lead to the generation of rich and meaningful data. An example of a health phenomenon that can be investigated in this manner is chronic pain management. To be sure, this area of research has received tremendous attention over the past 20 years and has generated fruitful evidence in causal mechanisms and predictors of chronic pain and disability (Kerns et al. 2011). For example, quantitative research has shown that personality traits such as fear of pain and catastrophizing influence success in pain rehabilitation programs (Heymans et al. 2009; Velly et al. 2011; Wideman et al. 2009) and that recovery from pain varies with time and context (MacEachen et al. 2010). Indeed, research that investigated the social context, meaning, and goals of individuals with chronic pain has led to in-depth findings about the phenomenon of managing low back pain. A recent interview-based study has found, for example, that farmers who suffer from chronic low back pain continue to work on the farm due to socially meaningful goals such as economic incentives and pride (Dean et al. 2011). To date, however, no studies have focused specifically on the actions, goals, and their underlying social meaning to individuals with chronic pain in a naturalistic manner. This information is important as it could help clinicians evaluate the appropriateness of certain assessment and treatment tools for particular patients. Research using the contextual action theory paradigm could reveal the immediate goals, meaningful midterm projects, and long-term "careers" of chronic pain sufferers, which would likely add an insightful dimension to the literature. For example, in the case of a particular client's chronic pain, specific actions in which fear of pain and catastrophizing occur may be linked to some projects that are part of long-term pursuits or a pain career. The substantial emotional underpinning of these actions, particularly as they include fear, may require special attention in clarifying related goal-directed systems.

Another phenomenon that may be appropriately viewed through the lens of a goal-oriented, action-focused, and context-emphasizing model is recovery from an illness or injury. For example, a qualitative study of individuals undergoing a rehabilitation program following a traumatic brain injury has shown that, for some individuals, the recovery process takes on different meanings and their goals evolve as time progresses (Kristensen 2004). Adapting to a Type II diabetes diagnosis is a similarly complex phenomenon that could be insightfully unpacked with the action–project method. Quantitative research has shown, for example, that social support is related to symptom severity more so in patients of African than Caucasian ethnicity (Rees et al. 2010). Without contextualized qualitative research, it would be difficult to understand why this trend occurs.

4.3.5 Health Studies Informed by Contextual Action Theory

In the last 20 years of our collaboration, we published a number of research studies in which we studied health as an action problem (Valach et al. 1998). That is, we did not study an organ, a function or handicap, or a diagnosis-based problem.

Instead, we asked what people do to achieve and maintain their health. Studying everyday joint actions and projects, we were able to describe family joint processes related to health maintenance and improvement, which we called family health promotion projects (Valach et al. 1996). With some variability in the procedures between studies, these projects were monitored over 6-month periods after they had been identified through a family conversation or interaction that had been video recorded, complemented with video-supported recall (self-confrontation interview), and analyzed (e.g., Young et al. 2001b). Specific projects included sun protection (Young et al. 2005a), suicide, and life-enhancing projects (Valach et al. 2002b, c, 2006a, b, 2010; Michel and Valach 2002, 2010), drug abuse project (Graham and Bitten 2015; Graham et al. 2008), and parental project of habilitation after child's cochlear implantation (Zaidman-Zait and Young 2008), neurological rehabilitation (Valach and Wald 2002), counseling (Young et al. 2011a, b), psychotherapy (Valach and Young 2012), and others. These studies provided descriptions of the joint projects in either conceptual or empirical terms. The empirical descriptions involved a qualitative outline of the systems of projects found and the sequences of actions within these projects. Conflicts and synergies as well as links between various actions and projects were pointed out. Equally, we also addressed ways contextual action theory and its methods could be used in counseling and psychotherapy intervention (Popadiuk et al. 2008; Valach and Young 2012; Young et al. 2015; Young and Valach 2002). As our research examples indicate, numerous health issues can be studied. Rather than a survey questionnaire, we monitor the actions in question in regard to the particular issue, as it occurs in everyday contexts, be it (a) the performance of an action, primarily, in the case of our research, joint conversations between important parties, or (b) the narrative of an action such as the one a person provides to a nurse, physician, psychotherapist, or relevant other, such as a parent or a peer (Young et al. 1999). The action that is the focus of inquiry can also be a professional action, such as neuro-rehabilitation, psychotherapy, teaching (Valach and Stevens 2008), playing with children, or supervising children, trainees, or psychotherapists. After describing the studied actions as indicated above, we, together with the research participants, infer the projects of which these actions are a part. These projects are then monitored for a further period of time.

4.4 Evaluation Informed by Contextual Action Theory

Dealing with evidence-based health research means addressing the issue of evaluation in research and practice. While there are conflicting views about whether evaluation is distinct from research (e.g., Levin-Rozalis 2003), it is unquestionably important in interventions, program development, and evidence-based practice. Evaluation does not simply entail scientific discovery, it also seeks to uncover the value or quality of something. While the field of research seeks knowledge about the *what*, evaluation seeks information about the *how*, *why*, and *under what circumstances*.

Everyday human action can be considered a qualitative phenomenon, because it is intentional and is always directed at an action object, whether mental, material, or social (Searle 1983). As *qualia*, which refers to our subjective conscious experience, is our primary awareness of the world, and thus of our behavior, it follows that these experiences are primarily qualitative (Young and Valach 2008). In addition, everyday action also inherently contains an evaluation component. Whenever we act, we are engaging in a process, whether consciously or not, of evaluating the importance, worth, and value of the action. For example, when washing one's hands, the evaluative feeling of performing an adequate action arises, and the thought of "better use soap" is generated. The very hot water may also engender the evaluative reaction "this water is too hot, I am going to scald my hands," and so forth. This does not imply that all action processes are highly conscious. However, we know that even when habitual and automatic everyday processes go wrong, the process of regulation based on evaluation steps in without our conscious decision (Duckworth et al. 2002). Nevertheless, these also are action processes. Hence, we maintain that intentional action necessarily involves evaluation.

Evaluation is a "built-in" process in every action and project (Aarts et al. 2012; Heider 1958). It is an important component to consider in professional disciplines that deal with the everyday lives of humans. A theory of evaluation should include some everyday evaluative concepts, such as worth, effectiveness, and efficiency. Professional health disciplines that deal with evaluation issues have to ask evaluative questions. That is, all the participants in health interventions should be monitored for their evaluative processes as they occur in their ongoing actions and projects. One way to get at these different levels is to conceptualize the processes involved from the perspective of goal-directed action. We can imagine the evaluation process that a rehabilitation professional engages in while engaging in a rehabilitation exercise with their client. The professional might evaluate the client's readiness before starting the intervention and continue to attend to their own internal thoughts and feelings as they observe the client's reactions during the rehabilitative exercise and change the exercise accordingly. Uncovering these subtle and subjective evaluative processes in healthcare clients would likely lead to rich information about the health phenomenon at hand and open doors to in-depth understanding about the worth, success, and importance of an evidence-based intervention. To date, however, organized and professional evaluations of occupational activity are often reduced to outcome evaluations of these practices without giving voice to the participants.

Valach and Wald (2002) illustrated how neuropsychological rehabilitation could be conceptualized from the perspective of goal-directed action and how the processes involved incorporated evaluation. They pointed out that neuropsychological rehabilitation—as are many other institutionalized processes dealing with health—is an interface of three complex systemic processes. Each can be conceptualized as involving goal-directed action, projects, and careers and, as such, includes evaluative components. That is, the conceptualization of the tasks needed to rehabilitate behavior and brain functions in the sense of motor and cognitive functions represents one system that has to be practiced in rehabilitation. The rehabilitation exercises in one session, as well as the whole rehabilitation process with one client lasting several weeks and months, comprise this systemic process (Belda-Lois et al. 2011; Feys et al. 1998; Green et al. 2002; Van Praag et al. 2000). Developing and establishing the rehabilitation procedure at a more general level, its codification and regulation represent another system of rehabilitation (such as developing a standard operating procedure) (de Treville et al. 2005; Zimmerman 1999). Finally, the organization processes of a rehabilitation clinic or hospital is the third systemic process, such as in total quality management (Richards 1994) or of a learning organization (Crites et al. 2009; Senge 1990).

For example, one can use contextual action theory as a blueprint for understanding and describing of these three systems. At the action level, neuropsychological rehabilitation aims at "reinstalling" lost brain functions within the brain plasticity (Morris and Bickel 2011). This represents the first system. It includes physical and occupational therapy exercises which are themselves organized into rehabilitative projects. The second action system includes the rehabilitation procedures, describing, establishing rules and conditions for their application, and so forth, as in the standard operating procedure. Further, as the dynamically developing neuropsychological rehabilitation is under scrutiny by traditional medicine, its support depends on their evidence-based practice. The latter is implemented in rehabilitation within the quality management of organizational development, which provides the third action system. To summarize, we consider the rehabilitative exercises, the first action system, the establishing of the general rehabilitation procedure in various disciplines (physical therapy, occupational therapy, etc.), the second action system, and the processes of a rehabilitation organization such as a rehabilitation center as the third action system.

The action–project research method may be useful to address the gap in the program evaluation literature by providing contextualized information about the effectiveness of interventions. In contrast, in traditional, causally oriented intervention studies, some variables are controlled, while others are minimized as having an extraneous effect on the results. Client perspectives are garnered by client satisfaction surveys or professionals' opinions. In basing evaluation on an understanding of goal-directed processes, evaluators are encouraged to consider participants' qualitative narrative data as a reliable and valuable source of evidence (e.g., Patel et al. 2008; van Huet et al. 2009).

4.5 WHO ICF 2001 and Contextual Action Theory

The World Health Organization International Classification of Functioning, Disability, and Health system (WHO ICF, World Health Organization 2001) is a widely acknowledged classification guideline for measuring disability (Brandt et al. 2014). This classification is based on a systemic conceptualization that takes a biopsychosocial approach to understanding human functioning and disability by integrating the medical model with social factors. It differs from traditional models because it views health, illness, and dysfunction as context-dependent and relational phenomena (Schultz et al. 2007). Specifically, it proposes that limitations to bodily functions are rendered disabling partly due to the broader social context in which the individual is embedded. According to the WHO ICF, impairment and disability can be comprehensively described based on one's body structures and functions, activities, and participation in society. For example, someone with a spinal injury is disabled because he or she has paralysis of the legs (bodily functions and structures), cannot take public transportation (activity), and thus may not be a part of cultural activities in the community (participation).

We propose that the WHO ICF is not dissimilar to the systemic order used in contextual action theory. Specifically, both the WHO ICF and contextual action theory regard human functioning from a rich, multilevel perspective. At the lowest and most concrete level, body structures and functions, as defined in the WHO ICF, can be understood as the manifest behaviors, skills, and resources that comprise human actions. In the middle level, the concept of activity is akin to the idea of functional steps in contextual action theory. At the top and most abstract level, the individual's participation in the community and society holds social meaning, which is not unlike the meaningful goal level in the contextual action paradigm.

While the WHO ICF has been instrumental in describing and classifying disability in clinical, vocational rehabilitation and epidemiological research settings (e.g., Leonardi et al. 2005; Saltychev et al. 2013), it has seldom been used for explaining health phenomena or conceptualizing interventions, that is, describing the intervention processes which go beyond the "what is" and "should be" state. The following illustrates both the possibilities and limits of the ICF:

> For health care professionals conceptualizing a case, they can use this framework to first explore biological bases of behavior (body functions and body structures). Once the physical and mental health and functioning of an individual are clarified at the individual level, then how that person functions in his or her environment can be explored with respect to the potential (activity) versus actual ability to participate within a social context (participation). The discrepancy between identified potential (activity) and actual participation can serve as the focus of clinical attention for intervention targeting.
> Peterson (2012 p. 411)

The fortuitous parallel between the ICF and contextual action theory—namely, the multilevel approach to understanding health—may open doors for this type of research.

Contextual action theory provides a tightly knitted conceptual system that can replace the existing patchwork of concepts and ad hoc explications, which are then ordered by quantitative methodology in conventional outcome studies. For example, consider the problem of chronic low back pain. There is one conceptualization behind the epidemiological studies on back pain problems (Manchikanti 2000), another behind the outcome studies for evidence of intervention effectiveness (Saper et al. 2014), and still another behind implementing back pain interventions (Ammendolia et al. 2009); another conceptualization leads the monitoring of interventions (Farin et al. 2013), and, finally, a different conceptualization is behind physicians' suggestions about what to do and what to avoid (Chibnall et al. 2000; Valach 1995). Thus, there are numerous approaches to understanding human health, here illustrated with back pain, including epidemiological studies, randomized controlled studies, treatment manuals, and so forth. To discuss the merits and limitations of these approaches would reach far beyond the scope of this chapter. However, the reader is invited to consider the assumptions underlying each of them, from large epidemiological studies to the more minute step-by-step prescription of clinical procedures with specific clients in specific contexts. We propose that contextual action theory can unify these approaches in providing a common ground for conceptualizing them. Understanding the development and treatment of health conditions, such as chronic low back pain, as occurring within systems of goal-directed actions, evaluating related intervention strategies as a part of action and project evaluation, and considering the goal directedness of all the participants in the health system represent how contextual action theory can provide a common conceptual base for all these concerns. In order to generate knowledge that is rich, applicable, and relevant, it is important to investigate issues like chronic low back pain beyond their mechanical conceptualizations and in a multidisciplinary, process-oriented, and contextualized manner (Fedoroff et al. 2014).

4.6 Constructing Evidence

In discussing evidence in quantitative and qualitative studies, one is faced with unequal assumptions. Quantitative research stresses issues of controlled research design and validity and reliability. However, the seemingly open access to empirical reality in quantitative research is rigorously predefined by philosophical assumptions, even if they are naïve philosophical assumptions. These assumptions are represented in the following methodological procedures: transforming everyday processes into the schema of the research study, formulating variables, and prescribing the research procedure, methodology, methods, and statistical analyses. The everyday processes that may be the subject of the research take on a new life in the form of variables, which in turn are processed by procedures that do not fully reflect everyday experience. For example, suppose persons eligible for a study are selected, the behavior that is the focus of the study is identified, and specific processes pertinent to that behavior are chosen. However, these selections—that is, the sampling of participants, behaviors, and processes—do not necessarily follow the meaningful, contextually embedded order of these processes within the person, within a long-term order, or within a group of people. All the sampling procedures assume a certain random distribution, which is not typical in living systems involving human goal-directed processes.

The following provides some examples of how researchers, informed by contextual action theory, conceptualized the process of constructing evidence. Contextual action explains and describes the meaningful processes and order of the studied phenomena, rather than explaining statistical relations among variables. Previous research has been able to empirically establish and describe the conceptual order of behavior in action, project, and career (von Cranach et al. 1982; Valach et al. 2002c, 2006a, b; Young et al. 2006). In our research, we have been able to apply this conceptualization to several health domains (Valach et al. 1996; Young et al. 2001a, b, 2005a, b). In this research, empirical methods are chosen to fit our understanding of the processes we are studying, as we explained earlier.

For the systematic observation of manifest behavior, the level of analysis at which the action processes are studied, as indicated above, determines the decision whether quantitative or qualitative coding is used. The means of establishing the validity or trustworthiness of the coding or analysis, determined by the level of analysis, is also outlined above.

4.6.1 Evidencing and Evaluation as a Part of Action

In the interventions traditionally based on evidence provided by RCTs and their evaluation in outcome studies, everyday evaluation as found in ongoing actions is not utilized. In RCTs, evaluation and evidence upon which interventions are based, firstly, are executed through specialized processes such as measurement and, secondly, only use a limited approach to how we gain knowledge, such as those providing quantitative data. The proponents of this view may end up stripping the intervention of its evaluative monitoring processes and ignoring their experiential value.

We suggest that by adhering to the everyday thinking of action theory, we include the evaluative monitoring of actions and projects and experiential evidencing. At present, this new proposition is for consideration at a conceptual level, as we have not fully described the specific processes of how to use evaluative monitoring in research. However, the methods of action–project analysis, which we have already described, might be helpful to consider (Young et al. 2005b). Seeing evaluative processes within action as providing legitimate research information is an important first step in this new perspective. Ongoing evaluation (we constantly evaluate while engaging in an action) and monitoring of everyday actions and projects (we constantly monitor our actions when engaging in them) and experiential ongoing evidencing (learning processes while enacting our actions provides evidence for the efficacy of our future actions) are part of this conceptualization that is specific to a whole range of qualitative approaches intended to inquire into and understand health processes. This conceptualization uses everyday action theory as outlined in many approaches such as phenomenology (Pacherie 2008), symbolic interactionism (Blumer 1969), commonsense psychology (Heider 1958), and so forth. Separating ongoing processes from their evaluation is an important part of quantitative conceptualizations.

Consequently, the call for quantitative evidencing and assessment within quality management is a call for the separation of intervention processes and their evaluation and evidencing. This separation is dictated by considering processes as analogous to the causation of nonliving structures.

In contrast, the processes we address here are human and social processes, processes centered around goal-directed actions. Using this approach, evidence and evaluation may themselves be understood as actions and projects. This is the most important suggestion in our discussion. We are not against engaging in specialized evaluation processes and developing research evidence upon which interventions can be based. Rather, we think that action theory provides a way to link evaluation, intervention, and experience more closely. In calling for evidence, we must simultaneously empower intervention participants to be able to engage responsibly in goal-directed processes that would then provide the ongoing evaluation of these processes. This step is a necessary and important feature of all action processes. When these processes are taken out of health-related intervention processes, we lose the input from the very participants whose goal-directed processes we set out to study.

An example of participant responsible engagement in goal-directed processes comes from the literature on goal attainment in mental health interventions. Essentially, this literature reports on the extent to which clients achieve goals over a term of psychotherapy (e.g., Proctor and Hargate 2013; Wilz et al. 2011). In addition, accountability can also be monitored through goal attainment between sessions, an approach very much endorsed by contextual action theory. Identifying, monitoring, and supporting clients' projects in treatment and also understanding short-term, midterm, and long-term activities of mental health professionals and their clients in terms of goal-directed activity reflect evaluative processes. Thus, a project, its process, and outcome monitoring in the treatment of one client are an issue of accountability, while the project with its process and outcome monitoring in the treatment of a number of clients is an issue of evidence-based treatment.

4.7 Conclusion

Keeping in mind the interdisciplinary nature of health-related processes in health promotion and treatment and in developing evidence-based treatments, we proposed an integrative conceptualization—contextual action theory. Based on the systemic, relational, and constructionist action paradigm of goal-directed processes, this approach accounts for the client's everyday goal-directed engagement in health-related processes and can describe treatments as joint projects health professionals engage in together with their clients. We proposed using contextual action theory with three goals in mind. Firstly, we critiqued the conceptualization and practice of developing evidence for treatment in randomized controlled trials. Secondly, we indicated that the human behavior health professionals deal with is goal-directed action and should be seen as such. Thirdly, we critiqued the reduction of treatment evaluation to outcome measures. Goal-directed action includes evaluation processes that should be included in the evaluation of health interventions.

4.7.1 Outlook

Perhaps more between the lines of this chapter, we implied that healthcare has developed far beyond the repair of dysfunctional body structures and functions. This repair orientation that was practiced in eighteenth-century medicine assumed a mechanical view of the person. When health and dealing with health and illness are considered as an intentional, purposeful human enterprise, then spelling out the conceptual consequences is called for. Thus, we proposed, firstly, that health is, to a certain degree, a goal-directed process organized in different forms, such as short-term actions, midterm projects, and long-term forms (career), and included the social organization of health. So whatever the specific explanations of particular health issues are, they still have to be addressed within an intentional conceptualization such as the one proposed in this chapter. Secondly, we proposed contextual action theory as a possible approach to understand the goal-directed processes.

Thirdly, we proposed that studies providing an evidence base for treatment must also be designed according to the assumptions about intentional human life. How interventions are designed in the future cannot be likened to a repair manual but rather must accommodate the psychological and social nature of the encounter between health professionals and clients within the framework of goal-directed systems. While the randomized double-blind placebo control group design might be suitable for studying drug effectiveness, in which the client's intentionality is not involved, once the client's intentionality is present, we have to conceptualize the intervention in terms appropriate to goal-directed processes.[2] In accepting these three propositions, we realize that goal-directed processes contain evaluative processes that should be used in providing evidence for any intervention. How this evaluative monitoring is organized as a group process, which most health treatments represent, is a question of the group structuring according to the task and not according to a research philosophy. Thus, we hope that such an approach will gain proponents who will then develop its rigorous scientific basis, because studying goal-directed systems is far from storytelling.

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[2] Other chapters in this *Handbook* note the considerable variation in adherence to prescribed medication, indicating that even in drug effectiveness studies the intentionality of participants is a factor.

4.7.2 Limitations and Vulnerabilities

In this chapter, we have taken the reader on an excursion to a world that does not include "treatment as usual." This world does not provide a fully developed alternative that can be adopted without making any sacrifices in one's professional life. Rather, what we have articulated is an invitation to step away from the highway of professional routines to the nature trail where personal experiences and convictions of one's everyday life and professional activities, theory and practice, and conceptualization and empirical research are connected. As such, many amenities of the professional ways of dealing routinely with human life issues must be constructed anew. For example, conducting research based on the approach we have described could be more cumbersome. It may not provide data ready for statistical processing leading to structural equation modeling. It also does not readily incorporate available measuring instruments, such as questionnaires, scales, and tests easy to administer and evaluate. Research assistants have to understand more than just the procedural rules of randomized double-blind placebo control studies, considered the "gold standard." They may require more intensive collaboration and supervision by the principal researcher. The proposed paradigm includes cultural sensitivity that requires that culture and context be attended to. Attending explicitly to culture suggests that obtained results are far from universal. Notwithstanding this partial list of the limitations and vulnerabilities of the proposed approach, we remain convinced that it is important to question routine procedures in health research that may have outlived their primary purpose.

4.7.3 Take-Home Message for Practitioners and Policymakers

If, as professionals, we want to engage in securing, maintaining, and advancing the health of our clients, we have not only to include psychological and social processes in our understanding of health and illness but also to consider these processes as goal directed. They are represented in short-term actions, midterm projects, and long-term pursuits not only of the clients themselves but also of healthcare workers and many others. The references discussed in this chapter indicate how to go about it.

Of particular importance is how evidence for evidence-based interventions and quality assurance is generated. In contrast to the view of the existing, mostly quantitative approaches, the participants' naturally occurring evaluation and monitoring of health goal-directed processes should be stressed. Moreover, these processes should be used as evidence. They are a critical part of health. Again, how to go about it in detail can be found in the research literature cited in this chapter.

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5 The World Health Organization Model of Health: What Evidence Is Needed?

David B. Peterson and Travis T. Threats

5.1 Models in Healthcare Provision, Conceptualizations of Disability

Understanding how concepts of functioning, disability, and health have manifested across various stakeholders in our healthcare system is very informative in framing our discussion regarding potential contributions of the ICF's conceptual framework to expanding notions of evidence in healthcare outcomes. These conceptions in healthcare draw our focus to specific attributes of it and help define what one considers evidence of healthcare effectiveness.

Several texts have compared and contrasted various models of healthcare and disability. The *Handbook of Counseling Psychology* (Brown and Lent 2008) includes a chapter discussing advancements in conceptualizing disability (Peterson and Elliott 2008). The text *Psychological and Social Impact of Illness and Disability* (Dell Orto and Powers 2007) provides a detailed review of how disability is defined and conceptualized in the literature (Lutz and Bowers 2007). Finally, the text *Psychological Aspects of Functioning, Disability, and Health* (Peterson 2011) provides an expanded review of such models. What follows is a concise review of the medical, social, and biopsychosocial models of healthcare provision and related conceptions in healthcare and of disability. A discussion of these models will help identify perspectives held by various stakeholders in the healthcare system and their potential impact on available evidences of healthcare service provision.

As a preview, the medical model of healthcare provision has been the most dominant force historically, focusing on things that make us sick and cause death. Because of the limitations associated with this perspective, and the emerging focus on the civil rights-related and disability activism, the literature from civil rights-related and disability activism resulted in the *social model* of disability. The most contemporary approach emerging in healthcare service provision, and as supported by the ICF's conceptual framework, is the biopsychosocial model, which draws from the most useful aspects of both approaches. The broad array of stakeholders in the healthcare system hold varying views on how to conceptualize healthcare and disability, and understanding these views can make the healthcare professional more effective in collaborating

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with them and facilitate research that provides the greatest opportunity for inclusion of a broad range of evidences for the effectiveness of healthcare service provision.

A criticism of the 1980 WHO International Classification of Impairments, Disabilities, and Handicaps (ICIDH) was that it applied the medical model to disability (Hurst 2003). As a result, in the development of the ICF, it was decided to fully engage disability rights groups and other stakeholders that have incorporated more qualitative research to develop the ICF (Hurst 2003). The ICF attempts to reconcile the medical and social models with its biopsychosocial model. In the next sections, each of these models will be described more fully.

5.1.1 Medical Model

The medical model has been the dominant force in healthcare service provision, focusing on the diagnosis of a disease, disorder, or injury. The medical model can be described as a treatment process that first identifies a pathogen or cause of injury or other disease process (often classified by the ICD) and then selects an appropriate treatment protocol for the condition identified (Reed et al. 2008). The medical model does not focus on contextual factors (e.g., social and environmental factors) or on the subjective experiences of individuals receiving healthcare. Within the medical model, disability tends to be conceptualized as a personal problem that requires treatment by medical professionals (WHO 2001). Since contemporary perspectives on disability suggest that behavioral and social factors affect the course of chronic disease and disability over the life span, the medical model and related diagnostic information have a limited utility for assessment and treatment and ultimately identifying healthcare outcomes (Peterson and Elliott 2008).

It is very important to note that the medical model is not without utility. It contributed to advances in science that helped researchers to better describe disease processes and related etiology, allowing more rapid and effective response to the acute needs of persons with physical and mental disabilities and other chronic functional health conditions. The medical model also informed early initiatives to address issues of improved care, survival, and quality of life. Medical definitions of disability provide the cornerstone for determining disability for legal and occupational purposes and for determining eligibility for financial assistance (Peterson and Elliott 2008).

5.1.2 Social Model

The medical model was challenged by the civil rights era and related disability advocacy efforts, encouraging a movement away from the medical model of disability and functioning toward a social model that considered the role of environmental barriers in health and functioning (Peterson and Elliott 2008). In fact, many proponents of the social model viewed the medical model as not only incomplete but in fact harmful to persons with disabilities. Consider the following quote regarding the standard clinical evaluation by Reeve (2002), who describes it as the "clinical gaze" and is a

> public stripping […] surveillance of medical experts who use the clinical gaze to identify deviance and disorder and to constitute the subject as a patient […] which leaves the recipient feeling vulnerable, exposed, humiliated and is an example of psychoemotional form of disability, as well as a form of institutional abuse. (p. 498)

This view is obviously not what the medical model considers the evaluation process.

The social model was crucial, however, to point out that people with disabilities were people first and not merely a compilation of their physical and mental functional limitations. It also became obvious that treating persons with functional disabilities with only the medical model was not effective because it did not consider all the important factors. Historical evidence suggests that diagnostic information alone, without functional data, may not adequately reflect an individual's health condition. It is very important to note that disease or impairment may manifest differently across individuals; similar functioning does not imply similar health conditions (Peterson 2011; Reed et al. 2005).

In the social model of healthcare, medical conditions are no longer a simple personal attribute, but a complex social construct reflecting the interaction between the individual and his or her environment (WHO 2001, p. 20). The social paradigm focuses on the barriers and facilitators to functioning, such as daily activities, life skills, social relations, life satisfaction, and participation in society. This model suggests that any problem related to functioning, disability, and health is influenced by, if not due in large part to, societal attitudes and barriers in the environment. Within the social model paradigm, the individual is seen as the organizing core, and impairments are defined according to environmental factors (Olkin 1999; Olkin and Pledger 2003). The environment is typically construed as the "[…] major determinant of individual functioning" (Pledger 2003, p. 281). These complex interactions cannot be captured by typical linear quantitative scales but often require qualitative research to demonstrate the diversity of responses to functional health difficulties.

5.1.3 Biopsychosocial Model

The biopsychosocial model of disability integrates useful aspects of both the medical and social models of disability, addressing biological, individual, and societal perspectives on health (Peterson 2005). Planning treatments and documenting outcomes of interventions from the body, individual, and societal perspectives can improve the quality of healthcare service provision and consequently the quality of life of people with disabilities, as well as increase the participation of individuals with disabilities in society (Peterson 2011; Peterson and Threats 2005). The biopsychosocial perspective and the ICF itself have the potential to inform healthcare in the broadest sense while providing specific benefits to people with disabilities by using a universal, culturally sensitive, integrative, and interactive model of health and disability that is sensitive to social and environmental aspects of functioning.

5.1.4 Implications for Healthcare Evidence

The medical model of healthcare and disability brings our attention to the specifics of what makes us sick and causes death. Evidences of healthcare outcomes from this perspective tend to be actuarial and quantitative and can be classified using a system like the ICD (described below). How often does a disease manifest itself (morbidity)? What is the probability of mortality? With respect to treatment planning, healthcare outcome research reflects the ubiquitous limited evidence-based-practice paradigm, seeking quantitative evidence to support that specific therapies eliminate or ameliorate identified medical conditions, and provides some indication of the likelihood of their success. Examples may include pharmacological research on the effectiveness of treatment a given condition or adjunctive therapies for conditions more resistant to treatment.

The social model of healthcare and disability shifts the lens of focus away from the individual and illness and highlights the environment as a central factor in an individual's ultimate functioning in the face of a given health state. The experience of the individual in his or her environment is arguably best explored using a combination of quantitative and qualitative methods to identify what is a successful environmental intervention in healthcare. The social model—and its corollaries within the biopsychosocial framework—provides a unique opportunity to employ patient or client-focused qualitative data that inform the researcher how one's context facilitates or hinders desired healthcare outcomes.

The biopsychosocial focus, and as we will see illustrated within the ICF conceptual framework, allows one to focus on medical and statistical data (quantitative), person-centered experiential data via qualitative methods, and unique to this perspective, one can explore through qualitative and quantitative methods dynamic, nonlinear, and reciprocal interactions between what persons can do optimally given their state of health and functioning and what they are ultimately allowed to do within society given facilitators and barriers present in the environmental context. This is likely the greatest contribution of the biopsychosocial model and the ICF's conceptual framework; it allows us to target our interventions and measure healthcare outcomes in a nontraditional manner that takes into account critical contextual factors that are not often a focus of clinical attention in healthcare (Peterson 2011).

The National Committee of Vital and Health Statistics, an academic medical advisory board of the USA's Department of Health and Human Services, stated the following about the need for integration of functional status into health records:

> The point has already been made that administrative data generally do not include information on functional status. The significance of this fact is that information on this dimension of health—increasingly the sine qua non for understanding health—is not available to the health care system (e.g. insurers and health plans), nor to the researchers, public health workers, and policy makers who depend on administrative data. What is needed, therefore, is a standardized code set that will enable providers, with minimal burden, to include functional status information in administrative data.
> (NCVHS 2001, p. 6)

Having described seminal conceptualizations of healthcare service provision and disability and related evidence for healthcare outcomes, let us present a model of functioning, disability, and health based on a biopsychosocial paradigm of healthcare, WHO's model of health as described within the ICF's conceptual framework.

5.2 WHO's Model of Health

5.2.1 Historical Context: The ICD

International classification of population health began with a focus on the prevalence of medical diagnoses and causes of death with the *International Statistical Classification of Diseases and Related Health Problems* (ICD, now in its 10th revision, WHO 1992), which provides an etiological classification of health conditions (e.g., diseases, disorders, injuries) related to mortality (death) and morbidity (illness). The ICD is a good example of the *medical model's* influence on the diagnostic classification of illness or injury.

The medical model and the ICD alone have significant limitations. Diagnostic information alone is limited in its utility to target and plan interventions and evaluate effectiveness of treatment/healthcare outcomes. Medical documentation classifies diagnoses using a system like the ICD, but it does not classify associated functioning. The functional implications of a given diagnosis across individuals may be quite disparate. Diagnoses may manifest through a variety of impairments that range in their potential impact on functioning. Individual differences in coping styles may impact an individual's reaction to a given impairment, for example, coping with or succumbing to a given difficulty. Diagnoses alone are limited without clear descriptions of associated functioning (Peterson 2011).

5.2.2 International Classification of Functioning, Disability and Health (ICF)

Before we begin, any introduction of the ICF and its conceptual framework runs the risk of being remarkably redundant with other similar published reviews. A variety of publications have discussed and critiqued the ICF (see volume 50 of Rehabilitation Psychology 2005, volume 19 of Rehabilitation Education 2005, and volume 25 of Disability and Rehabilitation 2003). Several book chapters have been written for seminal handbooks in the counseling and psychology professions (Peterson 2009, 2012; Peterson and Elliott 2008), including a text by this author (Peterson 2011). These publications notwithstanding, any explanation of the ICF can and should be referenced back to the ICF itself (WHO 2001).

The International Classification of Functioning, Disability and Health (ICF WHO 2001) was published in 2001 as the latest addition to the World Health Organization (WHO) family of classifications, as a new taxonomy of health and functioning that promotes the use of universal classifications of function that are complementary to the use of diagnostic information in healthcare service provision. A sister classification to the ICD, the two systems are meant to be used together to classify a holistic conceptualization of health and functioning.

The ICF does not classify people; rather, it describes the situation of the person being evaluated within an array of health or health-related domains, which are practical and meaningful sets of related physiological functions, anatomical structures, actions, tasks, or areas of life, within a given context. The ICF was designed to classify not only limitations in functioning but also positive experiences with respect to bodily functions, activities, and participation in the environment (Peterson 2011).

The purpose of the ICF is to "provide a unified and standard language and framework for the description of health and health-related states" (WHO 2001, p. 3). The aims of the ICF as indicated in the document include to (1) provide a scientific basis for understanding and studying health and health-related states, outcomes, and determinants; (2) establish a common language for describing health and health-related states in order to improve communication between different users, such as healthcare workers, researchers, policy makers, and the public, including people with disabilities; (3) permit comparison of data across counties, healthcare disciplines, services, and times; and (4) provide a systematic coding scheme for health information systems (WHO 2001, p. 5).

Using the ICF in combination with diagnostic information provided by systems like the ICD-10 allows the two together to provide more specific and complete conceptualizations of health and human functioning (Bruyère and Peterson 2005). A very important benefit of considering these two perspectives is that disease or impairment may be experienced very differently by two individuals; similar health conditions do not imply similar functioning (WHO 2001).

The ICF represents a new way for the world to conceptualize health and enhance communications regarding health. Research and clinical implementation efforts suggest that the ICF is a useful public health tool for classification of health conditions and functional status and can be applied to a number of clinical arenas (WHO 2001). For example, the ICF provides the basis for a systematic coding scheme for global health information systems. Data from these information systems can be used to identify facilitators and barriers that affect the full participation of people with disabilities in society.

The ICF embraces a biopsychosocial approach for conceptualizing and classifying mental and physical health functioning (body functions and structures), disability (activity limitations and participation restrictions), and environmental barriers and facilitators, in collaboration with the person being evaluated in determining these factors (personal factors), targeting interventions, and evaluating treatment efficacy (health outcomes). These terms are further defined below.

Because of the ICF's developmental history (see Peterson 2011 for greater detail), its concepts and assumptions reflect the holistic values and philosophies espoused in rehabilitation service provision: the dignity and worth of all people and the inclusion of people with illness and disabilities in society to the fullest extent possible (Frank and Elliott 2000; Frank et al. 2009; Peterson and Rosenthal 2005a, b; Riggar and Maki 2004; Scherer et al. 2004). The ICF is a significant development in healthcare, as it can be used as a standard for defining concepts, building constructs, hypothesizing relationships, and proposing new theories that will further research and practice in healthcare service provision (Peterson 2005).

It bears mentioning here that detailed classification of functioning requires reading the ICF and receiving training in its use. Adequate training in its use is outside the scope of this chapter. However, the reader is referred to various published references to become familiar with the full classification system and oriented to its use (Peterson 2011; Peterson and Paul 2009; Peterson and Rosenthal 2005a, b; WHO 2001).

5.2.3 Functioning, Disability, and Health

Within the ICF, the term *health* refers to components of health that are a focus of healthcare professionals (e.g., hearing, learning, remembering, seeing, speaking, walking) as well as health-related components of well-being that are not typically a focus of healthcare systems (e.g., education, labor, social interactions, transportation). The ICF defines *well-being* as "encompassing the total universe of human life domains, including physical, mental, and social aspects, that make up what can be called a 'good life'" (WHO 2001, p. 211).

Attending to contextual factors that are not typically a focus of healthcare systems may lead to improved treatment outcomes. The ICF conceptual framework can help healthcare providers and researchers account for various contextual factors that may be influencing someone's health and functioning as impacted by *disorder* or *disease*, including factors that may escape the focus of many healthcare providers.

Functioning within the ICF conceptual framework is defined as all body functions, activities, and participation in society. *Disability* refers to any impairments, activity limitations, or participation restrictions or "the outcome or result of a complex relationship between an individual's health condition and personal factors, and of the external factors that represent the circumstances in which the individual lives" (WHO 2001, p. 17).

5.2.4 ICF Conceptual Framework

The ICF conceptual framework portrays health as a dynamic interaction between a person's functioning and disability within a given context (see Fig. 5.1). Due to the complexity of interactions in a multidimensional model such as the ICF's model of functioning, health, and disability, the ICF text notes that this proposed conceptual framework is likely incomplete and prone to misrepresentation (WHO 2001, p. 18). WHO created the model to describe the process as an example of the building blocks for users to create their own models and study different aspects of the process of functioning and disability.

The conceptual framework of the ICF consists of two parts: functioning and disability and contextual factors. Each part contains two components; within the first part, functioning and disability, the body component consists of two parallel classifications, body functions and body structures. The second component, activities and participation, covers domains of functioning from both an individual and societal perspective. Conceptualizing healthcare outcomes within this context can first explore the biological bases of behavior (body functions and body structures). Once the physical and mental health and functioning of an individual are clarified at the individual level, how that person functions in his or her environment can be explored with respect to demonstrated potential (activity) versus actual ability to participate within a social context (participation). The discrepancy between identified potential activity and actual participation can serve as the focus of clinical attention for intervention targeting in healthcare treatment and in research for identifying healthcare outcomes.

The second part of the ICF classification addresses contextual factors through two components, the first is environmental factors, or factors in the physical, social, or attitudinal world ranging from the immediate to more general environment. The biopsychosocial model has supported the utility of considering facilitators and barriers present in the environment when planning treatment interventions for people with disabilities. The ICF's conceptual framework assists the healthcare professional in taking into account the physical, social, or attitudinal world, ranging from the immediate to more general environment, and its impact on the difference between an individual with a disability's potential functioning and actual functioning within a given context. Often changes to the environment are very effective in minimizing or eliminating the impact of impairment.

The second component of the second part of the ICF, personal factors, calls attention to the need to consider unique factors like gender, race, age, fitness, religion, lifestyle, habits, upbringing, coping styles, social background, education, profession, past and current experiences, overall behavior pattern and character, individual psychological assets, and other health conditions. Initially the ICF did not specifically code or classify this component due to the ipsative nature and diverse presentations of these factors worldwide. This was probably a reasonable decision with respect to quantitative aspects of healthcare, but disability advocates have highlighted the need to invest in this component of the ICF's conceptual framework (Peterson 2011). For example, race is often reduced to a simplified list for medical records, and it was recognized that trying to have a worldwide-accepted nominal system for race in the ICF can be futile. However, race could be included as advocated by disability rights scholars by using qualitative research and measures to capture not only the complexity of persons' racial and ethnic identities but also how these interact with the social environment, including healthcare. Personal factors call attention to the need for healthcare professionals to consider unique factors influencing an individual's health and functioning, and qualitative methods of research have the potential to provide the richest basis of healthcare evidence for this component of the ICF's conceptual framework, promising a bounty of foci for qualitative exploration of factors associated with healthcare outcomes that are sensitive to regional and cultural differences.

Ultimately the ICF conceptual framework is multidimensional in its scope, and the relationships that exist between its two parts and four components are reciprocal among all constructs. Thus any impact on any of these components of health and function, body functions or structures, and environmental or personal contexts, the resulting nonlinear interaction among constructs can help to predict the potential impact on someone's functional potential (activity) or his or her actual performance in his or her environment (participation). The concepts within the ICF conceptual framework will lend themselves very well to qualitative inquiry to help the allied health professions identify intervention targets and the resulting evidence of healthcare effectiveness.

5.2.5 Ethical Tenets of the ICF

Before presenting a clinical application of the ICF conceptual framework, it is important to note that the ethical tenets of the ICF direct us to use the system in collaboration with the patient or client. The ICF is a tool used "with" someone in a collaborative fashion, not something "done to" the individual (Peterson and Threats 2005; Threats and Worrall 2004). This is the very essence of many qualitative approaches to research, as well as the spirit of transdisciplinary inquiry, where the key source of critical information is the informant in the research process.

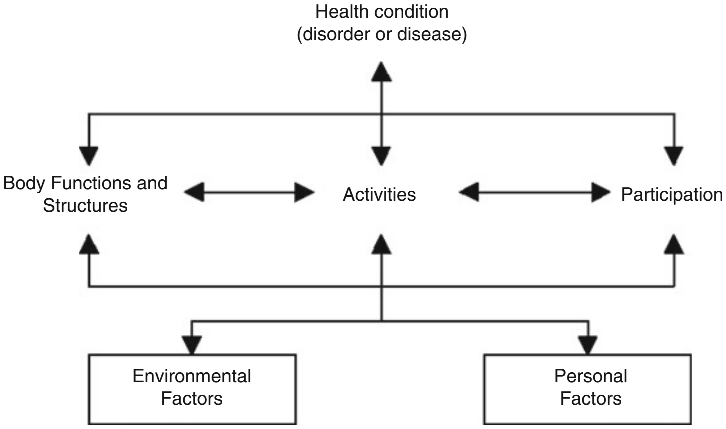

Fig. 5.1 Interactions between the components of ICF. Reproduced, with the permission of the publisher, from the *World Health Report: Health Systems Financing: The Path to Universal Coverage*. Geneva, World Health Organization, 2010 (Fig. 5.1, Page 92 http://whqlibdoc.who.int/whr/2010/9789241564021_eng.pdf, accessed 04 April 2013)

The ICF incorporates a set of ethical provisions that are complementary to major ethical tenets previously identified in counseling and psychology (Anderson and Kitchener 2010), where the ICF is used with consumer participation in a collaborative and informational process. The ICF is unique among classification systems in that the 11 ethical provisions are actually a part of the overall classification system. It is worth our attention in discussing how the ICF can inform how we define health and healthcare outcomes to carefully consider these guidelines and their helpful role in inviting qualitative and transdisciplinary inquiry into this endeavor.

The 11 ethical provisions were established in the sixth Annex of the ICF to reduce the risk of disrespectful or harmful use of the classification system. The provisions address three general areas: (1) respect and confidentiality, (2) clinical use of the ICF, and (3) social use of ICF information (WHO 2001, pp. 244–245). The sixth Annex of the ICF prefaces the ethical guidelines for the use of ICF as follows:

> Every scientific tool can be misused and abused. It would be naïve to believe that a classification system such as ICF will never be used in ways that are harmful to people. As explained in Appendix 5, the process of the revision of ICIDH has included persons with disabilities and their advocacy organizations from the beginning. Their input has lead to substantive changes in the terminology, content and structure of ICF. This annex sets out some basic guidelines for the ethical use of ICF. It is obvious that no set of guidelines can anticipate all forms of misuse of a classification or other scientific tool, or for that matter, that guidelines alone can prevent misuse. This document is no exception. It is hoped that attention to the provisions that follow will reduce the risk that ICF will be used in ways that are disrespectful and harmful to people with disabilities.
> WHO (2001, p. 244).

The 11 provisions are listed here according to three broad themes:

Respect and Confidentiality

1. ICF should always be used so as to respect the inherent value and autonomy of individual persons.
2. ICF should never be used to label people or otherwise identify them solely in terms of one or more disability categories.
3. In clinical settings, ICF should always be used with the full knowledge, cooperation, and consent of the persons whose levels of functioning are being classified. If limitations of an individual's cognitive capacity preclude this involvement, the individual's advocate should be an active participant.
4. The information coded using ICF should be viewed as personal information and subject to recognized rules of confidentiality appropriate for the manner in which the data will be used.

Clinical Use of ICF

5. Wherever possible, the clinician should explain to the individual or the individual's advocate the purpose of the use of ICF and invite questions about the appropriateness of using it to classify the person's levels of functioning.
6. Wherever possible, the person whose level of functioning is being classified (or the person's advocate) should have the opportunity to participate and in particular to challenge or affirm the appropriateness of the category being used and the assessment assigned.
7. Because the deficit being classified is a result of both a person's health condition and the physical and social context in which the person lives, ICF should be used holistically.

Social Use of ICF Information

8. ICF information should be used, to the greatest extent feasible, with the collaboration of individuals to enhance their choices and their control over their lives.
9. ICF information should be used toward the development of social policy and political change that seeks to enhance and support the participation of individuals.
10. ICF, and all information derived from its use, should not be employed to deny established rights or otherwise restrict legitimate entitlements to benefits for individuals or groups.

11. Individuals classed together under ICF may still differ in many ways. Laws and regulations that refer to ICF classifications should not assume more homogeneity than intended and should ensure that those whose levels of functioning are being classified are considered as individuals (WHO 2001, pp. 244–245).

It is clear that the contributors of the ICF shared values were consistent with the premises of various qualitative approaches to inquiry and obviously consistent with the stakeholder collaboration focus of transdisciplinary approaches to research.

5.3 Transdisciplinary Approach to Research

The 1990s was witness to the development of interdisciplinary and multidisciplinary approaches to research, drawing together social and health sciences to address a broad range of health problems (Rosenfield 1992). The difficulties encountered in these approaches included the lack of consensus across disciplines, as in the instance of the focus of this text, the definition of evidence for healthcare research. A transdisciplinary approach as defined in the aforementioned seminal article is a systematic, comprehensive theoretical framework for the definition and analysis of the social, economic, political, environmental, and institutional factors influencing human health and well-being. Progress over the next two decades yielded a more general definition of transdisciplinary research, partnerships of researchers from a wide range of disciplines working together with stakeholders (Hirsch Hadorn et al. 2008).

The ICF conceptual framework and the ethical tenets that guide its use lend themselves very well to provide many disciplines across diverse societies with a common language of functioning, disability, and health that encourages collaboration with stakeholders at all levels of its use in healthcare. In fact, as the ICF is more widely adopted and its constructs and tenets incorporated in healthcare service provision and research over time, the ICF conceptual framework may help remedy the lack of agreement on a general definition of evidence for healthcare research across disciplines. With a common language of functioning, disability, and health across disciplines and societies providing healthcare, problems facing stakeholders can be identified and analyzed, and the results can be brought to fruition connecting knowledge with practical application in a wide range of healthcare contexts.

5.4 Application of the ICF Conceptual Framework

The following scenario will help illustrate the utility of the biopsychosocial framework and the ICF for case conceptualization and research in healthcare. Consider a 22-year-old male who is gay, who due to a head trauma has a mild neurocognitive disorder and a co-occurring diagnosis of major depressive disorder, recurrent and severe, due to general medical condition (the head trauma). The ICF's conceptual framework would first encourage us to consider any changes in body structures (head trauma to brain structures and their sequelae, changes in brain chemistry that may be associated with depression) and related body functions (impaired neuropsychological functioning, including physical, cognitive, and emotional functioning, depressed mood, and all of its potential consequences). We may measure these changes through clinical interviews, psychological testing, and evaluations by other medical specialties like neurology, psychiatry, counseling, and psychotherapy, with both quantitative and qualitative data.

During this assessment process, the ICF conceptual framework encourages us to note the differences between functioning potential (activity) and actual functioning within the person's environmental context (participation). With careful analysis of the person's context, and sensitivity to personal differences (like being a gay man), the complex relationships between the person's optimal and actual functioning in their environment can serve as starting points for interventions that will enhance overall functioning, along with the research of associated healthcare outcomes.

With respect to contextual factors, if the head injury resulted in mobility impairment, it may be necessary to remove environmental barriers to functioning. If the resulting sequelae of trauma or symptoms of depression are difficult for the patient's coworkers to understand, psychoeducational interventions for coworkers and supervisors may be very useful in creating a supportive environment that maximizes potential for success. Such activities have historically been the domain of job development and support personnel within the vocational rehabilitation system, and the rehabilitation counseling literature has a great deal to offer healthcare professionals in this regard (see Homa and Peterson 2005).

The interaction between personal and environmental factors may provide targets for intervention or qualitative measurement in research. For our example, if the client had never come out to his family as a gay person prior to his injury and his family did not know any of his friends from that community, and now due to the injury the family is in close contact with his network of friends, there may be a need for healthcare professionals to provide support to the client or, with permission, to family and friends, as relationships evolve in a new social context. This is a particularly good of example of a scenario conceptualized by the ICF model of health that is rich in potential for qualitative exploration of factors influencing healthcare outcomes.

A healthcare professional or researcher may encounter a variety of perspectives across and within allied healthcare agencies. Understanding differing perspectives on healthcare provision can help to identify allies and inform strategies to address barriers in the system. For instance, if a therapist working with individuals is encountering a healthcare entity focused on the medical model of service provision, the counselor's advocacy efforts can focus on social and contextual factors to encourage a holistic program of healthcare. A hospital treating the young man in our example may be focused on medical presentations of impairment related to his head trauma and the degree of depressive symptomatology and related risks. The ICF's conceptual framework addresses these foci through body functions and body structures (which include the brain). In addition, the biopsychosocial approach embraced within the ICF's conceptual framework will take into careful account contextual issues such as the client's family system, social circles, and the greater community. Further, through a consideration of activities and participation, the client's potential based upon his functioning and impairments can be compared with how his current context facilitates or hinders his functioning.

Since disability is a complex entity, it can also affect the family members of the person with a disability, and this population's difficulties must be studied and understood to know the full impact of disability on society. The ICF refers to the difficulties of the family members of persons with disability as "third-party disability" and states that it is an important future area of research. Clinical research has shown the utility of using the ICF framework for qualitative research to study third-party disability. An article by Grawburg et al. (2013) entitled "A qualitative investigation into third-party functioning and third-party disability in aphasia: Positive and negative experiences of family members of people with aphasia" examined the family members of persons with aphasia, which is an acquired neurological disorder affecting language. They used a mixed-method study as a preliminary step to developing a tool for measuring third-party disability in family members with aphasia. They concluded:

> Interpreted within the framework of the ICF, this study showed how the pervasive effects of aphasia are associated with changes in Functioning and Disability in family members, providing a holistic description of family members' experience using the standardised language of the ICF. Clinically, these results emphasise the importance of recognising the positive and negative outcomes for close family members in the development of a rehabilitation plan for the family to address their experience of third-party disability.
> Grawburg et al. (2013, pp. 828–829)

Healthcare professionals and researchers may find that some healthcare systems are more open to the biopsychosocial approach than others. It is important to work with the strengths inherent in a given system and to carefully offer support for potential improvements based on the ICF framework. For example, in order to work most effectively with medically focused healthcare systems, healthcare professionals can benefit from the medical expertise present in such systems and then in turn use ICF-based expertise informed by a biopsychosocial framework to highlight the role of contextual factors in facilitating or hindering healthy functioning. Research exploring these dynamics qualitatively using best practices will provide healthcare evidence that supports adopting a more holistic perspective in healthcare service provision and research.

5.5 ICF Research Efforts

Keeping pace with the research that is emerging on the use of the ICF in healthcare is not as easy as it once was. Once the ICF was published in 2001, all member nations of the World Health Assembly were charged to use the ICF where appropriate within their healthcare-related systems. Early efforts in ICF-related literature encouraged familiarity with the ICF as it related to the ICD, as well as encouragement of its clinical implementation where useful. Implementation of the ICF needed to be sensitive to the context of its implementation, so globally coordinated efforts were not indicated. Adoption of the ICF had to be sensitive to the policies and structures in place for a given country or geographic region. Regional efforts resulted in the establishment of centers like the North American Collaborating Center for the ICF.

Since then, the literature related to the ICF has focused largely on two major themes, the establishment of over 30 core sets, or specific collections of ICF codes that would apply to specific healthcare areas or conditions, and efforts to link the ICF with seminal instruments in a wide range of healthcare disciplines. First I will provide a brief and thus incomplete overview of core set development efforts, followed by ongoing efforts to establish effective protocols to help link the ICF to specific instruments in healthcare.

5.5.1 ICF Core Set Development

ICF Core Set development was sanctioned by the World Health Organization in order to increase the likelihood of adaption in medical settings. Since the ICF has over 1400 codes, it is daunting for the clinician to search all of the codes for the description of their patients. The idea of a core set was to have lists of the most prevalent functional health limitations for given diseases.

Core set development efforts within the mental health realm have focused on those conditions most frequently encountered in clinical practice: psychiatry in general (Alvarez 2012); addiction (Amann et al. 2011); bipolar disorder (Avila et al. 2010); depressive disorders (Brockow et al. 2004; Cieza et al. 2004a; Ewert et al. 2004); and anxiety, depression, and schizophrenia (Tenorio-Martinez et al. 2009). Core set developments in physical medicine are increasingly diverse and include breast cancer (Brach et al. 2004), pain management (Cieza et al. 2004b), cardiopulmonary conditions (Boldt et al. 2005; Wildner et al. 2005), neurological conditions (Ewert et al. 2005; Stier-Jarmer et al 2005), amputation (Kohler et al. 2009), musculoskeletal conditions (Scheuringer et al. 2005; Stoll et al. 2005), and many others.

The core sets typically were generated through consensus-building processes involving experts in the area based upon their clinical expertise, specific instruments in wide use, and contextual factors as they relate to the ICF code structure. Generic ICF code sets were aspired through the use of regression modeling (Cieza et al. 2006). Ultimately the consensus in core set development is that there are a number of approaches necessary to construct them, including both quantitative and qualitative approaches; while more research appears necessary, the consensus appears to be the need for multiple approaches to core set development.

The ICF Core Set development protocol was eventually developed into a multistep empirical process. The preparatory phase involved four different methods: (1) an empirical multicenter study, (2) a systematic literature review, (3) a qualitative study, and (4) an expert survey

(Bickenbach et al. 2012). The qualitative study component of the development of the core sets ascertained the experiences of persons living with the different health conditions. There are ongoing validation studies of these core sets that will also involve qualitative data using patient focus groups. Thus, the ICF Core Set research team demonstrated understanding of the importance of qualitative research as well as quantitative research to inform practical use of the ICF.

5.5.2 ICF Linking Efforts

In addition to the development of the core set, another method to attempt to increase the clinical use of the ICF is to be able to link currently used assessment measures to specific ICF codes. Cieza et al. (2005) provide the most cited work on establishment of rules for linking assessments to ICF codes. Cieza et al. states, "the application of the ICF as a connecting framework between interventions and outcome measures can be extremely useful when comparing different investigations with respect to the interventions administered and the results obtained" (2005 p. 212). Researchers have developed and linked technical (laboratory, imaging, and electrophysiological) and clinical (physical and psychological tests) measures, health-status (patient or proxy reports on health or quality of life) measures, and interventions to the ICF as a common reference framework for functioning (Cieza et al. 2005). The linking literature states that it is crucial to note the source of the data being used to link. A given trait might be measured using either a quantitative or a qualitative measure, yet both may be linked to the same ICF code. Thus, for example, if a third party payer was comparing two rehabilitation facilities on the functioning represented by that trait, it could appear that one has disparate results from the other because they derived the ICF code from different types of assessments. For many of the ICF codes, that best measure may well be one developed from qualitative research.

The ICF Core Sets and the linking rules may best be developed in an interactive paradigm. The core sets need to be sensitive to ensuring that they include the subjective experiences of persons with disabilities and their families. There are assessments that are straightforward in their ability to link to specific ICF codes within a given ICF Core Set. However, there are many ICF codes that do not have an appropriate assessment (Ma et al., 2008). Qualitative research may hold promise for some of these areas including the activity/participation codes that require a method of getting the person's view of their functioning in a given area within their natural environments. As stated earlier in this paper, there is also great potential for qualitative research for development of research on the contextual factors of environmental factors and personal factors.

The ICF linking initiatives are consistent with transdisciplinary research developments noted earlier. With ongoing creation of instruments across disciplines, and ongoing use of existing time-tested preferred measures, the ICF linking efforts can help establish a record of linking disparate measures to common, universal constructs, facilitating comparisons of data across studies, disciplines, and even geographic regions.

5.5.3 Future Development Efforts

According to an analysis of the ICF-based literature, in order to shed some light on the reported use of the ICF, 243 papers were analyzed spanning from the publication of the ICF through 2008 (Jelsma 2009). The review produced several recommendations for future development of the ICF that for the most part addressed the classification at the specific code level, which has not been the focus of this chapter. See Peterson (2011) and the ICF itself (WHO 2001) for specifics on ICF coding protocols. That said, five of those recommendations are discussed below in light of the goals of this text.

First, the analysis revealed that the most of the ICF work was done in high-income developed countries. Given the aims of the ICF, it is clear that countries with resources may remedy this imbalance by supporting initiatives in collaboration with developing countries. Second, the analysis revealed that existing ICF codes contained some overlapping codes, and codes were needed that did not currently exist (see also Amann et al. 2011). This should not be surprising given that the ICF in its current state is basically a nascent iteration of older, less-complete versions of itself, and as contributors fulfill the aims of the ICF, the related scholarship will inform development of the details of the classification system. Specific to this text, both quantitative and qualitative measures will be useful to this end. Third, the operationalization of the concepts of activity and participation appeared to present the most challenges in the literature (e.g., Avila et al. 2010). When we consider the meaning of these constructs, the essence of them is how well one can manifest his or her potential given the circumstances in which one finds him or herself. Objective measures will help complement the subjective experiences that are critical to consider in meeting the aims of the ICF, again arguing for a combination of qualitative and quantitative inquiry.

Fourth, the use of qualifiers [demonstrating the degree of impact on function, see Peterson (2011) and WHO (2001)] was inconsistent in the literature reviewed. It is important to note that the WHO offered several options within the ICF as to how qualifiers could be used to modify codes sets, but reviews of local efforts to clinically implement the ICF reveal that these options were not universally adopted by all member nations (see Peterson 2011). One noted limitation of the qualifiers is that the primary definition in the ICF is in percentage ranges (e.g., "mild (5–25 %)" decrease in function), which may reflect a quantitative measure bias of the ICF developers. However, what would a "mild (5–25 %)" barrier in the environmental factor ICF code 450 ("individual attitudes of health professionals") represent? Thus, there are many codes where any reasonable degree of impairment or decrement must be expressed by measures different than a quantitative percentage measure. Since the ICF states that the ICF codes must be used with an appropriate and scientifically derived severity measure as represented by the qualifiers, qualitative research has much to offer in the development of appropriate qualifiers for many ICF codes.

Finally, and among the greatest controversies associated with this first iteration of the ICF proper, disability advocates and scholars alike noted the need to develop actual code sets for the personal factors component of the second part of the ICF conceptual framework, contextual factors. There was some intuitive logic to the notion that this component of the ICF's conceptual framework was so diverse that it may defy actual classification or perhaps that it could not yield coding that was universally useful because of geographic societal differences alone. More careful consideration of the utility of qualitative inquiry would argue for exploring the wealth of information surrounding this construct and developing a creative code structure informed by transdisciplinary inquiry consistent with the aims of the ICF.

Another paper exploring future research on the ICF focused on psychiatry specifically and suggested that there was a general lack of scholarship in the use of the ICF in psychiatry due to several barriers to progress in its adoption. First they suggested that, apart from being relatively new on the healthcare scene, the ICF's biopsychosocial framework may be at odds with the dominance of the medical model within psychiatry. The focus on medication as the first line of treatment may not value the more contextual focus of the ICF for intervention targeting efforts. Others within psychiatry may presume that "disability" as a construct deals with physical disability and not psychiatric ones. Ultimately this review noted the overall complexity of an instrument that aspires to classify health and functioning alongside the massive ICD structure and the intrinsic limitations that are being identified as this nascent instrument evolves through its current iteration (Alvarez 2012). See also Peterson (2011) and De Kleijn-De Vrankrijker (2003) for an overview of previous versions of the ICF such as the ICIDH (WHO 1980) and the ICIDH-2 (WHO 1999).

5.6 Conclusion

The ICF as a whole has made an impact on efforts to conceptualize, collect, and process data related to disability, health, and function (Jelsma 2009; Peterson 2011). The clear shift away from disease to health and function is the most salient contribution to this endeavor, which has had and will have tremendous impact on both qualitative and quantitative inquiry on research in healthcare outcomes. The focus on contextual factors within a biopsychosocial framework is the other principle and substantial contribution to presenting healthcare evidence that is more holistic and clinically useful.

Future research involving the ICF and healthcare outcomes may permit comparison of data across countries, healthcare disciplines, services, and time, contributing to an international database of scientific knowledge of health and health-related states and thus stimulating research on the consequences of health conditions in a truly transdisciplinary fashion. The ICF and its conceptual framework may assist in preparing the current and next generation of healthcare and health-related professionals for our increasingly complex healthcare systems (Peterson and Elliott 2008).

The ICF has the potential to increase communication efficiency among healthcare providers, clearly target necessary interventions, and provide a conceptual framework to analyze the success of interventions, all of which are critical to maintaining quality healthcare while controlling costs. The ICF is useful for a broad spectrum of applications within sectors of health-related settings including insurance/managed care, social security, labor, economics, population surveys, and social policy, including prevention and health promotion (Howard et al. 2008), general legislation development, and sectors associated with environmental modification (WHO 2001, p. 5).

The focus of the chapter has been on how the WHO model of health as operationalized in the conceptual framework of the ICF informs our inquiries into evidence in healthcare research and practice. We established that the biopsychosocial model has expanded considerably the domains formerly established by the medical model. The constructs within the ICF conceptual framework are friendly to the use of both quantitative and qualitative measures to help describe functioning, disability, and health.

Defining health in healthcare research from the body, individual and societal perspectives can improve the quality of healthcare research and subsequent healthcare service provision (Peterson and Threats 2005). The ICF has the potential to improve healthcare in the broadest sense, while providing specific benefit to people with disabilities, by using a universal, culturally sensitive, integrative, and interactive model of health and disability that is sensitive to social and environmental aspects of functioning.

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6 Qualitative and Quantitative Evidence in Health: The Critics' View

Kadriye Ercikan and Wolff-Michael Roth

6.1 Introduction

> Much of what medical researchers conclude in their studies is misleading, exaggerated, or flat-out wrong.
> Freedman (2010)

This is the beginning sentence of an article in the *Atlantic* magazine entitled "Lies, Damned Lies, and Medical Sciences." The entire article is about Dr. John Ioannidis, whose highly cited studies have been challenging medical research with similarly provoking claims about the accuracy of medical research results reported in reputable journals. For example, Ioannidis (2005) boldly states that most current medical research findings are false. The objects of his criticism are not limited to small-scale observation-based research studies with small sample sizes but also include what might be thought of as gold standards of research: randomized control trials (RCTs). In addition to the criticisms about accuracy of claims from RCTs, the external validity of RCTs has been questioned. Six main issues that may affect the generalizability of knowledge claims from RCTs have been identified (Rothwell 2005): (a) setting of the trial, (b) selection of patients, (c) characteristics of randomized patients, (d) differences between the trial protocol and routine practice, (e) outcome measures and follow-up, and (f) adverse effects of treatment. Underlying this chapter is our conviction that it is more important for health researchers to worry about the *quality* of research evidence than about whether the research is of the quantitative, qualitative, or mixed-method type. Independent of whether the research is qualitative or quantitative, we are as critical of research that overgeneralizes as we are of research that fails to offer generalizations beyond the actual case(s) studied.

The question of what constitutes "good" research evidence is at the heart of this chapter. Evidence, as is the term is typically used in evidence-based practice, refers to "an observation, fact, or organized body of information offered to support or justify inferences or beliefs in the demonstration of some proposition or matter at issue" (Upshur 2001, p. 7). Such research inferences typically involve making *generalizations* to populations and contexts beyond the specific samples used in the research. The question about generalizability of research findings—also referred to as external validity—is not simple, cut

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and dry, because the results' experimental studies and epidemiological studies *may not pertain* to the individual precisely because of their generalizing nature; and the results of some qualitative research approaches pertain to *every* individual, despite the extreme reluctance of many qualitatively working researchers to seek generalization of research results (Ercikan and Roth 2014; Roth 2009b). The ultimate questions about health research are these: "to whom do the knowledge claims from research apply?" and "if others cannot use the findings of my research, if my results do not generalize to other settings, what good is it to try reporting them?"

Evidence-based practice informed by empirical research is highly emphasized in many fields: at the time of this writing (June 2013), a simple search for the topic "evidence-based" in the ISI Thomson database yielded 48,230 articles. The first five of these articles are from health-related fields (occupational health, health education, nursing). The term "evidence-based," however, often has been taken as synonymous with the results of experimental research and large-scale statistical studies, whereas the results from observational and qualitative studies have been thought of as providing anecdotal evidence only. Yet the question "what constitutes evidence?" is much more complex than the association between evidence and statistical/experimental research.

On the one hand, quantitative research has well-established guidelines for determining what counts as evidence and which research findings can be generalized. These generalizations typically are tied to the research design (such as in RCTs) and representativeness of the sample relative to the target population of interest. The question remains whether the same evidence supports decisions for different groups and individuals. To answer these questions, we need to consider the extent to which health research conducted in one setting (a) can be used to inform other settings and (b) findings generalize from one sample to the target population and, thereby, apply to another subpopulation and other individuals. In a policy context that places great value on evidence-based research, experimental research and research using high-power statistics tend to be privileged as having the capacity to support generalizations that can contribute to decision-making in policy and practice (e.g., Slavin 2008; Song and Herman 2010). Group-level evidence—such as whether an intervention is effective based on an experimental design—likely is not sufficient to make decisions about effectiveness of the intervention for individuals or for subgroups such as males or females, age groups, or individuals from different ethnic and racial backgrounds. This is not only so because of the statistical nature of experimental design but also because almost all experiments are based on the logic of interindividual differences and covariations rather than on a logic of within-individual differences and causations (Borsboom et al. 2003). Moreover, a recent Bayesian analysis of 855 published studies in experimental psychology showed that in 70 % of the cases with *p*-values between 0.01 and 0.05, "the evidence is only *anecdotal*" (Wetzels et al. 2011, p. 291, emphasis added).

In qualitative research, on the other hand, claims are often restricted to the settings, to the subjects, and to the context of the research without efforts to derive generalizable claims from research. Thus, for example, one qualitative study concerned with pediatric oncology education reports positive impact and yet calls for "further evidence" that "truly analyses the effectiveness and impact of education on paediatric oncology practice" (McInally et al. 2012, p. 498). That is, there is a contradiction within the article that both claims to report on the impact of oncology education *and* calls for studies that *truly* analyze the impact.[1] This does not have to be this way, because there are ways of going about qualitative research such that the results are invariant across all members of a population; that is, they pertain to every individual.

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[1] This study was picked at random from the sample of articles that resulted from a search in the ISI Thomson Web of Science database with the search parameters "evidence based," "qualitative research," and "health." We do not "pick" on this particular article but use it as an example of a general tendency among qualitative researchers to refuse seeking the *general* rather than sticking with the particular.

Moreover, in some forms of research, such as the Bayesian approach, statistical and qualitative information is explicitly combined. Thus, one study concerned with identifying factors that mediate adherence to medication regiments in HIV situations synthesized a body of quantitative and qualitative studies by generating qualitative themes emerging from the former and by quantizing the information from the latter and then used Bayesian data augmentation methods to summarize all studies (Crandell et al. 2011). In this chapter, we articulate the structure and discuss limitations of different forms of generalizations across the spectrum of quantitative and qualitative research and argue for a set of criteria for evaluating research generalization and evidence.

6.2 Generalization in Quantitative and Qualitative Research

Similar to social science research, *generalization* in health research is a critical concept where the specific is expanded to the general ("generalized") and the general is reduced to the specific ("particularized") in the creation of knowledge to inform policy and practice (Ercikan and Roth 2009; Roe 2012). In both qualitative and quantitative research, generalization typically focuses narrowly on representativeness of the sample on individuals of the population the generalizations target. However, in addition to the target population, many facets of research determine generalization, including: time and context of research, attributes focused on, and methods utilized. The degree to which knowledge claims from research can inform practitioners who deal with individuals and policymakers who deal with groups depends on the degree to which such contexts, methods, and attributes are applicable to the target generalization situation. In this section we discuss three main forms of generalizations: *analytic*, *probabilistic*, and *essentialist*. We highlight their limitations in view of how they can be considered as evidence to inform policy and practice.

6.2.1 Analytic Generalization

Analytic generalization relies on the design of the research to allow making causal claims, for example, about the effectiveness of a health intervention (Shadish et al. 2002). The primary logic in this design is this: instances where a cause operates have to lead to significantly different observations than those instances where the cause is disabled. The design requires randomly assigning participants to control and experimental groups in the hope of achieving equivalence of these groups with respect to all moderating and mediating variables and an identical implementation of the intervention to the experimental group. The experimental and control groups are not expected to be representative samples of any particular target population. Instead, random equivalence of these two groups is central to the experimental design and is intended to rule out any potential alternative explanations of differences between the two groups. The causal claims from analytic generalization are closely tied to the degree to which the experimental design truly implements the theoretical relations between causes and effects. The statistical support for the effectiveness of the treatment is determined by comparing the difference between the mean outcome scores of control and experimental groups to the standard error of the mean differences. A statistically significant difference in the hypothesized direction between control and experimental groups provides evidence to support a causal claim about the effectiveness of the treatment.

Causal claims in analytic generalization are evaluated based on two key criteria. The first criterion is whether there is a systematic difference between experimental and control groups that can be supported by statistical evidence. The second criterion is the degree to which a true experiment has been conducted so that the change in experimental group outcomes can be attributed to the specific operating cause deriving from the treatment and explained by theory. The causal claims in analytic generalization is based on the logic of between-subjects rather than within-subjects variation (Borsboom et al. 2003) and can be supported only at the overall group level. In other words, treatment may have been effective "on the average" but the causal claim may not apply to some individuals or some subgroups. Figure 6.1 presents distributions of outcome scores for experimental and control groups from a hypothetical experiment. As the overlapping area in Fig. 6.1 shows, a considerable number of individuals in the control group may have higher scores than individuals in the experimental group. Even though individuals from the experimental group are more likely to be on the higher end of the outcome score scale and those from the control group are more likely to be at the lower end of the scale, we cannot tell how the change in scores varied for different individuals or subgroups and whether the change was uniformly in the same direction. The degree of change and the direction of change for individuals in the experimental group cannot be determined by comparing score distributions with the control group.

6.2.2 Probabilistic (Sample-to-Population) Generalization

Probabilistic generalization—also known as statistical or sample-to-population generalization—relies on representativeness of a sample of a target population. It is used to describe population characteristics and does not include causal claims (Eisenhart 2009; Yin 2008). Researchers and consumers of research judge knowledge claims by the degree to which samples of subjects, outcomes, and contexts used in research are representative of the populations to which the research is intended to generalize (Ercikan 2009; Firestone 1993). Two broad types of probabilistic generalizations are common. One type of generalization claim is with respect to relationships between variables. An example of such research includes an investigation of the relationship between anxiety and suicide attempts based on a nationally representative data of US adult population from the National Epidemiologic Survey on Alcohol and Related Conditions Wave 2 (NESARC II) (Nepon et al. 2010). This research demonstrated that of all those who made a suicide attempt, over 70 % had at least one anxiety disorder. In this research, statistics is used to estimate the probability that a systematic relation between each disorder and suicide attempt exists beyond chance level. The second type of research generalization is related to relative frequency for demographic or other groups of interest. For example in the Nepon et al. (2010) study, these generalizations include the proportion of individuals identified with anxiety disorders or suicide attempts by gender groups. In both of these probabilistic generalizations, generalization claims are derived from observations from the sample. The criteria by which the generalization is judged—i.e., the validity of claims about the correlation between anxiety disorders and suicide attempts or gender differences in anxiety disorders—center on one of the same criteria used for judging analytic generalization, that is, whether there is statistical evidence of a systematic pattern in the data. Even though probabilistic generalizations may include group comparison, such as comparing gender or ethnic groups, these generalizations do not require a specific research design such as random equivalence of groups or standardized implementation of an intervention. Instead, the representativeness of the samples of the target populations is the second key criterion used for probabilistic generalizations.

Within-group heterogeneity limits the meaningfulness of *causal* claims in analytic generalization for subgroups or individuals and leads to similar limitations in probabilistic generalization.

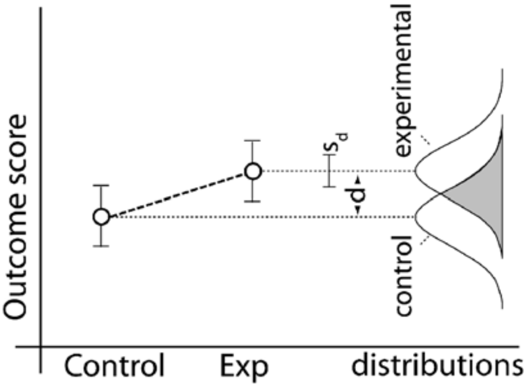

Fig. 6.1 Hypothetical distribution of outcome scores for experimental and control groups

When there is great diversity within the target population, such diversity will be reflected in the nationally representative sample the research is based on. It has been argued that cultures differ in fundamental aspects such as reasoning styles, conceptions of the self, the importance of choice, notions of fairness, and even visual perception (Henrich et al. 2010). Research claims regarding such psychological constructs at national levels will have limited generalizability to different cultural groups. It is easy to see how prevalence statistics, for example, for anxiety disorders, may vary for subgroups, such as people with illnesses, gender, or age groups. In fact, one study found that in cancer patients the risk of psychiatric distress was nearly twice that of the general population (Hinz et al. 2010). Therefore, a claim about prevalence of illnesses—a probabilistic generalization—has limitations in its accuracy and meaningfulness for different subgroups. Population heterogeneity may lead to similar problems in generalizations of correlational relationships. Based on their research, Nepon et al. (2010) conclude that panic disorders are associated with suicide attempts. These researchers established evidence that individuals who are diagnosed with panic disorder are two and a half times more likely to attempt suicide than those who are not diagnosed with this disorder. Research has demonstrated a great degree of variation in the prevalence of suicide attempts across cultures—participating countries were the United States, Canada, Puerto Rico, France, West Germany, Lebanon, Taiwan, Korea, and New Zealand—ranging from 0.72 in Lebanon to 5.93 in Puerto Rico (Weissman et al. 1999). Such diversity limits the applicability of single prevalence statistics across cultures. It is also expected to affect the degree to which correlation between suicide attempts and other variables. In summary, therefore, when population heterogeneity is present, probabilistic generalization focusing on describing population characteristics can lead to knowledge claims that involve statistical concepts—e.g., mean, frequency, mean differences, or correlations—that may not apply to subgroups and may have limited value for guiding policy and practice.

6.2.3 Essentialist Generalization

Essentialist generalization systematically interrogates "the particular case by constituting it as a 'particular instance of the possible' [...] to extract general or invariant properties that can be uncovered only by such interrogation" (Bourdieu 1992, p. 233). Because *every* particular is as good as any other, such research therefore identifies invariants of the phenomenon that hold across *all* particulars related to the phenomenon of interest. Therefore, essentialist generalization involves identifying aspects of the phenomenon that applies to *all* individuals in the population. The identification of invariants, and therefore the construction of a generalization, is possible by focusing on the *process* by means of which a phenomenon manifests itself rather than on the manifestations themselves (as this would be reported in phenomenographic studies). Classical examples of essentialist generalization derive from studies within the dialectical tradition, which seeks to understand the diversity of social life and phenomena based on cultural-historical and evolutionary precursors. An example of such research is the Russian psychologist L. S. Vygotsky's (1971) generation of a *general theory* of the psychology of art. He was interested not in the psychology of any particular art form but of art in general: "*I talk about all art* and do not verify my conclusions on music, painting, etc." (Vygotsky 1927/1997, p. 319, original emphasis). Thus, he took as his "very special task to find *the precise factual boundaries* of a general principle in practice and the *degree* to which it can be applied to different species of the given genus" (p. 319).

In his analysis, Vygotsky begins with one fable and, having articulated some general principles that make up the basis of all art forms, uses *one* short story and *one* tragedy as a test-bed of his findings (Fig. 6.2). Just as stated in the above quotation, Vygotsky took the particular case of the fable and isolated with his analysis *affective contradiction* and *catharsis* as the essential processes in/of any art form. This required him to "abstract from the concrete characteristics of the fable as such, a specific genre, and [to] concentrate the forces upon the *essence* of the aesthetic reaction" (Vygotsky 1927/1997, p. 319, our emphasis). That is, he ascended in a way the tree and located properties that are typical not only in the specific art form but in all forms of art that descended from the same essential aesthetic reaction (Fig. 6.2). This essence is true for and generalizes to all art forms. For this reason, we refer to such generalization as *essentialist*. Commenting on the approach, the author of the introduction to *The Psychology of Art*— —who himself has used the essentialist method to trace the origin of human emotion to the first forms of life, such as, single-cellular organisms—notes that:

> […] the significance and function of a poem about sorrow is not at all to transmit the author's sadness to the reader […] but that it changes this sorrow in such a manner as to reveal something new and pertinent to man on a higher level of truth.
> Leontiev in Vygotsky (1971, p. vii)

To arrive at the essence of art, the analysis focused on the "aesthetic reaction," that is, on "*the processes in their essence*" (Vygotsky 1927/1997, p. 319). In concrete contexts, which for the psychology of arts constitute the different art forms, the *essential* processes bring forth phenomena that *appear* different (e.g., fable, pottery, blues music, Fig. 6.2), that seem to constitute difference, when in fact the processes are the same. The author concludes that this method is similar to the classical experiment: the "meaning" of the result "is broader than its field of observation" (p. 319), though the principle "*never manifested itself* in pure form, but always with its 'coefficient of specification'" (p. 319).

Pertaining to health research, one can find this essentialist generalization in a philosophical tradition of E. Husserl, such as the analysis of organ transplants, beginning with the experience of: (a) receiving a new heart (Nancy 2000) or a new liver (Varela 2001), (b) long-term chronic fatigue syndrome (Roth 2009a, 2014), (c) taking psychoactive drugs (Roth 2011), or (d) suffering in general (Roth 2011). In these instances, the analyses do not strive to communicate the singular experiences of these authors/patients but are designed to reveal fundamental processes and phenomena that underlie the experience of an organ transplant *generally*, including "the lived body and its exploration, the unalienable alterity of our lives,

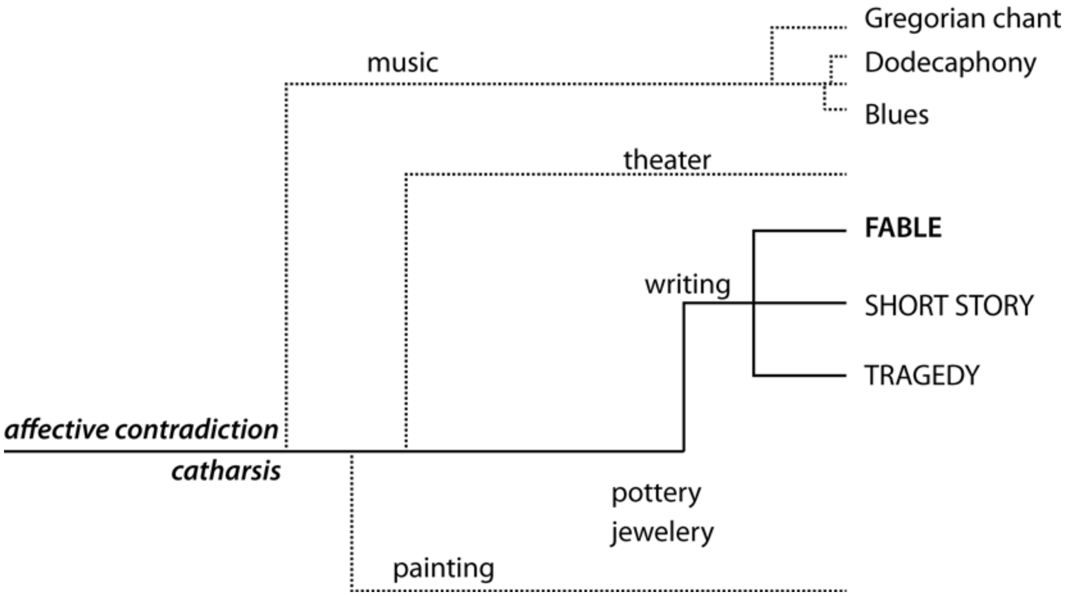

Fig. 6.2 Vygotsky's essentialist generalization derived a general law for the psychology of art on the basis of one case (here the *fable*); the law was tested in a small number of other cases (here *short story* and *tragedy*)

the key ground of temporality, body-technologies and ethics" (p. 271). The purpose of this type of phenomenological study is to arrive at descriptions of experience that make it possible to allow collaboration with those "hard sciences" that investigate true causes (i.e., at the individual level) rather than impute causes that only describe relations at the group level. For this reason, the "*disciplined first-person* accounts should be an integral element of the validation of a neurobiological proposal and not merely coincidental or heuristic information" (Varela 1996, p. 344, original emphasis, underline added). That is, there is an explicit rapprochement of "hard" experimental work and "soft" (but essentialist) qualitative research; and there are calls for the explicit coordination of research combining essentialism with forms of research in the natural and experimentally working social sciences (Bourdieu 1992; Roth and Jornet 2013).

Recent studies have shown that first- and second-person phenomenological methods in physical and emotional health research may be used to arrive at generalizations of phenomena that may be identified in the study of one individual but that are observable in *every* individual case (e.g., Roth 2012; Vygotsky 1927/1997). One study concerned with predicting the occurrence of epileptic seizures exhibited the possibility to, "establish correlations between precise 'first person' descriptions of the subjective experience of a given cognitive process […] and 'third person' measures of the corresponding neuroelectric activity" (Petitmengin et al. 2006, p. 299). Thus, the correct identification of signs of seizures can be used for alternative, non-medication-based therapies that actually prevent or interrupt a seizure. Other studies from a neurophenomenological perspective exhibit the viability of connecting the qualitative descriptions of experience with hard evidence from EEG and fMRI studies of physiological and psychiatric phenomena (e.g., Micoulaud-Franchi et al. 2012).

Research conducted in this vein identifies in the singular case a particular instance *of the possible*. This possible constitutes the general. In this way, the general is as concrete as the particular. The following genetic analogy further specifies this relation. The genes of the parents constitute the possible with respect to their offspring. Even though all children may look different, they constitute a particular instance of the possible. If we tried to identify the general in an inductive way, by analyzing the identical features of all children, we may not be able to identify any commonality (Il'enkov 1982). Rather, essentialist generalizations are found "through *analysis* of at least one typical case rather than through *abstraction* of those identical features that all possible cases have in common" (p. 170).

One approach to qualitative research that pursues an agenda of identifying general processes that lead to situated particulars is *ethnomethodology* (Garfinkel 1967). As its name suggests, the approach investigates the methods by means of which ordinary people constitute, in concert with others, the structured everyday world of our experience—e.g., practices underlying sex change, "bad" clinic records, or psychiatric outpatient clinic selection. Rather than concerning itself with the panoply of a type of social phenomenon, such as queues that exist in a multitude of ways—e.g., at a movie ticket counter, supermarket cash register, highway ramp, or bus stop—ethnomethodology is concerned with the methods people use and make visible to each other in lining up, recognizing beginnings and ends of queues, identifying problems with queuing, and so on. These methods underlying queuing transcend any particular lineup and, therefore, constitute the general. The identification of these methods does not require special research methods because every person competently lining up implicitly practices them. In this way, ethnomethodology is a radical alternate method that is incommensurable with all other standard—qualitative or quantitative—researches (Garfinkel 2007). It is a radical alternate because it provides answers to the question: what more is there to social practices than what all qualitative or quantitative formal analytical research has established? (Roth 2009c). The tremendous opportunities and promises arising from this approach for health research have been recognized and outlined but have yet to be realized in research practice (e.g., Dowling 2007).

6.3 Quantitative Research: The Critic's View I

6.3.1 Assumptions in Generalization

Research generalization involves making some assumptions in order for knowledge claims based on specific research to apply to individuals and contexts not involved in the research. Three key assumptions in generalizations from both social science and health research may be identified: (a) *uniformity-of-nature*, (b) *continuity*, and (c) *ceteris paribus* assumptions (Roe 2012). The *uniformity-of-nature* assumption posits that all people are similar in their properties and behaviors and are hence exchangeable. The *continuity assumption* refers to constancy of individuals' characteristics and behavior and to the fact that these do not change over time. This makes it possible to examine them any time. The *ceteris paribus assumption* refers to constancy of other factors and hence to assume the possibility of their influence on characteristics and behaviors being investigated.

Uniformity-of-Nature Assumption Most inferential research assumes invariance of constructs, behaviors, and processes among individuals. Excluding clear constraints—e.g., adults, people living in rural or urban areas, etc.—that are targeted by the research, this assumption leads to the situation that all people are possible candidates for the research and its claims. As long as the individuals meet the broad categories, heterogeneity within these groups is overlooked or neglected. The *uniformity-of-nature assumption* has its roots in the natural sciences where it may hold reasonably well for physical characteristics. However, this assumption cannot be expected to hold for human beings who are affected by, and *react to*, the physical and social environments they live in.

Continuity Assumption Another key assumption in most inferential research is that human characteristics are invariant over time. This leads to researchers investigating human characteristics without taking time into account. Time can include seasons of the year, time of the day, periods such as decades, etc. Very little research focuses on change over time as the targeted construct (Roth and Jornet 2013). This assumption does not match reality where clear differences are observed between generations and eras.

Ceteris Paribus Assumption Researchers typically manipulate a limited number of factors in their research and generalizations are made assuming that "all other things are equal." However, we have to ask how reasonable it is to assume that all other things can possibly be equal? Researchers frame their generalization either by arguing that the results are invariant under other conditions or may caution that the results may be different under different conditions. To the degree that individuals vary in different settings, over time, and the research effects vary under different conditions, violation of these assumptions will lead to inaccurate generalizations.

In the next section we provide examples of research where these three assumptions are implicitly made and where there is evidence of violation of these assumptions. In addition, we provide examples of psychological research that lacks explicit identification of target generalizations.

6.3.2 Violation of Generalization Assumptions and Lack of Explicit Identification of Target Generalizations

Even when generalization to people is implicit, typical research does not even identify and describe to which population the results are intended to generalize. In fact, in typical research, researchers start with the sample and representativeness of the sample is either not recognized at all or recognized when the results are discussed after the fact (Roe 2012). Lack of reference to a population exists even in research that includes inferential statistics, which implies claims targeted to a population. For example, an abovementioned study conducted with adults in 2004 and 2005 concludes that "[a]nxiety disorders, especially panic disorder and PTSD, are independently associated with suicide attempts. Clinicians need to assess suicidal behavior among patients presenting with anxiety problems" (p. 791). This research claim makes no reference to which adult population this conclusion applies to and under what conditions. Without an explicit statement of what the results are intended to generalize to, however, it is impossible to know to whom the findings may apply and what the limits of the generalization are. Replicability or verifiability of such studies is also limited if the researchers do not know from which population samples should be drawn.

Time is another facet of research that is typically not considered in generalizations (though it is explicitly theorized in cultural-historical approaches to psychology). Time is expected to be a factor in populations, contexts, settings, or interventions. Individuals' psychological structures in different decades and periods may be different. For example, IQ measures and personality type tend to be taken as invariants. The sociocultural context of the research undergoes continuous change and, thereby, may influence how people perceive and react to things. Interventions that may have been effective in the 1960s—e.g., women struggling with self-esteem issues—may be irrelevant and ineffective for women today. For example, one study describes gender differences in self-esteem (SE) based on empirical research without any reference to its temporal context:

> Three experiments explored the idea that men's and women's SE arise, in part, from different sources. It was hypothesized that SE is related to successfully measuring up to culturally mandated, gender-appropriate norms—separation and independence for men and connection and interdependence for women. Results from Study 1 suggested that men's SE can be linked to a individuation process in which one's personal distinguishing achievements are emphasized. Results from Study 2 suggested that women's SE can be linked to a process in which connections and attachments to important others are emphasized. Study 3 demonstrated that failing to perform well on gender-appropriate tasks engendered a defensive, compensatory reaction, but only in subjects with high SE.
> Josephs et al. (1992, p. 391)

But can we really make the assumption that self-esteem issues do not change over time within the same population? In fact, in current research practices not contextualizing interpretation of research findings in temporal contexts is the norm, not the exception.

6.3.3 Implications for Determining Evidence

Evidence-based practice involves using research results to inform decisions affecting groups or individuals. Violation of the three assumptions above leads to inaccurate inferences from research for evidence-based practice. In essence, such a process involves generalizing from the "universal" to the "particular." How can we determine if a treatment that was effective on the average will be effective for the individual? Such an inference ignores individual differences and changes over time. These inferences ignore heterogeneity in populations as well as effects of time on research generalizations leading to inaccurate inferences. Improving generalizations will require identifying the extent to which the assumptions hold. Only then researchers can determine whether the research provides evidence for the individual(s), time, and contexts, for evidence-based practice.

6.4 Qualitative Health Research: The Critic's View II

In this section, we take a critical look at current qualitative health research methods with respect to the criteria that have been articulated for determining its quality and with respect to the methods of arriving at true generalizations through qualitative research that we articulate in Sect. 6.2. The purpose of the critique is to prepare qualitative health research to make a step toward taking their responsibility in the research communication and translation process, clearly identifying and articulating invariants across settings to be expected in their results just as we expect this to be the case for good quantitative research. We briefly analyze a randomly selected article.

In qualitative research, generalization tends to be thought of differently from that used in experimental research and large-scale statistical studies and sometimes authors are explicit about non-generalizability of their findings. For example, there are researchers claiming to do "phenomenological studies" focusing on the experience of one individual or a few individuals. This is in evident contradiction to the phenomenological method reviewed above, which is designed to arrive at understandings that are valid *for every* human being—e.g., in the work of Husserl, Heidegger, or Merleau-Ponty—right up to the present day, for example, in the phenomenological analyses of the experiences of organ transplants conducted by the affected individuals themselves (Nancy 2000; Varela 2001). If, however, research results were not generalizable to some extent, then these would not transfer (could not be transported) to and thereby inform a new context. If research results can inform settings other than those in which the research has been conducted, then it behooves the authors to articulate which other settings might benefit and the limitations that occur in the transfer of claims between settings. To distinguish the nature of quality criteria that differentiate qualitative from quantitative studies, a set of parallel criteria has been proposed (Lincoln and Guba 1985). Subsequently, Guba and Lincoln (1989) presented a set of criteria that should be used for judging the quality of qualitative research.

In *naturalistic inquiry* (Lincoln and Guba 1985), the authors explicitly reject the idea of generalizability, arguing that it is a positivistic idea. They argue for a move to the question of *transferability*, which denotes the extent to which findings from one qualitatively studied setting can be transferred to another qualitatively studied setting. They rightly suggest that transferability cannot be based on the sending context alone but requires an understanding of the receiving context. This, however, is nothing other than thinking about the user and usage as one criterion of generalizability (Ercikan and Roth 2014). Whereas it may be correct that investigators who know only the sending context cannot make generalizability (transferability) inferences, it is also correct that investigators interested in publishing their findings need to know just what in their findings is of interest to others generally, and to readers of the journal article more specifically. In this move, they have thereby done a first step in generalization by extending their site-specific findings to the sites of interest to their readers. Other researchers focus on receiving contexts and refer to external validity of qualitative research as *recognizability* (Konradsen et al. 2013). These researchers define recognizability as "[t]he degree to which individuals are able to recognize their own experience or the experiences of others in the findings of a qualitative study" (p. 70) and identify four categories of recognizability: full, partial recognition, recognition in others, and no recognition.

Meta-ethnographic studies (e.g., Noblit and Hare 1988) constitute one possible way in which qualitative health research can be compared and contrasted across ethnographic contexts. This then leads to syntheses of an ensemble of studies that overcomes a proliferation of apparently independent studies. Thus, for example, one recent systematic study reviewed the findings on smoking during pregnancy that derived from 26 studies (involving 640 pregnant women) reported in 29 papers (Flemming et al. 2013). If there had not existed a sufficient degree of generalizability, these studies could not have been synthesized. Things and phenomena become comparable only when they are categorized in the same way; and categorization inherently constitutes abstraction from situational particulars (Kant 1956). It therefore does not suffice when qualitative health researchers do not indicate in which way their findings and distinctions are transportable to and relevant in other settings, as in "I *hope that some of these distinctions resonate* with health care providers" (van Manen 1998, p. 10). That is, researchers often refuse to state in which way their findings are relevant to contexts other than their own use of the adjective "phenomenological." Thus, rather than seeking to identify *general principles* (Vygotsky 1927/1997), studies tend to limit their findings to the particular sample in their study, for example, "*participants in this study* are pointing to a different understanding of the relationship between personal experience and fear" or "participants on a white water raft trip experienced fear which helped to cement a sense of self" (Brymer and Schweitzer 2012, p. 484).

In contrast, the idea underlying the classical phenomenological approach is to identify, as Vygotsky had done, the general principles of underlying processes. These only manifest themselves in different form because of contextual particulars. This is very different from phenomenographic research, for example, which identifies, categorizes, and describes forms of experience. Thus, one health-related phenomenographic study was interested in describing and characterizing "what women with rheumatoid arthritis (RA) and juvenile idiopathic arthritis (JIA) perceive as important in considering the performance of daily occupations to perceive good health" (Ottenvall-Hammar and Håkansson 2013, p. 82). Because of their approach, the authors are at pains to ascertain the representativeness of their sample to achieve "heterogeneity." Nevertheless, they state that a limitation of their study was that they "did not involve all demographics that could have been of interest" (p. 90). Moreover, they explicitly address the question of the trustworthiness of their study and, therefore, expose its possibility to be untrustworthy. Finally, "transportability"—i.e., the qualitative researcher's equivalence to generalizability (Lincoln and Guba 1985)—is not ascertained on the part of the researchers but transferred to the journal audience, who is asked to "decide whether the results can be transferred to the reader's own contexts or not" (Ottenvall-Hammar and Håkansson 2013, p. 84). The authors point out the challenging part of their study: how to handle their own preconceptions and perceptions.

6.5 Conclusions

> Now, we often proceed as if what counts as evidence was evident because we trust a cultural routine, most often imposed and inculcated through schooling (the famous "methodology" courses taught at American universities). The fetishism of "evidence" will sometimes lead one to reject empirical works that do not accept as self-evident the very definition of "evidence."
> Bourdieu (1992, p. 225)

In this section, we take a step back, articulating similarities and differences between research methods presented and critiqued in Sects. 6.3 and 6.4. We also situate this discussion in the context of research methods that explicitly combine quantitative and qualitative research, such as the Bayesian approach, which is concerned with evaluating the probabilities of scientific hypotheses, given prior evidence of quantitative and qualitative nature and using new data for updating the probability of these hypotheses. The Bayesian approach is useful as it offers a means of formalizing prior beliefs—the identification of which requires a qualitative approach—and combining the results with quantitative studies for the purpose of supporting decision-making, risk assessment, diagnosis and prognosis, or health technology assessment (Barbini et al. 2013).

In the introductory quotation to this section, Bourdieu notes that an effort to extract general or invariant properties from the particular "is too often lacking in the work of historians" (p. 233). He attributes this to the definition of the historian's task and a less ambitious or pretentious, as well as less demanding, task thrust upon their discipline than that thrust upon, for example, sociologists. This may be just as true for researchers who define themselves as working within a qualitative tradition, as if *method* was the defining characteristic of what a scholar does. Rigid adherence to this or that method does not take us any further in understanding evidence and generalizability. Thus, "methodological indictments are too often no more than a disguised way of making a virtue out of necessity, of feigning to dismiss, to ignore in an active way, what one is ignorant of in fact" (Bourdieu 1992, p. 226).

Synthesizing research from multiple studies is an important way of generalizing research findings across settings. Such studies inherently are concerned with comparing findings, which can be done only at a more abstract level where studies are comparable. Here, the Bayesian approach in particular provides tremendous opportunities because it allows the integration of qualitative and quantitative information. Most frequently, the qualitative information enters Bayesian analysis in the characterization of prior beliefs that enter the determination of probabilities prior to the research, probabilities that are then updated as a result of a research project (e.g., Roberts et al. 2002). Instead, as one study of the factors that influence nonadherence/adherence to HIV medication regimens shows, the results of quantitative and qualitative studies can enter syntheses at the same level and with equal weight (Crandell et al. 2011). The method allows the "borrowing of information across studies" and thereby "makes this method uniquely suited to the case where a variable is more heavily covered in qualitative or quantitative studies" (p. 667). There are other meta-analytic methods as well. But, in our view, those that integrate qualitative and quantitative studies are of particular value as they force researchers to push the boundaries of quantitative work to consider the nature of variance, on the one side, and push the boundaries of qualitative work to consider those aspects that will be invariant across settings.

To end, we encourage readers to heed a commentary made in reference to sociology to health research. Our research is:

> […] too serious and too difficult for us to allow ourselves to mistake scientific *rigidity*, which is the nemesis of intelligence and invention, for scientific *rigor*, and thus to deprive ourselves of this or that resource available in the full panoply of intellectual traditions of our discipline.
> Bourdieu (1992, p. 227)

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Part II

Reviews of Qualitative Health Research

7 Evaluating Qualitative Health Research from Inside and Outside

Lynn Meadows and Ardene Robinson Vollman

7.1 Introduction

Criteria for ensuring rigor for qualitative research are well documented in existing literature (e.g., Cohen and Crabtree 2008; Morse et al. 2001; Morse et al. 2002). Given the important role that recognition of the determinants of health (Public Health Agency of Canada 2013) plays in moving forward health sciences research, and the contributions that qualitative approaches are making to this body of evidence, there is an ongoing need for clarity in the processes that contribute to the rigor of research and its outcomes (Cohen and Crabtree 2008; Meadows and Morse 2001; Morse et al. 2002; Tracy 2010). Morse et al. (2002) note that strategies that are part of the overall research design and that are fully integrated into the research process demonstrate and provide evidence for the rigor of qualitative research. They further note that debates regarding rigor in qualitative research have ranged from arguments over terminology (Hammersley 1992; Kuzel and Engel 2001; Yin 1994) to debates over the universality of strategies of rigor across theoretical paradigms (Bochner 2000; Guba and Lincoln 1989; Guba and Lincoln 2005; Tracy 2010). We agree with Morse et al. (2002) that the debates referenced above led to a focus on evaluation of research outcomes, leaving the attention to rigor during the research process (from conceptualization to publication) lacking.

Identification of the techniques that support rigor is ongoing. Cohen and Crabtree (2008) use terms including the importance of the research, doing ethical research, coherence, validity, and verification of the research. Meadows and Morse (2001) use strategies of verification and validation within the research process, including techniques of study design, bracketing, member checks, and auditing, among others. Tracy (2010) presents a model for quality in qualitative research through eight "Big-Tent" (Denzin 2008) criteria for excellence in qualitative research. These include "worthy topic, credibility, sincerity, meaningful coherence and ethical research" (p. 839). Morse et al. (2002) argue for a return to the use of the terms and strategies of validity and reliability, including techniques of verification as a process internal to the research and the responsibility of the researchers. Very simply, Morse et al. (2002) write, "*Verification* is the process of checking, confirming, making sure, and being certain." They note the need for methodological coherence, sufficient sampling, and engaging in a dynamic and iterative process throughout the research that addresses sampling, data collection,

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data analysis, and other techniques of verification. Readers who want more information on how to implement the various techniques of verification and validation are referred to the cited articles.

The focus of this chapter now turns to further discussion of verification and validation. Strategies of verification are internal to the research process, and are the responsibility of the researchers and their team. The techniques used in the verification process incrementally contribute to the validity of the research (Meadows and Morse 2001). Qualitative research is iterative: that characteristic provides the opportunity and demands the attention to the work and fit of the research as a whole to ensure rigor. The process of validation is also internal to the research project, and also the responsibility of the research team.

The strategies that, taken together, are inherent to the verification process include the following: the preparatory literature review that situates the research questions; the study design that identifies the strategies and techniques that will coherently and cohesively guide the research; a budget that reflects and fully supports the research project; and careful choice of the research team (*internal* such as investigators, partners, research assistants, transcriptionists, and managers and those *external* to the funded team such as auditors or evaluators).

Similarly, traditional and evolving strategies have been established for the validation process. These include establishing an audit trail to make clear the timing and rationale of methodological decisions during the research process (Lincoln and Guba 1985); inter-rater reliability; the use of multiple methods; and the often misunderstood technique of member checks. Recently Morse et al. (2002) have noted that member checks constitute a technique of rigor early in the research process but invalidate the researcher's analysis and interpretation if used inappropriately.[1] Their use must be appropriate to the task.

Good researchers have to pay attention to the quality of qualitative research while they are doing it and also evaluate the results after the research is done. Quality qualitative research is important for many reasons: to educate those new to qualitative paradigms; to ensure funders and evaluators are exposed to excellence in qualitative research; to debunk the myth that qualitative research is simple and easy; and to provide evidence for policy and practice decisions, among others. Terms that are common in qualitative research must be identified and put into practice during the research process with adequate understanding of their use and utility. While many terms are well established, the dogmatic use of terms without understanding undermines, rather than supports, the processes of ensuring rigor. The field of qualitative research continues to make strong contributions to a variety of scientific disciplines; additional tools for ensuring rigor are being developed and tested. Sometimes funding agencies require assessments of rigor by the research team as part of the overall research design; in other instances the research team members realize the value of engaging an expert in qualitative rigor from outside the project team to work with them, and provide ongoing feedback throughout the tenure of the project. No matter the source of the decision to include a person whose specific role is to assess rigor internal to the research project, these experts play an important role and make an essential contribution to the nature of qualitative evidence.

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[1] "The problem of member checks is that, with the exception of case study research and some narrative inquiry, study results have been synthesized, decontextualized, and abstracted from (and across) individual participants, so there is no reason for individuals to be able to recognize themselves or their particular experiences (Morse 1998; Sandelowski 1993). Investigators who want to be responsive to the particular concerns of their participants may be forced to restrain their results to a more descriptive level in order to address participants' individual concerns. Therefore, member checks may actually invalidate the work of the researcher and keep the level of analysis inappropriately close to the data. The result is that there is presently no distinction between procedures that determine validity during the course of inquiry, and those that provide the research with such credentials on completion of the project (Wolcott 1994)" (Morse et al. 2002, p. 16).

The remaining sections of this chapter provide illustrations of rigor in qualitative research as assessed from within a research project by its team members and assessment of quality from outside the research team by an independent scientist. These two approaches have been identified by Reynolds et al. (2011) in the context of health research policy. Reynolds and her team used a meta-narrative approach in a search of journals, databases and grey literature to investigate the nature of quality in qualitative research. They identified two main narratives in the literature: "The first focuses on demonstrating quality within research outputs; the second focuses on principles for quality practice throughout the research process" (p. 43). They again reiterate the importance of steadfast attention to quality throughout the research process.

Two strategies for assessing the reliability, validity and trustworthiness of qualitative health research, are addressed in the following pages. In the first section we discuss evaluation, and illustrate a rigorous approach to evaluation of qualitative health research from the inside. While the word evaluation may hold connotations of external assessment in qualitative research, evaluation as an internal approach is the recognition of evaluation as an a priori part of the research design. In the second section of the chapter we discuss auditing qualitative health research and present an example of auditing a research project, as it is in process, by an expert external to the research team.

Evaluation is concerned with assessing how well a project's processes operate. Evaluation requires careful design, collection, analysis, and interpretation of data. Evaluation also has an important learning purpose. It should provide clear feedback to everyone involved in the research project: researchers, staff, funders, and the wider community (Hart et al. n.d., p. 9). Audit is a quality assessment process where performance is measured against predetermined standards within defined parameters or criteria, which are chosen as important indicators of overall performance. Changes can then be implemented to improve performance (Hart et al. n.d., p. 7).

7.2 Evaluation of Qualitative Health Research

To assess the quality of qualitative health research, we support the notion of using guidelines on the condition that they keep the key features of qualitative research in mind and are not rigidly prescriptive. As an alternative approach, we suggest the use of guiding principles and questions because, in this way, we can retain flexibility and creativity and promote rigor and transparency.

There are many labels for evaluation approaches, and the labeling is contradictory. Some evaluations are classified by their purpose (e.g., formative and summative (Scriven 1986)), the end user (e.g., utilization focused (Patton 2002)), evaluator role (e.g., internal or external), stakeholder role (e.g., participatory), methodology (e.g., qualitative), and ideology (e.g., feminist). With this in mind, we take an approach that is inclusive of evaluation types and approaches and does not privilege one over another. Rather, the approach used to assess rigor of the qualitative research process must be consistent philosophically and methodologically throughout the evaluation process.

What is quality in qualitative evaluation? Similar to the criteria for qualitative research, the evaluation of the research process should be valid and reliable (however these terms are assessed in qualitative research), methodologically sound, ethical, and logical and should have congruence between evidence and judgements. Regardless of whether the person responsible for assessing the quality of the research process (the evaluator) is internal or external to the research team, some attention ought to be paid to his/her credentials and expertise. For example, the American Evaluation Association (2004) proposed five principles (including 25 standards) that evaluators should uphold:

- Systematic inquiry: Evaluators conduct systematic, data-based inquiries about whatever is being evaluated.
- Competence: Evaluators provide competent performance to stakeholders.

- Integrity/honesty: Evaluators ensure the honesty and integrity of the entire evaluation process.
- Respect for people: Evaluators respect the security, dignity and self-worth of the respondents, program participants, clients, and other stakeholders with whom they interact.
- Responsibilities for general and public welfare: Evaluators articulate and take into account the diversity of interests and values that may be related to the general and public welfare.

The research team should ensure that whoever is responsible for assessing the quality of the research enterprise is qualified for the role, that he/she understands the research process from conceptualization, design and analysis, and is able to assess the integrity of the analytic process and the interpretations thus derived. The evaluator ought to have full access to the research team and documentation, while still enjoying a degree of autonomy that allows independence and lends credibility to the findings of the assessment. The evaluator's findings must be forthright and honest while still respecting the dignity of the research team and the inevitable challenges that they faced while carrying out the research. Above all, the evaluator must be cognizant of the ethics of qualitative research and ensure that no harm has come to any participants.

Further, the evaluator should uphold the following four key principles:

- Utility: The assessment of the qualitative research process should serve the information needs of the research team and funders.
- Feasibility: The assessment should be realistic, prudent, diplomatic, and frugal.
- Propriety: The assessment should be conducted legally, ethically and with respect for the welfare of those affected by the results.
- Accuracy: The assessment should be conducted rigorously and be well documented so that conclusions are defensible, valid, and reliable.

(Adapted from The Joint Committee on Standards for Educational Evaluation (1980; revised 1994))

Whether you are an internal or an external evaluator, these guiding principles should inform how you do your work. Further, consideration should be given also to timeliness, clarity about the context of the program and the evaluation, and (as far as possible) perspectives of all stakeholder groups.

7.3 A Case Example of Evaluation from Inside a Project

A call for proposals for cardiovascular risk reduction projects was released and, with the collaboration of key community leaders, the principal investigator (PI) put together a proposal for funding that addressed the community's concern about the health status and health knowledge of a particular ethnic community in a large urban Canadian city (Jones et al. 2013). The project was designed as a mixed method cardiovascular risk reduction screening program that took place in faith institutions in a number of neighborhoods over a period of several months. After funds were received, a condition on the grant was that an external evaluation be conducted. The PI contacted the evaluator for a consultation and it was decided that the evaluator would become an integral part of the project team.

7.3.1 Understanding the Project

The first step in the process was to use the proposal and, with team members, create a logic model of the project. This important step allows the epistemology, that is, the knowledge and assumptions underpinning the project, to be articulated and used as a framework for judging the research process. Epistemology is critical to the development of research (and evaluation) questions, methods, and interpretation of the data collected. Using Dwyer and Makin's (1997) framework, a logic model was developed that described the project goals, target groups, component activities, long- and short-term process and outcome objectives, and the resources available to the project. After some discussion explicitly linked to quality assurance, indicators were determined for each objective, and the evaluator then designed the evaluation, determined data collection and analysis methods, created the instruments for data collection, and submitted the evaluation proposal to a Research Ethics Board (REB) for approval. The evaluation question was straightforward: What went well, what did not, and what do we need to change for next time? The PI had a set of research questions that guided the research itself and a parallel application was submitted to the REB for the research project.

To ensure transparency that the principles of qualitative research were being followed, journals describing the processes of research readiness were kept by team members. Thus began the assessment of decisions, assumptions, interpretations, and adherence to best practices in community-based research. During the pre-intervention period, journals detailed access and entry processes and challenges, research team communications with key stakeholders (e.g., community physicians, faith leaders, volunteer coordinators), and kept track of the various activities to set the screening initiative in place.

While waiting for REB approval for the research and the evaluation to be granted, equipment and supplies were ordered and delivered, faith leaders were approached to gain access and entry to the community, documents were translated into the several languages prominent in the community, and lay volunteers were sought and trained by the project team. The PI met with physicians in the target community to explain the project and prepare them to receive letters if screenings indicated there was need for a referral for hypertension, hyperlipidemia, and hyperglycemia. All activities were documented for process evaluation purposes.

Upon implementation, the faith leaders helped to inform their members by announcing the clinics during services, and posters were placed in prominent places to encourage people to attend. Clinics were set up to take place once services were over; lay volunteers manned stations (welcome and registration, consent, weight and waist circumference, blood pressure, random glucose, cholesterol, and consultation).

7.3.2 Ensuring Adherence to the Principles and Protocols of Quality Research

Once the actual intervention began, demographic data were collected to describe the attendees and baseline health data were recorded; unique identifiers were assigned so that attendees' names would not appear on the data set. Attendees were provided with educational materials in their language and letters to their family physicians if their screening results were not in the preferred range of normal, and received consultation about what their results meant. While the actual screening results were part of the outcomes of the research itself, how the clinic processes worked and participant satisfaction were part of the quality assessment of the project in accordance with the epistemological position of the research.

Attendees were then randomly assigned to buddy support or no ongoing support. In the second screening clinics that took place several months later, attendees were again screened, and a questionnaire collected information about any lifestyle changes they had made since the first clinic and if there had been consultation with their physicians. During this period of time the community coordinator (CC) maintained a journal to capture her interactions with attendees, volunteers and the research team. This journal allowed the evaluator to assess whether or not the principles of the research had been upheld since the CC worked remotely from the research team. The journal was used in triangulation efforts with the project coordinator (PC) and the PI (who were also maintaining records) as a method to examine research rigor during the time between screening and re-screening. Team members did not share their journals with the evaluator; rather, they used them to assist with recall when they were interviewed.

7.3.3 Ensuring the Clarity of the Role of Evaluator Within the Team

Although the evaluator was a part of the team, her role was at arm's length as far as project implementation. She was available to answer questions and provide advice throughout when evaluation issues arose that needed resolution. Since the intent was to do a combination formative-summative evaluation, it was expected that the research process would be tweaked during implementation. Key team members used reflective journaling to capture their experiences, and regular team meetings allowed emerging issues to be discussed with the PI. Forms of evaluation data collection throughout the project included document collection and analysis, observation, surveys, and key informant interviews. It is worth reiterating that, because human subjects were involved, the evaluation plan had been approved by a REB.

7.3.4 Ensuring the Quality of the Resources Used

Since the project was in part sponsored by Hypertension Canada, documents from that source were used to inform hypertension education. A manual was prepared by the PI to inform volunteers about hyperlipidemia and hyperglycemia. Educational materials were prepared and compared to the literature and best practice guidelines for the various topics. Pamphlets and posters were translated and back-translated to ensure accuracy. The evaluator assessed the quality of the materials created for the project against the documents from Hypertension Canada to ensure their consistency.

7.3.5 Ensuring Quality Data Collection

Volunteers were trained by the CC and the PI with respect to the various aspects of the screening process and the machines used. Surveys were used to capture the confidence, competence and comfort of lay volunteers with the various machines and the new information they had been taught. A survey was used also to assess the degree of collaboration intended and knowledge gained by physicians that attended the informational seminar lead by the PI.

The evaluator attended several screening clinics to capture the essence and culture of the project as it was being conducted. She acted as a pure observer and did not interact in any way with the attendees or the volunteers. Any questions were directed to the PC who was in attendance at every clinic. The PI and the PC collected and analyzed the health data and made comparisons between those that were in the buddy group and those that were not. The PI reported on the data collected for the project.

For evaluation purposes, particularly to ensure transparency and responsibility of decision making, good ethical practice, and that a systematic approach was being honored, key informant interviews were conducted after the first set of clinics had been completed and then again after the project had come to a conclusion. After the first phase, the evaluation report was used to make changes to the process and inform the second phase.

Not everything went smoothly. Focus groups had been planned for the volunteers and some attendees to share their experiences but this was not implemented for a variety of reasons: volunteer fatigue; lack of willingness by attendees to participate; and extremely inclement winter weather.

7.3.6 Understanding the Context of the Research

Before and during the project the evaluator kept notes and reflections on the context within which the project was taking place. Also captured was information about the various inputs to the project, including several in-kind contributions. This information was important because Stufflebeam's (2003) Context-Inputs-Processes-Products (CIPP) approach was being used as the theoretical foundation for the evaluation. This approach allowed for the creation of an audit or decision trail and for ongoing discussion with the team about quality issues, assumptions, and biases.

7.3.7 Assuring the Accuracy of the Evaluation Results

Once the summative evaluation report was drafted, the evaluator presented it to the PI and key team members for feedback, and as a member checking process to ensure validity. At a closure meeting, the evaluator sought feedback, insights, whether or not the report "told the story" accurately and if the conclusions drawn were supported by the results of the evaluation. When challenged to soften some of the comments about "things that went wrong," the evaluator tried to determine if there was sensitivity or embarrassment, or if she had read the situation incorrectly. When team members agreed that the report was accurate, she helped them to understand that the things that went right outweighed those that did not, and that knowing about those issues would be helpful next time a similar project were implemented.

In addition to the evaluation of the research process, the PI and the evaluator assessed also whether the research itself met its objectives. The overall evaluation question for this activity was: Have the objectives of the research project been delivered in the specified time frame? Component questions included the following:

- What was the environmental context in which the research operated?
- What resources were needed to complete the research?
- What research activities occurred and how?
- What were the outputs of the research?
- What dissemination activities occurred?
- What impact will this research have on the field?

A short report was written that was used to inform future replication of this project with different ethnic groups in multiple sites across the country. The benefit of this approach was that the evaluator, charged with assessing the quality of the research process, was an integral part of the research team, had full access to all aspects of the process, and was able to use a wide variety of strategies to ensure the quality of the research. In this instance, the evaluator was conducting *evaluation research* on a community-based cardiovascular risk assessment research project from the inside.

7.4 Auditing of Qualitative Health Research

The foregoing section has focused on evaluation of quality from within the research project; we now turn to a discussion of qualitative audits. The two processes are not mutually exclusive, although we make a distinction here for heuristic purposes. In the cases used in this chapter we also differentiate between *inside* (evaluating qualitative health research by a member of the research team) and *outside* (auditing health research using an expert external to the research team). The differences between evaluation and audit are posed as guides for this chapter; they are however to be considered as appropriate ultimately by the various classifications of audits and evaluations. An identified approach must be consistent with the views and theories of the guidelines being used and applied methodologically throughout.

The concept of the audit in social science research was first discussed by Halpern (1983) and addressed the concern of trustworthiness in the growing area of naturalistic inquiry (Akkerman et al. 2008; Lincoln and Guba 1985; Schwandt and Halpern 1988). Initially the concept was *built on the metaphor of a fiscal audit* (Akkerman et al. 2008; Guba 1981; Lincoln and Guba 1985). Ideally, the audit procedure is negotiated before implementation of the research to be audited, and is negotiated between the auditee and the auditor. As with an evaluation, an audit is best supported by an a priori objective for the audit, and the accompanying goals from which a logic model, including timeline, can be developed. The auditee and auditor must also agree upon the extent and nature of materials that will be provided for the audit, that is, the audit trail.

Large-scale qualitative research studies can be incredibly complex (e.g., multiple case studies with diverse cases) and face the challenges of working in the everyday world subject to contingencies that arise during the course of the study. An iterative process of application of research strategies often characterizes studies of even some complexity. There are challenges to making clear the rigor of all research, for research that is iterative and may involve the need to addresses decision points in the study as they arise is an important part of supporting evidence of quality. Building on earlier work discussed above, Akkerman et al. (2008) identify three generic criteria that act as underlying standards to support decisions during the research process. These criteria are visibility, comprehensibility, and acceptability (p. 258). Visibility is conceptualized as the transparency of decisions made through the research process noted as appropriate for each stage of the study. Comprehensibility is conceptualized as having documentation to support the progress of the project to date, for example the funding proposal, logic model, and implementation process. Acceptability is conceptualized as the substantiation of decisions made by the researchers according to the standards, norms, and values of qualitative research methods and their disciplinary and accrediting bodies.

7.5 A Case Example of Auditing Qualitative Health Research from the Outside

A call for proposals was issued to assess the endpoint knowledge differentials across a number of subspecialties in an allied health care profession. The call for proposals was in part aimed at better understanding graduates' preparedness for their scope of practice; the information was also expected to be useful in understanding pedagogical standards across several institutions providing education for the profession. One proposal was duly deemed fundable and the multi-disciplinary research team, including a project coordinator, academics, research assistants, and research associates, as well as administration from the profession's education institutions agreed to work together in the project (CARNA 2009). A Steering Committee composed of representatives from each subspecialty and supporting government agencies was also formed to oversee the overall project.

In the research described below, the auditor was engaged *on behalf* of the investigative team approximately 1 year after funding and ethical approval had been received. In order to best serve the project and its verification and validation needs, a number of applicants for the position of auditor external to the research team were solicited and the successful candidate, a recognized international expert on qualitative methods, was selected. Subsequent to ethical approval of the auditor's proposed audit logic model, the auditor was given access to existing documentation for the project and its progress.

During the audit the auditor created and maintained a spreadsheet based on the project proposal. This spreadsheet noted all of the elements of the audit process: recorded audit timelines and project timelines; tracked meetings and audit trail materials requested and received; cross-indexed location and type of materials used in the audit; and essentially created an audit trail of the audit. Given the complexity, iterative nature and need for transparency, this type of tracking and checklist is essential for an auditor to establish and maintain.

7.5.1 First Stage of the Audit

The auditor reviewed the rationale and planning for the project, investigated the credentials of those engaged to work on the project across roles, and reviewed the proposal as approved by ethics as a first step. Sampling and recruitment for the project and data collection were found to be interdependent and iterative processes, as data included: a literature review of current knowledge and theories relevant to the project; curriculum, legislation, and professional statements relevant to the profession; site visits to the educational institutes; and key informant and interview data from personnel at the educational institutes for the early project stages. One challenge to the initial audit was to understand the breadth of the project and the various stakeholders, as well as the educational institutions, administrators, instructors, and students forming the body of the project. This challenge was in part because the profession being studied was not familiar, pedagogically, to the auditor. Another challenge, one that remained throughout the project, was that the research team chose a paper-based data collection and analysis approach to the project.

The initial stage of the project was duly found acceptable in visibility, comprehensibility, and acceptability. A Letter of Attestation (LoA) (see sample in Appendix) was provided to the project PI approximately 3 months after the auditor was engaged. The LoA included recommendations for next stages of the project, including a strong recommendation that a computer-based qualitative analytic program be used to support data management, organization, and analysis.

7.5.2 The Second Stage of the Audit

The second stage of the audit examined the analysis of all data collected during the initial audit stage plus further data collection based on the first round of analysis. For the purposes of the audit, data analysis was defined to include transcription of the recorded data; checking the transcribed data for accuracy; checking coding of the transcribed data; examination of the analysis of the transcribed data; review and inclusion of data from individual interviews; and document review of materials provided by the various educational programs.

As in the first stage of the audit, the work done by the auditor was challenged by the research team's commitment to a paper-based data management, organization and analysis process. It was necessary to hold several meetings, either by phone or face to face, with the data collection/analysis staff to clarify visual coding, color coding, and decision points in these strategies and the actual decisions themselves. Usual and accepted techniques in qualitative analysis, include journaling, memoing, and field notes, had been well and appropriately used by the research team and duly recorded. These documents again added to the volume of data to be audited, as they were handwritten in some cases and typed in others. These paper-based data in their entirety, audited through charting and checklists, resulted in a confirmation of both visibility (literally and figuratively) and comprehensibility. And finally, the process and its complex components were adjudged acceptable. Again, recommendations were made regarding data form, management and final analysis and report writing as part of the second LoA.

In order to evaluate students from each of the three types of professional programs, it had been decided that case scenarios would be used in focus group interviews with the graduating students to assess their knowledge of the issues being presented and the care plans that they, as a group, developed. The resultant data were to be used to identify the competencies of each of the three groups, and make comparisons among and between them to ascertain systematic and patterned similarities and differences. The researchers developed a template to identify themes and patterns in the students' focus group interview work. The coding templates were based on the results of analyses that were audited in stage 2. A codebook was developed by the researchers with the key concepts that had been identified as competencies. Each analyst then coded the focus group interview transcripts using their own color coding scheme. The two analysts held a series of meetings that resulted in themes to which they both agreed. These themes were then presented to the full research team and the Steering Committee. The analysts were provided with feedback from this meeting that was to be incorporated into their final report for the project.

7.5.3 Auditing the Final Product

The auditor's role during this final stage was complex, as an understanding had to be achieved of how and why each decision had been made in the analysis, if all data had been used by the research analysts, and if their conclusions were acceptable given their work and the feedback received from the full research team and Steering Committee. At this stage of the audit the original deadline had been delayed due to late availability of the audit materials. Furthermore, a need for the project results to be reported to the funders was imminent. In due course the final LoA was delivered to the research PI.

As the researchers are supported and their work enhanced by due diligence, an auditor demonstrates her or his credibility by the self-audit process. The results of this process during the project discussed above suggest the following points for future audits, resulting from lessons learned in applying a theoretical process to a qualitative project, but also mindful of how evidence in qualitative research is assessed and accredited.

- There are significant advantages to engaging a project auditor prior to implementation stages of a project; the conceptualization stage is ideal.
- Mutual agreement on the project timeline, nature of the audit trail, and timing and discussion of feedback from the auditor benefit the project.
- Given the mutual agreement stated in the last point, an iterative process between auditor and auditee throughout the project is ideal, and should be considered when developing a timeline.

7.6 Discussion

The field of qualitative research has a long history; however, the process of recognizing and acknowledging the powerful contributions this paradigm can make to scientific knowledge across disciplines has been slow. Dating from early work by Lincoln and Guba (1985) and others (Crabtree and Miller 1992; Guba 1981), strategies for rigor and their associated techniques have gained recognition and implementation. An important part of ensuring continuing rigor in qualitative research is periodic review and assessment of various strategies to ensure changes in knowledge, including science, technology, and disciplinary advances, are taken into account in the field of qualitative research. Good qualitative research and important contributions to science may require years of careful work; sometimes a program of qualitative research may require a career to address the complexity and contexts of the subjects that are studied. Acknowledging the expertise of others, and inviting experts to be an a priori part of the research team as either part of the team or external experts, will continue to support excellent and mature research.

7.7 Conclusion

In this chapter, we discussed the importance of addressing quality in qualitative research throughout the research process—from conceptualization to final outcomes of the research. The introduction of this chapter provided a brief review of the dynamic nature of the science and debates that characterize the quest for rigor in qualitative research. We noted debates that focused on narratives regarding choice of language as well as techniques that are used to facilitate verification and validation strategies. In our case studies we illustrated practical examples of the importance of addressing rigor *inside* the research project by the research team as recommended by Morse et al. (2002) among others and from *outside* the research project and team (Akkerman et al. 2008; Reynolds et al. 2011). The first strategy—evaluation—usually considered to address reliability and validity, was illustrated by an evaluation within a community-based mixed methods health research project. In that section the importance of having a qualified evaluator was stressed. In addition, the principles of utility, feasibility, propriety, and accuracy were presented, along with an explanation of each of the terms. Auditing, usually considered to address trustworthiness, was illustrated through a case audited from outside the research project. Akkerman et al.'s (2008) three generic criteria of visibility, comprehensibility, and acceptability, the underlying principles to support decisions during the research process, were presented.

Audits and evaluations need to be part of conceptualization and planning stages of qualitative health research, be included in proposals with sufficient budgets and time, and should involve mutual negotiations among the research team members and evaluator or auditor. These strategies are invaluable to building a solid body of rigorous qualitative health research, and across all research paradigms.

While there are many named concepts used in the processes of verification and validation in qualitative research the goal is shared: reliability and validity of the process that is undertaken by the research team to ensure high standards of solid scientific outcomes. The acknowledgement that qualitative methods are dictated by the research questions being asked in health research requires that researchers truly understand and implement strategies for rigor as appropriate for their projects, and with expertise as appropriate, whether inside or outside the research team.

7.8 Appendix: Sample Letter of Attestation for Audit

DATE

ADRESSEE

RE: Audit Point One

This Letter of Attestation refers to work done in the conceptualization, staffing, proposal development, ethical approval, sampling, recruitment, and data collection phases of the PROJECT NAME.

The Audit of the first phase of the PROJECT was done in the following way. First, the Auditor was required to sign a contract stipulating conditions, including confidentiality of study proposal and resultant data, including identities of programs that participated in the Project. After a meeting with the Research Committee the Auditor was provide with electronic copies of the following documents:

- Meeting notes for the Project Steering Committee dated XXXX
- Meeting notes for the Project Research Committee dated XXXX
- Ethics application and supporting documents
- Ethical Approval
- Ethical Approval extension
- Documents used to inform Topic A of the Project
- Documents from those agreeing to participate in the Project (organizations or individuals)
- Data collection instruments including interview guides and scenarios
- Identification of programs from which data collection was done plus schedule and confirmation of that data collection
- Receipts from participants of honoraria/participant costs as appropriate
- Opportunities to ask questions (and receive answers) from the Project Coordinator and Project Associate Coordinator
- Teleconference with Project Research Committee including Research Assistants

Once in possession of documents and information provided by the Research Committee and Steering Committee and using an iterative process, a random sample was initially used to examine documents supporting rigor of the PROJECT. As the audit progressed specific documents and information were requested so that audit trails could be identified and examined. During the examination of information and documentation, evidence of linkages among research design, implementation (including drawing upon expert consultation as appropriate and hiring of qualified staff) and data gathering was sought to verify that they were appropriate and met accepted and rigorous standards in current use. Specifically the Auditor was looking for compelling evidence of visibility, comprehensibility and acceptability of the initial phase of the PROJECT as it progressed from research design to data collection. The audit criteria are based in large part on earlier research by Halpern (1983) that was further developed by Akkerman et al. (2008).

The findings of the Auditor are as follows.

With regard to **Visibility**:

Visibility is conceptualized as the transparency of decision made through the research process—in this document up to and including data collection. Upon examination of [list documents and other materials] the Logic Model provided by the Project and guiding the study is complete and compelling. The discussions and consultation that moved the PROJECT from a proposed idea to conceptualization of the nature of the Project to the decision to hire staff to support the development of a technical proposal that would be vetted for funding and move forward to the research project are well documented.

With regard to **Comprehensibility**:

Comprehensibility is here conceptualized as having documentation to support the progress of the project to date; once the audit proceeds to examination of the data collected and ensuing analysis and interpretation comprehensibility will include that aspect of the project. Upon examination of the information provided to the Auditor, […].

With regard to **Acceptability**:

Acceptability is here conceptualized as the substantiation of decisions made by the researchers according to the standards, norms and values of qualitative research methods and educational enquiry and discipline practice and accrediting bodies. The decision to hire an Auditor stands as one decision made by the Steering Committee and supported by the Research Committee in their commitment to the accepted norms, standards and values that support the PROJECT. As mentioned in the visibility and comprehensibility sections above, the documentation of the initiation and implementation of the Project has been exacting and complete. Therefore it is clear to the Auditor that standards of rigor have been followed in this study to date. For example: […].

[…] I have agreed to disagree with the Research Team on this point, given that it is a topic of much debate in the literature.

The Research Team, supported through the excellent work of the Project Coordinator and Associate Coordinator have maintained an impressive audit trail at the same time that they have followed the standards and norms of qualitative research and upheld the values and intent of the PROJECT. Personnel who have been hired to support the PROJECT from the early stages […]. The Team has been transparent in both successes and at points where practical issues in field work have needed to be addressed and the study progressed.

I hereby attest to the visibility, comprehensibility and acceptability of the PROJECT based upon the documentation, conversations and other information provided to me.

Respectfully submitted,
[NAME]
Auditor

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8 The Contributions of Qualitative Research to Cardiac Conditions

Alexander M. Clark, Lis Neubeck, Pat H. Strachan, Kay Currie, and Jan E. Angus

8.1 Introduction

Are any conditions more amenable to the contributions of qualitative research than cardiac conditions? We doubt it. Coronary heart disease (CHD) is still the world's biggest single cause of premature death and disability via its symptomatic presentation as angina, myocardial infarction or heart failure. Its causation, management, care, rehabilitation, and risk reduction are each influenced by and involve a rich and complex fusion of biology, health behaviors, beliefs, knowledge, and attitudes. These themselves are situated in bodies, places, societies, and cultures. Moreover, while CHD is often represented as a condition that mostly affects men in high-income countries, actually the social and economic burdens of CHD are currently five to six times greater in low and middle-income countries (Lopez et al. 2006) and lifetime risk of CHD is the same for both sexes. CHD is then a global problem in need of urgent, responsive and effective strategies to ensure that health systems are more sustainable and unnecessary human suffering and loss is avoided.

How can this colossal global burden be best reduced and what evidence has qualitative research contributed to how this task could be addressed? While the pharmaceutical industry continues to develop new medicines, government policy and research continues to point to the overriding importance of behaviors related to primary and secondary prevention, disease management, use of health services and support for health behaviors and effective self care (World Health Organization 2005). To discuss the important evidence provided by qualitative research into cardiac conditions, we will then examine this evidence in four key areas of contemporary health care:

1. Improving patient access to effective health services.
2. Meeting the needs of vulnerable populations.
3. Understanding self-care.
4. Supporting difficult decisions.

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We selected these four areas of focus based on our clinical experience and previous research, rather than a systematic search process, as they are areas central to our daily work, but acknowledge that additional areas of focus may have been identified if a systematic search had been conducted. In each area, we provide a list of databases that index studies relevant to that topic, along with limits related to search terms and years of publication. The studies we review below represent the best examples of how we think qualitative research could inform clinical practice in cardiology. While the qualitative evidence is eclectic and inductive it nevertheless constitutes *evidence* because, as Porta (2008) recognizes, it is research-based, responsive to patients' circumstances, culture and preferences and can be used to inform health care. Qualitative evidence often conveys new and important insights on how patients can comprehend and understand aspects of their cardiac condition and their health care, and also sheds new light on their misconceptions and aspirations. In this way, qualitative evidence allows health professionals to understand patients better and to provide better health care.

8.2 Improving Patient Access to Effective Services

Epidemiology has produced unusually detailed and useful knowledge for the prevention of CHD. Across the world—irrespective of age, social status, and sex—nine behavioral risk factors explain 90% of cases of CHD (Rosengren et al. 2004; Yusuf et al. 2004). These behaviors are all related to common but complex health behaviors, and include behaviors related to: smoking, diet, weight, physical activity, and psychosocial well-being. Over 60 randomized trials have shown that people with CHD can benefit from health services focusing on education and support as provided by multidisciplinary teams (Clark et al. 2005). Meta-analyses of trials have shown that these interventions, usually called *secondary prevention* or *cardiac rehabilitation* programs, when targeted to improve key health behaviors in people with CHD, can reduce CHD risk, and both improve and lengthen life (Clark et al. 2005; McAlister et al. 2001; Taylor et al. 2004). The volume and strength of research into these programs has led many international guidelines to recommend that *all* patients with CHD should get the opportunity to participate in them (Balady et al. 2011). Yet, despite this persuasive evidence, fewer than 66% of eligible patients use these effective services (Bjarnason-Wehrens et al. 2010; Suaya et al. 2007). Further, patient groups who could benefit most from the interventions are even less likely to participate, such as women, the elderly, low income citizens, and people from ethnic minority groups (Cortes & Arthur 2006; Daly et al. 2002). Quantitative research studies have consistently identified that a number of factors are associated with lower participation. Typically programs are conducted during working hours, require travel to attend, and car parking at the location is often poor (Neubeck et al. 2012). These quantitative data tend to focus on correlates of participation rather than what actually influences participation—describing trends without explaining underlying reasons why such trends exist. Qualitative research has provided important insights to support the move from knowledge of who is likely to benefit to why this is so—and has found contextual, personal and social factors to be influential (Clark et al. 2012a, b, c; Neubeck et al. 2012).

In terms of contextual factors, when a patient is ambivalent about participating, receiving a recommendation from their physician leads to a much greater likelihood of attendance (Dolansky et al. 2006; Jones et al. 2003; Mitoff et al. 2005). Yet qualitative studies have shown that physicians are often perceived to discourage patients from participation (Heid and Schmelzer 2004; McSweeney and Crane 2001) or are viewed as poor communicators (Mead et al. 2010a, b). If the patient has positive in-patient experiences and there is good communication with health care providers, there is an increased likelihood of going on to attend outpatient rehabilitation (Banerjee et al. 2010; McSweeney and Crane 2001).

Other health professionals matter too, yet communication with patients from other professionals when they are in hospital prior to programs commencing is also often seen to be poor (Mead et al. 2010a, b), with information on programs provided at inappropriate times (Mitoff et al. 2005), and key messages about the nature and benefits of the services being perceived as contradictory (Goodman et al. 2009; O'Driscoll et al. 2007), disrespectful (Caldwell et al. 2005) or culturally insensitive (Visram et al. 2008). Vitally, all this occurs when patients are struggling to cope emotionally with a new diagnosis and may not be receptive to new or challenging information (Mitoff et al. 2005; O'Driscoll et al. 2007). Indeed, qualitative research has conveyed that receiving a diagnosis of CHD is profound and often deeply distressing for patients (Bergman and Berterö 2001; Condon and McCarthy 2006), often leading to considerable introspection, distress and denial (Clark et al. 2004; Condon and McCarthy 2006; Wingham et al. 2006). The seemingly rational perspective around the diagnosis of the health professional contrasts with the patients' ambiguous experience and confusion in the face of a diagnosis that was unexpected and inexplicable (Jones et al. 2003) and does not lead to a perception of future need for healthier behaviors (Jones et al. 2003; Mitoff et al. 2005).

Decisions about attendance occur in the context of wider culturally mediated beliefs about CHD and its causes. Those patients who attend cardiac rehabilitation tend to believe that CHD is caused by modifiable biomedical risk factors (Clark et al. 2004; Heid and Schmelzer 2004; Jones et al. 2003) that programs will help them improve (Clark et al. 2005; Cooper et al. 2005). They can perceive the health care professionals as experts (McSweeney and Crane 2001) who provide consistent information and support (Clark et al. 2004; McSweeney and Crane 2001; Wingham et al. 2006). Alternatively, patients may see CHD as both unpredictable and unchangeable (Hird et al. 2004), with stress or other uncontrollable psychosocial factors cited as causes (Clark et al. 2004; Tod et al. 2002). With CHD being out of their control, accessing a program is then viewed as pointless (McCorry et al. 2009; Mitoff et al. 2005). Worryingly, researchers have found that the health care and support which patients receive both during hospitalization and in programs often does not respond to these differences in attitudes and beliefs (Day and Batten 2006).

Interventions and strategies to improve access should use these important qualitative research findings to both better acknowledge the full range of contextual and personal determinants of service use, and to be more responsive to patients' underlying perspectives. Qualitative research has provided key insights that communications provided by health professionals can play a vital role and that considerable judgment is required to ensure that encouragement and support to participate in rehabilitation are consistently and appropriately framed, well timed, and address the range of practical and contextual factors influencing participation.

8.3 Meeting the Needs of Vulnerable Populations

Qualitative research provides evidence that can move cardiac research toward a stance that is more sensitive to the diverse nature and needs of vulnerable populations. These vulnerable groups can, but predominantly do not, benefit from potentially effective health care treatments and services. Compounding this, often these populations are those in greatest need of support. Qualitative research, as we will show, has illuminated this point and shows how the biological and social dimensions of the human body are intertwined with health behaviors and CHD health outcomes (Wainwright and Forbes 2000), and shows how these outcomes are influenced by key determinants of health and access to health services, that then lead to health inequalities (Williams 1999). These patterns are exemplified in women's access to secondary prevention programs, such as cardiac rehabilitation.

Although there is quantitative evidence that women and men equally benefit from secondary prevention interventions (Grace et al. 2008;

Todaro et al. 2004), women are consistently less likely than men to participate in programs and this gap widens with age (Allen et al. 2004; Beckie and Beckstead 2010; Suaya et al. 2007). This makes women a sizable vulnerable population in particular need of prevention but less likely to participate in and benefit from health services. To explain these patterns, there is sufficient qualitative evidence to discover persistent flaws in the service referral process, and also to indicate that gender-related factors limit women's uptake of referrals more than health systems factors which act to curtail referral across both sexes. Many qualitative studies have highlighted the complexity of the domestic world, illustrating the tensions felt when women's health needs conflict with those of family members (Banner et al. 2012; Boogaard 1984; Caldwell et al. 2005; Hamilton and Seidman 1993; King and Jensen 1994; Moore 1996; Rolfe et al. 2010).

Research on the interplay between gender and uptake of secondary prevention was recently examined via qualitative meta-analysis (Angus et al. unpublished manuscript; Clark et al. 2012a, b, c). Sixty-nine articles published between 1995 and 2011 were analyzed and three major themes emerged, revealing some of the causal mechanisms underlying women's lower uptake and participation in prevention programs after referral. These causal mechanisms included gendered interpretations of prevention programs; gender-related costs and resources required to attend prevention programs; and gender-related program needs. The three groups of mechanisms could align differently depending on additional conditions such as socioeconomic position, geographic location, and life stage.

Patients interpreted referrals to programs in terms of gender discourses or ideals of behavior, comparing what they knew or imagined about programs and the fit with personal and social expectations associated with gender. Women interpreted the exercise component of services as similar to gyms or "men's clubs" (Moore 1996; Northrup-Snyder 2002) which did not fit older women's ideals of "ladylike" comportment (Cooper et al. 2005; Traywick and Schoenberg 2008). Many women interpreted attendance at programs as the privileging of their own health needs over their gendered positioning as reliable homemakers and family supporters (Angus 2001; Davidson et al. 2008; Day and Batten 2006; Dombroski 2006; LaCharity 1997; McSweeney and Coon 2004; Norris and King 2009; Schou et al. 2008). Compared with men, women more frequently cited familial caregiving commitments as barriers to uptake of secondary prevention and cardiac rehabilitation programs (DeAngelis et al. 2008; Jones et al. 2007; Norris and King 2009), as well as the responsibility for domestic tasks (Astin et al. 2008; Tod et al. 2002).

In relation to gender-related costs and resources required to attend programs, women's concerns about the costs and resources needed to attend programs were consistent with their conditions of living. For some women, the financial costs of program participation posed a barrier (Day and Batten 2006; LaCharity 1997; McSweeney and Crane 2001). Even when programs were free, others found that employment, family responsibilities, and the costs of attendance were difficult to balance, particularly when time and financial resources were scarce (Angus 2001; Rankin et al. 2005). Women were mainly dependent on public transit or family members with vehicles for transportation to CR programs (Caldwell et al. 2005; De Angelis et al. 2008; Dolansky et al. 2006; Gallagher et al. 2008; McSweeney and Crane 2001; Pullen et al. 2009; Rolfe et al. 2010). Transportation barriers for women could reflect gender differences in financial means; however, driving is not permitted after MI or surgery, so some authors reported that men voiced similar complaints about transportation, especially if they had low incomes (Hird et al. 2004; Madden et al. 2011). An additional resource that facilitated women's CR uptake was familial encouragement to attend (Pullen et al. 2009). Several qualitative comparisons indicated that women apparently did not receive as much spousal support for health behavior change as men did (Alsen et al. 2008; Astin et al. 2008; Gregory et al. 2006; Gulanick et al. 1998; Tod et al. 2002).

In relation to programs, women and men in the qualitative studies valued different program features. Women with CHD seemed more prone to anxiety or stress (Tolmie et al. 2009) and they were motivated to enrol in programs if services were seen to support stress reduction (Lisk and Grau 1999). Women worried about cardiac strain, pain, or appearing unfit during exercise (Austin 2009; Cooper et al. 2005). In several studies, women indicated that they valued the support of health professionals who monitored the safety of exercise activities, as well as social connection with other program participants (Doiron-Maillet and Meagher-Stewart 2003; Dolansky et al. 2006; Kristofferzon et al. 2008; Leung et al. 2008; McSweeney and Crane 2001; Moore 1996; Rolfe et al. 2010). Women also wanted exercise options that were more enjoyable than walking and treadmills (Leung et al. 2008; Moore 1996).

Many of the social barriers to women's uptake of programs suggest that there is a pronounced lack of fit between women's needs as consumers and the very programs that are designed to reduce their mortality and morbidity from CHD. Program uptake for women is therefore not simply a matter of choice, but one of weighing current social vulnerability against potential future benefit. In the case of women's uptake of programs, the described process of weighing of costs against benefits is a causal mechanism that is as crucial to uptake of programs as it is to realization of other personal projects (Archer 2003). However, many women do opt to enrol in a program, indicating that there are disparities among women that hinge on additional advantages and disadvantages aligned with intersecting social identities (Hankivsky et al. 2010; Johnson and Repta 2012).

Interventions to promote health service participation may not be effective unless they are adapted to target vulnerable populations; indeed such interventions may inadvertently further worsen inequalities unless they successfully address the distinctive needs and context of these populations. Collectively, this qualitative research illustrates that gender is an aspect of social identity which also intersects with other social attributes (such as age, class, ability and ethno-racial membership) to shape life circumstances and influence the nature and ability of the women to address personal projects such as health service usage, behavioral change, and ultimately risk factor reduction (Archer 2003; Johnson and Repta 2012). As such, it is not the individual actions of single factors associated with gender that influence CHD behaviors outcomes in women but a wide range of intersecting layers (Hankivsky et al. 2010). CHD is then not only about individuals' health behaviors but also about the societies, places, and cultures in which women live. To encourage women's participation in secondary prevention programs, deep and quite distinctive approaches are needed to better ensure that services respond to the nature of women's lives, identities and preferences.

Thus far we have focused on participation in health services. While these services remain vital, over the last 10 years there has been an increasing recognition of the unsustainability of this approach alone. In addition, patient and family members also play an integral role in maintaining health. Emphasis has then broadened from what health professionals and services can do for patients to also include what patients and their significant others can and should do for themselves. This shift has been epitomized in heart failure (HF)—the chronic stage of CHD that frequently results from a myocardial infarction or chronic hypertension—under the guise of research on self-care.

8.4 Understanding Self-Care

Effective self-care offers the best means to maintaining life quality and expectancy for people with HF (Jessup et al. 2009; Lainscak et al. 2011; McMurray et al. 2012). This is crucial because HF reduces quality of life more than any other medical condition (McMurray et al. 2012). Yet, as with participation in health services, the fact that patients can benefit from HF self-care provides little or no guarantee that this will occur. This type of self-care is especially complex, requires ongoing and daily attention and effort around medication consumption, psychosocial well-being, diet, physical activity, fluid intake, and weight monitoring (Riegel et al. 2009).

Compounding these factors, patients with HF are often depressed, have lower cognitive function, and are more socially isolated (Rutledge et al. 2006). Unsurprisingly, despite a gamut of potentially effective self-care measures, evidence of poor adherence and subsequent hospitalization persists, with conflicting evidence on the effectiveness of health services interventions (Jaarsma and van Veldhuisen 2008; Savard et al. 2011). Crucially, qualitative research and resultant theories can help understand the complexity of HF self care: *what* should be included in interventions to promote effective HF self-care, and *how* patients may respond to these attempts.

A large volume of qualitative research has been done into aspects of HF self-care in HF in the past two decades (Currie et al. 2013). Many qualitative studies identified a range of factors related to the individual patient including: formal and informal knowledge; beliefs and attitudes; self-efficacy; learning and experience; cognitive function; and mental health. Importantly, whilst formal knowledge of *what* to do is clearly important; qualitative research indicates that patients and their family may have difficulty knowing *how* to use this knowledge in the context of their real and often complicated lives (Clark et al. 2009; Granger et al. 2009). Patients may have several comorbidities, for example pulmonary disease, arthritis, and diabetes, which makes it difficult for them to tell whether the symptoms they are experiencing, such as breathlessness, tiredness or swollen ankles, are due to a deterioration in their heart failure, or something else; symptoms are often attributed to "old age." Beliefs, or misconceptions, about the nature of HF and the relative importance of the various aspects of self-care may influence patients' attitudes and therefore behaviors towards their management (Rodriguez et al. 2008; Schnell et al. 2006). Conversely, a sound understanding of the *what, why,* and *how* of self-care—often developed over time with patients and their families able to learn from experience—facilitates self-care (Clark et al. 2009; Riegel et al. 2007). Finding out what works best for patients in their circumstances can lead to increased self-efficacy of confidence in their ability to manage their condition. Mental health issues, particularly depression, have been shown to impact individuals' capacity and motivation to engage in self-care. Similarly, even mild cognitive impairment can affect the person's attention, comprehension, concentration and memory. This makes it more challenging to learn about and integrate self-care into daily routines (Cameron et al. 2010).

The impact of these factors can change depending on a variety of contextual influences, which interact subtly and unpredictably in different situations. Cultural beliefs and norms, the ability to work or remain employed, and financial circumstances can all affect the individuals' capacity to manage self-care. Crucially, support from an informal carer, often a family member, can be pivotal in both day-to-day organization of self-care, and in detecting the often subtle changes in the patient's condition which herald a deterioration; often carers are instrumental in seeking help, when the patient is more inclined to adopt a "wait and see" approach (Clark et al. 2012a, b, c). Equally, being involved in a support group facilitates self-care by sharing learning with others, and also by reducing anxiety and isolation with the realization that there are others "in the same boat": surviving the challenges (Clark et al. 2012a, b, c).

An important contextual factor affecting the individuals' ability and willingness to engage in self-care is their relationship with their health-care provider. Qualitative research provides evidence of the benefits of effective communication, where health-care providers listen to patients' needs and preferences, openly share information, demonstrate respect for patient choices, and adopt a partnership approach, involving patients and their family in care decisions (Riegel and Carlson 2002). Conversely, poor communication—where patients feel rushed, perceive health-care providers as impersonal or uncaring, feel a lack of support or respect, or experience a lack of involvement in care decisions—can act as a barrier to effective self-care (Mead et al. 2010a, b). Of particular concern are patient reports of lack of information or poor continuity of care. This is especially evident in relation to medication, where studies demonstrate low patient understanding of drug therapy and how it links to symptom management.

How can this qualitative research influence clinical practice? Arguably, these studies could aid in the design of programs that take into account an understanding of the needs and priorities of HF patients and their caregivers; yet HF management programs are currently more likely to be designed around health-care providers' perceptions of what is important (Clark and Thompson 2008). Health-care providers need to understand the complexities faced by patients and explore the facilitators and barriers to effective self-care from the perspectives of those most closely affected; in other words, to use existing evidence from qualitative research to go *inside* the lives of those who will be using the programs. Currently, the common approach to promoting self-care in HF is to provide patients with standardized information and education, often via HF management programs. However, recent debate suggests that an alternative approach might be needed (Clark and Thompson 2012; Savard et al. 2011). This meta-synthesis has highlighted the wide range of individual and contextual factors that can facilitate or present barriers to effective self-care; importantly this research is from the patient, not professional, perspective. Bringing together the varied findings from qualitative research has shown that providing formal knowledge via education programs is an important, but rather limited, part of what is necessary to support self-care. A more sophisticated approach is necessary to respond to the complexity faced by patients and their families as they try to cope with this serious and debilitating long-term condition at home. The relationship between health-care providers and patients is crucial; effective communication and listening skills to build constructive relationships with patients and their families is paramount. Accessible information about all aspects of self-care in HF should be provided and *discussed*; "know-how" ideas for daily life drawn from suggestions other patients find helpful should be shared. It is important to evaluate both patients' understanding of information provided and the way in which the information was provided. Patients should routinely and regularly be assessed for any factor that might adversely affect their capacity for self-care, including cognitive impairment, depression, or excessive fatigue. A more tailored approach to information giving should then be used, taking into account the impact of these factors. Where possible, and with the consent of patients, caregivers could be involved in consultations, becoming partners in care decisions. If available, patients should be encouraged to attend rehabilitation programs or support groups to enhance social networks and share experience with others.

Managing HF at home is a complex task for patients and their families; understanding the patient and carer perspectives of the challenges and successes of this task can enable health-care providers to take a more person-centered approach to providing support. Qualitative research is an ideal way to gain insight into the experience and concerns of patients and their families.

8.5 Supporting Difficult Decisions

The new challenge to health systems from the growing burden of HF is but one example of how demands and issues change over time. Just as qualitative researchers can assist in understanding issues around access and personal behaviors, so too they can provide an understanding of the most complicated of decisions in ways that better incorporate patients' perceptions, values and preferences. The benefits of advancements in technology have been a common historical theme in the field of cardiac health care, but the use of these technologies may raise new and very challenging issues that require support for difficult decisions. This is typified in the field of electronic devices (notably implantable cardioverter defibrillators or ICDs) and the related decisions for patients and their families at the end-of-life.

Patients with cardiac illness are likely to reach a point when treatment has been optimized according to clinical practice guidelines and they continue to deteriorate and experience increasing symptom burden that may arise from various causes, such as cancer, HF, or any other progressive, life-limiting illness. At this point, end-of-life issues become paramount. The management of end-of-life issues has not been the traditional focus or domain of cardiac health care; instead, the focus has been on the prevention of sudden cardiac death (SCD) and the preservation of life; some might say at great, or even any, cost.

The ICD is a small device surgically implanted into the chest consisting of a generator (battery) and one or more wire leads that are placed through the veins and connected into the heart (Canadian Heart Rhythm Society 2013). Although some ICDs help regulate the heart beat, they are specifically designed to sense life-threatening ventricular cardiac arrhythmias and deliver an electrical shock so that cardiac rhythm is restored and sudden death is prevented (Kaufman et al. 2011). Over the last 20 years, the numbers of patients who are candidates for, and who receive, ICDs has grown exponentially and this trend is predicted to continue worldwide (Clark et al. 2011).

Negative effects of ICDs are not uncommon (Gibson et al. 2008; Palacios-Ceña et al. 2011) most notably painful shocks during the naturally occurring dying process (Lewis et al. 2006). Anecdotal evidence indicates that difficulties arise for the patient and practitioner when an ICD continues to shock a dying patient, thereby increasing suffering and making the death experience painful, and physically and morally distressing (Clark et al. 2011). Driven by compelling quantitative evidence about the benefits of the ICD, and in the absence of long-term consideration and planning regarding the implications of ICD when death can no longer be avoided, the stage has been set for the perfect storm of technology, ethical practice and the human condition.

While quantitative evidence has focused on establishing physiologic criteria on which clinicians can base a recommendation for ICD, as we now show reviews have identified many qualitative studies that explored decision-making from patients' perspectives (Clark et al. 2011). This qualitative evidence offers a crucial addition to our understanding of the intricacies of what may appear as a purely "rational," information-centered and linear decision-making process. These data highlight that although device implantation may be medically indicated to address cardiac pathology, in the future, a holistic patient-centered approach to the decision to implant a device must be adopted in relation to contextual patient issues.

Two studies have investigated the patients' perspectives about the ICD decision-making process with regard to primary prevention and importantly, included participants who accepted and those who declined. Carroll et al. (2013) used a grounded theory approach and described the process by which patients made this decision. In an effort to be removed from influencing the decision-making process or raise self-doubt in participants, interviews were conducted after the ICD implant or weeks after the decision to decline. It was found that the patient's involvement in decision-making occurred on a continuum. Patients varied from very active to very passive in their desire to be involved in the decision. This was influenced by their perceived health status, the opinions of their social supporters, their usual patterns of involvement in health decisions within their family systems, and their trust in information from the physician, family and other information sources. Physician influence on the decision was considerable and most participants had a limited understanding of the ICD beyond its lifesaving potential. Employing a descriptive content analysis approach, Matlock et al. (2011) also interviewed cardiologists and patients who had accepted and declined the ICD. Cardiologists' adhered heavily to the published guidelines and tended toward a paternalistic or patient-centered approach. As identified by Carroll et al., ICD recipients tended to take the physician's recommendation with little question.

In both studies, many patients recounted the decision to receive an ICD as a relatively simple choice between life and death (Carroll et al. 2013; Matlock et al. 2011). Simple because it is often presented that way by the recommending physician and at first glance seems an obvious choice. Yet while the ICD focuses on preventing sudden unanticipated death, consideration of the possible and different modes of death has also emerged in these and other qualitative studies as an important issue (Strachan et al. 2011). Sudden cardiac death is presented simultaneously as a death to be avoided and one for which the answer is an ICD. For some, this news carries with it an urgency to act and decide (Strachan et al. 2011)—as one elderly man sobbed to his daughter, “he told me I need one right away or I will die” (Kaufman et al. 2011).

The power of language and its potential to influence, soothe and/or incite decisional conflict in patients is clear in the studies described above, and they could be used by physicians having conversations with patients meeting criteria for ICD insertion. The way in which the message for an ICD is communicated influences the decisions patients make. This influence takes many forms. Clinicians and written materials have equated the ICD with having an insurance policy (Matlock et al. 2011) or having a paramedic with you at all times (Strachan et al. 2011). An 82 year old described the brief conversation when he was offered the ICD: “‘I said well what will it do to me and he (the physician) said it will give you 5 more years of life. I said I’ll take it’” (Carroll et al. 2013). Observational ethnographic data also highlights the persuasive power of language when a patient is encouraged to see the offer of an ICD as his good fortune, on being told repeatedly in a consult that he is *eligible* and *qualifies* for an ICD (Kaufman et al. 2011).

The need to explore the possible deactivation of the ICD when death is imminent has been driven by practitioners’ and patients’ experiences with ICD recipients who experience shocks as death approaches. Patients’ suffering from ICD shocks during the dying experience lead qualitative researchers to ask research questions about what patients want in this regard. Goldstein et al. (2008) investigated the barriers to deactivation discussions with ICD recipients in focus groups using hypothetical scenarios. Distinct from other study findings, Goldstein and colleagues found that most participants believed they would not want to talk about deactivation, believing it should be the physician’s decision, and equated deactivation to *an act of suicide* (Goldstein et al. 2008). The researchers postulated that this finding may be explained by the fact that interviewees were “healthy” at the time of the interview, may have required some time to contemplate the new knowledge about ICD deactivation, and/or may have found it difficult to contemplate a future in which deactivation was an option. Other studies have also found that although patients were poorly informed, many were open to the deactivation discussion prior to implant though very few had contemplated the need for deactivation to occur (Raphael et al. 2011; Strachan et al. 2011).

As such, qualitative literature reveals that fear of sudden cardiac death drives patients’ decisions for an ICD. Patients rely quite heavily on their physician’s recommendations for the ICD and that prior to receiving and living with the device, patients’ have a relatively poor understanding of the ICD in general and its relationship to their eventual death by another cause. While clinical practice guidelines and cardiac consensus documents promote the uptake of criteria for implantation of the ICD, these criteria are devoid of consideration of the psychosocial and contextual influences on the process of helping patients contemplate the device, live with it, and make sense of its potential meaning to the eventual end of their lives. Qualitative research focused on the sense-making and meaning-making of the experiences of those who are ICD candidates and recipients offers critical insights to inform and maintain the ethical imperative to support patient-oriented decisions when they accept, decline, and/or deactivate ICDs.

8.6 Conclusions

What then are the contributions of this qualitative research to the evidence base guiding care of people with cardiac conditions? Across the four areas we have discussed, qualitative methods have extended and deepened knowledge about what matters most: what factors actually influence patients’ decisions and behaviors whether around participation in health services, insertion or deactivation of ICDs or all manner of self-care and health behaviors. Often findings using other methods can supplement the knowledge generated from qualitative research, but seldom can those methods substitute for this qualitative research.

The evidence guiding future health care policy, systems and services has to be different than that of the past. Too often, as we have shown, past research has provided guidance of limited relevance and depth to foster the breadth and size of improvement needed. As the focus on the burden of CHD outside of high income countries increases, the limitations of this evidence in terms of relevance and responsiveness will be increasingly glaring.

The findings from the qualitative evidence presented suggest that moves in health systems towards provision that is more oriented and responsive to patients' preferences, needs and experiences are well justified. Across all the clinical areas discussed, the patient care needs and trends noted by the qualitative research are often surprisingly pivotal but have far reaching implications for health-care access, ethics, and outcomes. Interventions to promote better patient experiences, care, and health outcomes should systematically tap this qualitative evidence and harness it in systems design and care recommendations.

For clinical practice, qualitative research provides valuable and elusive insights into what should be done to maximize the likelihood of improved health outcomes. In the fields we have discussed, seldom is information alone sufficient to foster improvements in participation in health services, improved self-care, or better decision-making. Health practitioners and policy makers could use the evidence provided by qualitative research to creatively develop interventions that better address the full range of individual factors influencing behaviors in the context of the wider social, geographical and cultural factors influencing outcomes. As exemplified by efforts to understand women's use of prevention services, these attempts cannot be generic but must be adapted to the distinctive needs of key vulnerable populations who experience adversity in risk and outcomes. Qualitative research, as we have shown, can provide key insights into the nature and complex processes through which various factors influence outcomes in these vulnerable populations. For health professionals, useful and specific indications can be generated around various dimensions of communication, service content/design and the nature and range of determinants of outcomes.

In terms of methods, it is apparent in relation to cardiac conditions that qualitative research is often most valuable when used in tandem with quantitative methods. Whether building on the trends in epidemiological patterns in health services usage, explaining outcomes of past randomized trials or informing the content of interventions to be evaluated in future trials, qualitative research and quantitative research into cardiac conditions add value to each other. More mixed method studies that incorporate both are to be welcomed. Qualitative researchers should collaborate more with colleagues using quantitative methods to fully incorporate qualitative research into study designs.

Secondly, we urge the focus of these collaborations on clinically useful and focused research. Future qualitative studies should prioritize explaining well-established but intractable patterns in cardiac conditions, especially when these occur in vulnerable populations. Studies that explore illness experiences of cardiac conditions at a very generic level in generic study populations should be avoided. These types of studies do not respond to the public health burdens evident around access, self-care and decision-making, or the tendency of these burdens to be higher in vulnerable populations.

Those conducting qualitative research into cardiac conditions are obliged to know the past research in their area and ensure that their studies build sufficiently on existing knowledge. Many systematic reviews now exist that synthesize this past research in key areas. All researchers—qualitative or quantitative—should be mindful that it is not only inefficient, but also unethical, to duplicate past research studies. Finally, and to return to our starting point of this chapter, as cardiac conditions involve a fusion of biological, social and psychological factors, the promise of qualitative research to make future contributions is immense. This will require new and exciting collaborations that address difficult and challenging questions. What is evident thus far is that quantitative research alone has not provided convincing solutions to common but increasingly crucial challenges around health services access, self-care and difficult decisions. We urge researchers everywhere to take up these challenges with renewed enthusiasm and see the contributions that qualitative research can make.

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9 Qualitative Evidence in Pain

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9.1 Introduction

The objective of this chapter is to critically evaluate and present qualitative evidence for health interventions in the domain of pain conditions. There are a great number of different clinical pain conditions, each with particular descriptions and definitions. For instance, in the *Classification of Chronic Pain* produced by the International Association for the Study of Pain (IASP) (*Classification of Chronic Pain*, *2nd Ed.*, 1994) there are a couple of hundred pain syndromes described. Pain syndromes can be classified along different dimensions, such as (1) body region (low back pain, cervical pain), (2) organ system (e.g., musculoskeletal system, nervous system), (3) temporal characteristics (continuous, recurrent), (4) time since onset/duration (e.g., acute, subacute, chronic), (5) etiology (e.g., trauma, inflammatory, degenerative mechanical).

In regular clinical work, diseases are categorized according to the WHO's ICD-10 (WHO 1996) in which all internationally accepted diseases and injuries are listed. There is no specific chapter addressing diseases or injuries categorized according to the symptom *pain*, since the structure is mainly based on organ systems. However, diseases in which pain is the dominating symptom are, of course, listed. Examples of such diseases are G43.1 Classic Migraine, M16.1 Primary Coxarthrosis, M51.1 Lumbar disc disease with radiculopathy, and M79.0 Fibromyalgia. Also, there is a chapter with "Symptoms, Signs and non-normal Clinical and Laboratory findings" in which situations with pain as a symptom are listed, e.g., Pain from abdomen and pelvis (R10), Headache (R51), Pain not elsewhere classified with subheading Acute pain (R52.0), Chronic therapy-resistant pain (R52.1), Other chronic pain or ache (R52.2), and Pain or ache not specified/generalized pain (R52.9).

In the WHO's other relevant classification, the International Classification of Functioning, Disability and Health—ICF (WHO 2001), pain is a subsection (b280–b289) of the component Body functions. Pain has 17 categories, e.g., Generalized pain (b2800) and Pain in body parts (b2001) with five-digit subcategories for head and neck, chest, stomach and abdomen, back, upper limb, lower limb, joints, Pain in multiple body parts (b2802), Radiating pain in a dermatome (i.e., skin area innervated by a nerve root) (b2803) and Radiating pain in a segment or region (b2804).

There is an essential difference between pain in which the pain input nerve signals pass from,

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for example, an inflamed joint in an intact nervous system (also termed nociceptive pain) and pain caused by injured nerve fibers, for example, compression of nerve root due to disc disease (also termedneuropathic pain), as the therapy strategies are different for these two types of pain. An important pathophysiological mechanism is based on the plasticity of the nervous system. After long-lasting nociceptive input of pain nerve signals, changes can occur in the central nervous system, e.g., in a segment of the spinal cord, reducing the normal pain inhibitory mechanisms. The result can be that pain is perceived more intensively than before this change occurred—so-called pain sensitization (Kosek et al. 1996). This influences the treatment strategy. Furthermore, pain can be triggered, maintained, or exacerbated by psychological factors.

Different models have been proposed to understand and explain disability and functioning in pain. The biopsychosocial model, used by the ICF (WHO 2001), attempts to achieve a synthesis of the biological, individual, and social perspectives on health in order to present a coherent view of health and disability. Since pain, and particularly long-term pain, is a complex and not fully understood phenomenon, the biopsychosocial model can be a suitable base for improving knowledge. Qualitative methodology starts with the perceptions of the individual and thus takes into account the individual psychological and social perspectives. Qualitative methods are suitable in areas where there is little or no knowledge, and for exploring social phenomena as experienced by individuals themselves (Lincoln and Guba 1985). To increase the understanding of pain and the consequences of pain, qualitative research provides us with important elements that complement other research methodology.

Evidence is a complex and debated issue when it comes to qualitative research (Sandelowski 2004). Qualitative studies do not provide laws or relationships that can be transferred from samples and applied to populations. Instead, qualitative results can be tailored to unique individuals in their special context (Miller 2010). The body of qualitative knowledge is growing fast; reviews and meta-synthesis of qualitative studies are becoming more common. As we will show in our overview, there are in some areas consistent and complementary data from several hundreds of individuals with the same pain diagnosis. We argue that these results should be viewed as qualitative evidence. In other areas in which the numbers of studies are few, those studies can alert us to important aspects that need consideration.

To accomplish this summary of evidence, the literature has been reviewed and consolidated. The studies included comply in principle with the standards for quality according to Popay et al. (1998). The study methods are presented in the tables after each section and are therefore not further discussed in the text. The studies were identified by repeated searches in the database PubMed during January to July 2013. The used MeSH headings are presented in each chapter. Studies were also identified from reference lists.

9.2 Patients' Experiences of Acute Pain and Acute Pain Care

Only five qualitative studies on acute pain were found and all deal with aspects of acute pain other than those addressed in the huge amount of quantitative studies published about acute pain conditions. MeSH headings used were: qualitative research, qualitative methods, experience, interviews, acute pain, care.

Two studies deal with problems related to acute low back pain. The other qualitative studies address aspects of stressors in acute whiplash-related disorders, acute pain management of drug users and experience following blunt trauma. In many countries there are evidence-based clinical guidelines for primary care of acute low back pain (LBP), usually recommending restrictions in image diagnostics at an early stage. However, the general practitioners (GP) do not always adhere to the evidence-based guidelines. This problem is raised in a study with the aim to explore the care expectations in patients who came to see their GP for acute LBP (Hoffmann et al. 2013). Most patients expected their GP to refer them for an X-ray, particularly patients who felt that their pain was severe. Many patients believed that an X-ray would enable the cause of the pain to be determined. Patients felt that X-rays played an important role in providing reassurance as well as confirmation of their GP's diagnosis. Very few patients expected a physical examination to be performed. There was variation among patients regarding the treatment they expected from their GP. When asked about the option of no treatment for LBP with the exception of analgesics, most believed in a biomechanical approach of needing to find the problem and fix it in a timely manner. There was no expressed dissatisfaction with GP treatment. Patients' expectations about diagnostic investigations had been influenced by family, friends and/or other health professionals particularly osteopaths and chiropractors. Most patient expectations were incongruent with guideline recommendations.

Patients' low recovery expectations are held to be a core predictor of poor outcome in people with non-chronic nonspecific low back pain (NSLBP) (Iles et al. 2012). It is interesting to extend the understanding of recovery expectations to general activity limitations in order to understand their influence on the progression from non-chronic to chronic NSLBP. When an individual reports a low expectation of recovery, it is not known what factors are considered to arrive at that conclusion. With this background, the aim of a study was to gain a deeper understanding of low recovery expectations, to explore how people determine their own recovery expectation during an episode of non-chronic NSLBP (Iles et al. 2012). The formation of the patients' recovery expectations was dependent on their unique appraisal of their (1) pain, (2) how the condition had progressed, (3) the limitation of their performance of activities, and (4) the impact of different aspects of treatment. The authors recommend that health professionals should explore the patient's perception of these factors as part of a tailored intervention to prevent non-chronic NSLBP from progressing to chronic NSLBP.

In another study the aims were to describe the most stressful daily situation or event reported by individuals with acute whiplash associated disorder (WAD) grade I–III and to describe the meaning and significance of these daily stressors (Bring et al. 2012). Thirteen categories emerged: domestic and family-related activities, leisure, social activities, occupation, self-care, sleeping behavior, physical symptoms (not related to any activity), general functional activity, weather, contact with authorities, feelings/cognitions, driving/traffic-related stressors, multiple stressors. The most common stressor categories reported were occupation and physical symptoms. The most disabling stressors were occupation and physical symptoms. In conclusion the results show that individuals with acute WAD report stressors from a variety of areas in everyday life.

Adolescent injuries, frequently the result of blunt trauma due to motor vehicle accidents, are a major cause of adolescent pain, disability and mortality in the USA. Nonfatal injuries account for approximately 20 % of all emergency department visits per year in the USA (Crandall et al. 2007). The purpose was to explore the experience of pain as perceived by adolescents following blunt trauma injury (Crandall et al. 2007). Adolescents' behavioral and cognitive actions (i.e., "internal control") to manage and endure pain were influenced by their pain perceptions, physical losses, and clinicians' actions. Adolescents' perceived potential losses included their potential loss of life, a pain-free life, vision, mobility, body image, and lifestyle. Potential or actual losses of others included friends and family members who were involved in the accident.

Approximately 11 % of all emergency admissions are likely to include drug users, mainly injecting drug users. Drug users present unique challenges in acute settings with pain management noted to be at best suboptimal, at worst nonexistent. With this background, a study of the perceptions and strategies of drug users and nurses with regard to pain management in acute care settings was carried out (McCreaddie et al. 2010). The results indicate that the nurses and drug users struggle with "moral relativism" when addressing the issue of pain management in the acute care setting. Drug users' individual sensitivities, anxieties and perceived stigma in conjunction with opioid-induced hyperalgesia complicated the process. Nurses' and hospitals' organizational routines challenged drug users' rituals and vice versa leading both protagonists to become disaffected. Consequently therapeutic effectiveness was compromised.

9.2.1 Conclusion from Patients' Experiences of Acute Pain and Acute Pain Care

There is a scarcity of qualitative research about acute pain conditions, as well as about acute whiplash-related pain and other neck pain conditions. The few studies presented cannot provide evidence, but they do give examples of important areas to be addressed. The informants' expectations about diagnostic investigations, treatment options in different acute settings and acute pain management were incongruent with current guidelines. Also, recovery expectations from acute LBP, which are of great importance for the prognosis, were dependent on the individual's unique appraisal. Taken together, this emphasizes the importance of accurate individually adapted information to patients with acute pain. It is recommended that more qualitative research is done in the field of acute pain, e.g., not only in unspecific but also specific spinal pain conditions and in the prevalent hip, knee, and thumb joint osteoarthritis and, in addition, that the effectiveness of giving general information to inhabitants about the scientific basis behind clinical guidelines is further developed [See Table 9.1]

Table 9.1 Description of included studies for experiences of acute pain and pain care

Study	Data collection	Data analysis
Hoffmann et al. (2013)	Semi-structured interviews with 11 patients (10 F, 1 M) with acute LBP	Analysis by descriptive phenomenology
Iles et al. (2012)	In-depth interviews with 13 patients at emergency department (6 F, 7 M) with low back pain	Analysis by coding and constant comparison method
Bring et al. (2012)	51 persons (35 F, 16 M) who had visited an emergency ward after an accident with acute WAD answered open-ended questions	Content analysis
Crandall et al. (2007)	Semi-structured interviews and review of medical records from 13 adolescents (6 F, 7 M) referred to an pediatric adolescent trauma center following blunt trauma	Grounded Theory
McCreaddie et al. (2010)	Individual interviews with 11 drug users and focus-group interviews with 22 nurses and recovering drug users	Grounded Theory

9.3 Patients' Experiences of Living with and Managing Long-Term Pain

The objective of this section is to critically evaluate and present qualitative evidence for how patients with long-term pain, in general and in different conditions, experience living with and managing long-term pain. MeSH headings used were: qualitative research, qualitative methods, experience, interviews, chronic pain, long-term pain, fibromyalgia, low-back pain, back pain, neck pain, WAD.

One of the most frequently explored areas within qualitative research of pain is that of patients' experiences of living with and managing long-term pain. Numerous interview studies report about patients with fibromyalgia (FM) and chronic low-back pain (CLBP). There are also studies describing living with other pain conditions. The studies can provide us with an extensive in-depth understanding of what it is like to live with long-term pain. The experiences include symptoms, loss of identity, problems with legitimacy (issues of social and moral legitimacy (Sim and Madden 2008)), process of reevaluation of life and strategies used to cope with pain and its consequences. Those different aspects will be described for each diagnosis presented below.

Miles et al. (2005) have presented a model where the basic problem for people with long-term pain is defined as the constraint to body, activity and identity pain entails when trying to live a normal life, and how this challenge is perceived and met. Bodily constraint is defined as fundamental; it affects the individual's relationship to their body and their environment, what the person can do (activity) and who the person can be (identity). The study identified four ways to respond to the constraint. (1) Assimilation; the person maintained the pre-pain way of life by minor lifestyle changes and/or accepting help from others. (2) Accommodation; the person acknowledged and accepted that certain things could no longer be done as before and adapted their normal life to the new conditions. (3) Subversion; the person did not accept the constraint imposed by pain or help from others. The person concentrated on keeping up the appearance of life as much like the pre-pain life as possible, resulting in major restrictions in identity and activity. (4) Confrontation; the person concentrated on doing as much as possible, regardless of pain.

Models like this can help to understand different ways of coping with pain and associated symptoms, and when treatment or rehabilitation is to be planned, the model can be supportive in clarifying each individual's need of support. The model is used in the description of the diagnoses below.

9.3.1 Chronic Pain

The general experience of living and coping with chronic pain has been explored, 10 studies of a total of 140 persons suffering from chronic pain are presented in this overview. In these studies chronic pain was defined as pain persisting for at least 6 months, and included a variety of diagnoses.

Pain as the main symptom was described as an invisible, unpredictable condition, hard to communicate and hard to receive recognition for from others (Clarke and Iphofen 2008; Dow et al. 2012; Lavie-Ajayi et al. 2012; Zander et al. 2013). The bodily experience of pain was overwhelming and dominant. It was always in the body and in the mind, with distress and distraction, causing sleep disorders and fatigue (Clarke and Iphofen 2008; Zander et al. 2013). The changes of intensity and impact were dramatic and hard to anticipate, making pain difficult to adapt to (Lavie-Ajayi et al. 2012).

The informants' identity was severely affected. They described how pain ruined their lives. The pain forced the suffering person to limit and change all aspects of life, all functions and at every level. The pain made the sufferer dependent on others and often caused problems in relations, from family life to work (Lavie-Ajayi et al. 2012; Zander et al. 2013). When the experience of pain and its consequences was questioned by people who were supposed to provide support, the informants started to doubt their own experiences and bodily sensations (Lavie-Ajayi et al. 2012).

The need to constantly explain and legitimize limitations related to pain was frustrating and never-ending; it seemed as if family, friends and colleagues did not believe or forgot about the problem (Clarke and Iphofen 2008; Dow et al. 2012; Lavie-Ajayi et al. 2012). When the symptoms could not be explained, the informants felt that the health professionals viewed them as difficult patients and that the pain was all in their minds (Clarke and Iphofen 2008; Dow et al. 2012). Physicians were viewed as suspicious, disrespectful and as accusing people with pain of malingering (Lavie-Ajayi et al. 2012; Werner and Malterud 2003).

Life often had to be reevaluated. Lack of explanation added to fears and concerns and also to the belief that hope for a cure was an unrealistic expectation. Some felt that without a clear cause their pain became labeled as a "psychological condition," and this questioned their morals and integrity (Clarke and Iphofen 2008; Dow et al. 2012; Werner and Malterud 2003). Those who found a health professional who listened, responded sympathetically and explained both the physical and psychological mechanisms of chronic pain found this to be of great help (Dow et al. 2012; Werner and Malterud 2003).

Strategies used for accommodating the constraint of pain are described in a study exploring the meaning of resilience for people with chronic pain. Four themes were identified which describe important strategies used for managing life (West et al. 2012a, b).

1. Recognizing individual strength, by not giving in, developing tolerance to pain, understand how to manage pain, just getting on with it and gaining strength from past experiences.
2. Looking for the positive aspects of life, by learning to see the funny side of things, looking for the best in things, remembering it could be worse and expecting things to improve.
3. Accepting the pain by thinking along the lines of "the pain doesn't stop so learn to live with it," learning to accept the pain as part of who you are and fighting to be strong and live up to expectations.
4. Learning to accept help, by helping others to help you, learning to ask for help and gaining strength from partners and friends.

Resilient persons were found to be more likely to adopt adaptive strategies and to believe that they can control their life and their pain and see the possible benefits and positive aspects of the situation (West et al. 2012b). Other strategies used to accommodate to pain were; taking into account the signals from the body when planning daily life (Damsgard et al. 2011), learning to understand the meaning of the signals by, over time and trial-and-error, finding trust in the body and seeking an explanation for the pain, in which getting a diagnosis was an important part. In a study of Iraqi women living in Sweden (Zander et al. 2013), strategies that mainly resist the constraint of pain (Miles et al. 2005) are described. The strategies used were trust and faith in God's ability to cure and that, with God's will, hoping that a physician or specialist might find the cause of the pain and a treatment. When no help was found, the search for a cure continued: for the right specialist: for regaining control with a trustworthy diagnosis; for the right treatment. Strategies used in daily life for relieving pain were: taking medication; avoiding physical activity; rest; keeping warm; using technical aids. Praying gave comfort and helped in keeping the spirits up. Spending time with family enhanced well-being, gave a sense of calm and could distract attention from the pain (Zander et al. 2013) [See Table 9.2]

9.3.2 Fibromyalgia

A metasynthesis of illness experiences among patients with fibromyalgia syndrome (FM) (Sim and Madden 2008) from 2008 included 23 qualitative reports exploring the area. Since then, additional studies have been published. Below follows an overview of the findings in the metasynthesis complemented with later publications including more than 500 informants with FM from 32 studies:

FM is described as unpredictable, invisible, and incapacitating (Hellstrom et al. 1999; Juuso et al. 2011). Pain was the most important symptom, specific and at the same time diffuse (Hallberg and Carlsson 2000; Soderberg et al. 2002; Sturge-Jacobs 2002), both constant and varying (Cunningham and Jillings 2006) and difficult to describe as a single quality. The pain was invisible, difficult to explain (Hellstrom et al. 1999), and challenging for others to understand (Paulson et al. 2002). Although pain is the main symptom, some experienced fatigue as being the most debilitating (Arnold et al. 2008; Humphrey et al. 2010; Sturge-Jacobs 2002; Theadom and Cropley 2010). Personal relationships and participating in daily activities were constantly negatively affected by fatigue and lack of strength (Soderberg et al. 2002; Sturge-Jacobs 2002). Psychological problems like depression and cognitive impairments were reported. It was reported that depression was caused by the impact of other symptoms and losing control of life in general (Arnold et al. 2008; Cudney et al. 2002). Cognitive difficulties such as limitations concerning problem solving and abstract thinking (Paulson et al. 2002; Sturge-Jacobs 2002) were common and affected working capacity.

Table 9.2 Description of included studies for experiences of living and coping with long-term pain, chronic pain

Study	Data collection	Data analysis
Clarke and Iphofen (2008)	Low-structured interviews combined with diaries ($n=8$) with various pain diagnoses	Interpretative phenomenology according to Heidegger
Damsgard et al. (2011)	Semi-structured interviews ($n=10$, 5 F, 5 M) with chronic pain	Thematic analysis according to Malterud
Dow et al. (2012)	In-depth interviews ($n=30$, 17 F, 13 M) with various pain diagnoses	Qualitative thematic analysis
Lavie-Ajayi et al. (2012)	Narrative interviews ($n=6$, 4 F, 2 M) with various pain diagnoses	Interpretative phenomenology analysis
Miles et al. (2005)	Interviews ($n=29$, 20 F, 9 M) with various pain diagnoses	Grounded Theory
Werner and Malterud (2003)	In-depth interviews with 10 women with various pain diagnoses	Analysis according to the principles of Giorgi's phenomenological analysis
West et al. (2012a)	In-depth interviews ($n=10$) with various pain diagnoses	Thematic analysis by an interpretive analytic approach
West et al. (2012b)	In-depth interviews ($n=9$) with partners of an individual with chronic pain	Thematic analysis by an interpretive analytic approach
Zander et al. (2013)	Interviews ($n=11$ F) with various pain diagnoses, born in Iraq and living in Sweden	Grounded Theory

Informants described how they had to reorganize their identity according to the illness (Hellstrom et al. 1999). It was no longer possible to rely on the body as it used to be (Juuso et al. 2011; Lempp et al. 2009). Pain and fatigue disrupted the ongoing involvement by making the body the focus of attention, the body was perceived as an obstacle or a burden that served as a barrier to everyday life (McMahon et al. 2012; Soderberg et al. 2002). Leisure activities like sports, camping and traveling were given up. The difficulties to participate in social activities resulted in difficulties to maintain friends or meet new friends. Time with family had to be reduced, some reported difficulties in caring for children and roles within the family had to be changed (Arnold et al. 2008; Rodham et al. 2010). Unemployment or reduced working hours are common results of FM, which affects psychological well-being negatively with loss of professional identity, sense of achievement, and purpose in life (Arnold et al. 2008; Liedberg and Henriksson 2002).

The lack of clear signs of illness or sometimes disability caused problems with moral and social legitimacy (Hallberg and Carlsson 1998; Henriksson 1995a; Rodham et al. 2010). There was a discrepancy between how persons with FM look and how they felt/what activities they were able to manage (Cunningham and Jillings 2006; Hallberg and Carlsson 2000; Soderberg et al. 1999). They struggled to maintain credibility when met with disbelief or doubt from others, and others' perception that FM is psychological (and thus not legitimate) (Juuso et al. 2011; Rodham et al. 2010).

People with FM described how they have been forced to change their way of living regarding family, social relationships, employment, and leisure time (Cudney et al. 2002; Gustafsson et al. 2004; Hallberg and Carlsson 1998; Henriksson 1995a, b; Lachapelle et al. 2008; Liedberg and Henriksson 2002; Löfgren et al. 2006; Mengshoel and Heggen 2004; Soderberg and Lundman 2001). In order to maintain some balance in life, these changes lead to a life with restrictions or careful planning in family life, employment, and social contacts (Cunningham and Jillings 2006; Henriksson 1995a, b; Liedberg and Henriksson 2002).

Acceptance was a help to reevaluate life with long-term pain (Löfgren et al. 2006; Miles et al. 2005). Acceptance in FM was described as a process of realization and acknowledgement

(Lachapelle et al. 2008). Factors that were found to promote acceptance were: getting a diagnosis; social support; educating self and others; and self-care. Barriers to acceptance were: struggling to retain their pre-pain identity; others not accepting their pain; and the unspoken message that the pain was “all in their head” (Lachapelle et al. 2008).

According to the model of Miles, Curran and Allan (Miles et al. 2005) people with FM use different strategies to accommodate or resist the constraints on the body, activity and identity. Several authors have described how important it was for the ability to use successful strategies that the individual had acknowledged the changed life-situation, was able to “listen to one’s body,” was knowledgeable about FM and had accepted losses from the illness (Löfgren et al. 2006; Mengshoel and Heggen 2004; Schaefer 1997; Sim and Madden 2008; Sturge-Jacobs 2002). Examples of accommodating strategies included seeking information/being knowledgeable (Löfgren et al. 2006; Raymond and Brown 2000; Soderberg et al. 1999), positive thinking (Cudney et al. 2002; Löfgren et al. 2006) and finding distraction in pleasurable activities (Hallberg and Carlsson 1998; Juuso et al. 2011; Paulson et al. 2002; Schaefer 1997). Taking care of the body, pacing or restricting daily activity, working part-time (Cudney et al. 2002; Cunningham and Jillings 2006; Hallberg and Carlsson 2000; Henriksson 1995b; Kengen Traska et al. 2012; Löfgren et al. 2006; Mannerkorpi et al. 1999), being physically active (Gustafsson et al. 2004; Mannerkorpi et al. 1999) and carefully prioritizing, planning, and structuring activities and daily routines (Hallberg and Carlsson 1998; Kengen Traska et al. 2012; Löfgren et al. 2006; Raymond and Brown 2000; Schaefer 1997) were all important for accommodation. Strategies used to resist included ignoring pain (Gustafsson et al. 2004; Hallberg and Carlsson 2000; Mannerkorpi et al. 1999), giving up social activities and interests, avoiding physical activity and resting most of the day. The informants were somewhat uncertain of their ability to participate and therefore avoided planning any activities ahead of time (Hallberg and Carlsson 2000; Mannerkorpi et al. 1999) [See Table 9.3]

9.3.3 Chronic Low Back Pain (CLBP)

A qualitative synthesis from 2013 explored the experience of living with low-back pain (Bunzli et al. 2013). Twenty-five articles were included in the synthesis, which addressed similar areas as the earlier described metasynthesis of experiences of patients with FM (Sim and Madden 2008). An overview of the results of the synthesis (Bunzli et al. 2013) complemented with later studies, and including more than 240 informants with CLBP, is presented below.

The CLBP pain was described as constantly present, salient and with unpredictable variations in intensity with an ability to disrupt every activity of daily living (Osborn and Smith 2006). Mobility limitations are commonly described, such as in standing and walking. The pain disturbed sleep; informants suffered sleep deprivation (de Souza and Frank 2007) and tiredness. The uncertainty imposed by the fluctuations in pain made it difficult to plan daily activities and for the future at work and with the family; simple tasks such as dressing or housekeeping became a strain and leisure activities had to be reduced or given up (Corbett et al. 2007; Crowe et al. 2010; de Souza and Frank 2007; Snelgrove and Liossi 2009; Young et al. 2011).

Since the pain is invisible, the experience of not being believed by health care professionals, friends, family, or colleagues was a major problem (Slade et al. 2009b; Snelgrove and Liossi 2009; Toye and Barker 2010). The stigmatization of CLBP was described, such as the picture in the media of people with CLBP as fraudulent and how society views people with CLBP as burdens (Holloway et al. 2007; Slade et al. 2009b). To receive support from the family, the workplace and the welfare system, it was important that the pain could be explained from a biomedical perspective (May et al. 2000; Snelgrove and Liossi 2009; Toye and Barker 2010; Walker et al. 1999). Psychological explanations were experienced as if integrity was being questioned (May et al. 2000; Slade et al. 2009b; Walker et al. 1999; Young et al. 2011). The informants needed to establish themselves as credible persons (May et al. 2000; Snelgrove and Liossi 2009; Toye and

Table 9.3 Description of included studies for experiences of living with and managing long-term pain infibromyalgia

Study	Data collection	Data analysis
Arnold et al. (2008)	Six focus-groups with in total 48 F with FM	Analysis according to principles of Glaser and Strauss
Cudney et al. (2002)	On-line conversations of 10 FM (F) from a computer support group were recorded	Content analysis
Cunningham and Jillings (2006)	In-depth interviews with 8 FM (7 F, 1 M)	Constant comparative method according to Glaser and Strauss
Gustafsson et al. (2004)	Semi-structured interviews with 16 F, 10 chronic widespread pain and 6 FM	Constant comparative method according to Glaser and Strauss
Hallberg and Carlsson (1998)	In-depth interviews with 22 FM (F)	Grounded Theory
Hallberg and Carlsson (2000)	In-depth interviews with 22 FM (F)	Grounded Theory
Hellstrom et al. (1999)	Interviews with 10 FM (9 F 1 M)	Empirical phenomenological psychological method according to Karlsson
Henriksson (1995a, b)	Semi-structured interviews with 40 FM (F)	Content analysis
Humphrey et al. (2010)	Interviews with 40 FM (28 F, 12 M), 20 from the USA, 10 from Germany, and 10 from France	Qualitative analysis based on Grounded Theory
Juuso et al. (2011)	Interviews with 15 FM (F)	Phenomenological hermeneutic interpretation
Kengen Traska et al. (2012)	A focus group interview with 8 FM (F)	Content analysis
Lachapelle et al. (2008)	Focus groups with women with FM and RA (*n*=45)	Thematic analyses according to Braun and Clarke
Lempp et al. (2009)	Interviews with 12 FM (11 F, 1 M)	Content analysis
Liedberg and Henriksson (2002)	Interviews with 39 FM (F)	Content analysis
Löfgren et al. (2006)	Diaries, focus groups and individual interviews with 12 FM (F)	Content analysis of dairies, Grounded Theory of total data
Mannerkorpi et al. (1999)	Qualitative interviews 11 FM (F), each informant was interviewed twice	Phenomenological method according to Karlsson
Mengshoel and Heggen (2004)	Interviews with 5 FM (F)	Qualitative thematic content analyses
Paulson et al. (2002)	Narrative interviews with 14 FM (M)	Phenomenological hermeneutic interpretation inspired by Ricoeur
Raymond and Brown (2000)	Semi-structured interviews with 7 FM (6 F 1 M)	Thematic analysis
Rodham et al. (2010)	Semi-structured interviews with 4 FM (F) and 4 spouses (M)	Interpretative phenomenological analysis
Schaefer (1995)	Interviews with 36 FM (F)	Constant comparative method according to Glaser and Strauss
Schaefer (1997)	Diaries from 8 FM (F) written daily for 3 months	Thematic analysis
Sim and Madden (2008)	Review including 23 studies	Synthesis of 23 studies with persons with FM
Sturge-Jacobs (2002)	Interviews with 9 FM (F)	Phenomenological thematic analysis according to van Manen
Soderberg and Lundman (2001)	Interviews with 25 FM (F)	Content analysis
Soderberg et al. (2002)	Narrative interviews with 25 FM (F)	Phenomenological hermeneutic method inspired by Ricoeur
Soderberg et al. (1999)	Interviews with 14 FM (F)	Phenomenological analysis
Theadom and Cropley (2010)	Semi-structured interviews with 16 (14 F, 2 M) with FM	Interpretative phenomenological analysis
Undeland and Malterud (2007)	Qualitative focus groups with 11 FM (F)	A systematic text condensation with the aim to generalize descriptions and concepts

Barker 2010), justify that their pain was real (May et al. 2000; Walker et al. 1999) and appear ill or disabled enough in order to avoid being viewed as an imposter (Bowman 1991; Holloway et al. 2007; Toye and Barker 2010; Walker et al. 1999, 2006).

When a satisfactory explanation was not at hand, many informants felt at risk of not being believed (Bowman 1991; Holloway et al. 2007; Snelgrove and Liossi 2009; Toye and Barker 2010; Walker et al. 1999; Young et al. 2011), the hope for a cure was shaken and anxiety about the future increased (Corbett et al. 2007; Snelgrove and Liossi 2009; Young et al. 2011). The informants often described anger and frustration towards health professionals who failed to explain and cure the pain (Corbett et al. 2007; Snelgrove and Liossi 2009; Toye and Barker 2010; Walker et al. 2006). Still, many individuals hoped for medical advances and that their pain would be resolved in the future.

The pain had a major negative impact on the sufferers' identity and sense of self, and was described as an assault on the self (Smith and Osborn 2007). Due to limitations imposed by the pain, roles had to be changed within the family (Bowman 1991; Corbett et al. 2007; de Souza and Frank 2011; Holloway et al. 2007; Snelgrove and Liossi 2009; Walker et al. 2006). Dependency on others could lead to feelings of helplessness (de Souza and Frank 2007, 2011; Walker et al. 2006), and the conjugal relationship was at risk of strain and breakdown (Walker et al. 2006). There was a gap between the past ideal self and the present perceived self, which could lead to feelings of shame and self-loathing (Osborn and Smith 2006; Snelgrove and Liossi 2009; Walker et al. 2006). The informants did, on the other hand, also acknowledge the need to learn to live with the pain (Bowman 1991; Corbett et al. 2007; Toye and Barker 2010). Learning to live with pain facilitated a turning point from despair to hope for the future (Corbett et al. 2007).

Strategies were described that accommodated or resisted the constraint imposed by the nature of low-back pain. Strategies commonly used to resist and control pain were hyper vigilance to painful or threatening movements (Bowman 1991; Crowe et al. 2010; Osborn and Smith 2006), avoiding or restricting activity (Corbett et al. 2007; de Souza and Frank 2007; Young et al. 2011) and taking medication. Strategies used to control the "assault on the self" (Smith and Osborn 2007) were avoidance and withdrawal from social contacts, although this led to isolation and feelings of depression (de Souza and Frank 2011; Holloway et al. 2007; Walker et al. 2006). Another strategy was to exceed the perceived functional capability attempting to fight back against the pain (Corbett et al. 2007; de Souza and Frank 2011; Osborn and Smith 2006). Strategies used to accommodate to the constraint from pain were trying to live with pain (Bowman 1991; Corbett et al. 2007; Toye and Barker 2010) and making an analysis of risk and benefit when deciding whether to engage in an activity or not (Young et al. 2011) [See Table 9.4]

9.3.4 Chronic Whiplash Associated Disorder (Chronic WAD)

The experience of living with chronic WAD is described in two studies. People with WAD describe three major groups of symptoms that affect their daily life: cephalic and cervical pain, sensory hypersensitivity and cognitive dysfunction (Krohne and Ihlebaek 2010). The pain is described as intolerable, fluctuating and periodically constant day and night causing sleeping problems. The pain is described as resulting in limited physical function in the neck and shoulders (Krohne and Ihlebaek 2010). Hypersensitivity to light and sounds, reduced eyesight and hearing caused major problems in daily life activities. Cognitive dysfunction was perceived as a pain trigger and a barrier to participation in social life and employment (Krohne and Ihlebaek 2010). Everyday life was divided into good periods when symptoms were manageable and into bad periods, when the symptoms took control of life and could lead to anger, frustration and depres-

Table 9.4 Description of included studies for experiences of living with and managing long-term pain in chronic low back pain (CLBP)

Study	Data collection	Data analysis
Bunzli et al. (2013)	Review including 25 studies	Synthesis of 25 studies with persons with low back pain
Osborn and Smith (2006), Smith and Osborn (2007)	Semi-structured interviews with 6 CLBP (2 F 4 M)	Interpretative phenomenological analysis (IPA)
de Souza and Frank (2007), de Souza and Frank (2011)	Unstructured interviews with 11 CLBP (6 F 5 M)	Content analysis
Corbett et al. (2007)	Narrative interviews with 6 CLBP (3 F, 3 M)	Thematic analysis
Crowe et al. (2010)	Semi-structured interviews with 64 CLBP (31 F, 33 M)	Thematic analysis according to Boyatzis
Snelgrove and Liossi (2009)	Narrative interviews with 8 CLBP (5 F, 3 M)	Interpretative phenomenological analysis (IPA)
Young et al. (2011)	Focus group interviews with 31 CLBP (14 F, 17 M)	Thematic analysis with the International Classification of Function as a frame
Slade et al. (2009a, b)	Focus group interviews with 18 CLBP (12 F, 6 M)	Grounded theory
Toye and Barker (2010)	Interviews with 20 CLBP (13 F, 7 M) every person was interviewed 3 times	Grounded theory
Holloway et al. (2007)	In-depth interviews with 18 CLBP (6 F, 12 M)	Thematic analysis
May et al. (2000)	Semi-structured interviews with 12 CLBP (6 F, 6 M)	Content analysis
Walker et al. (1999)	Interviews with 20 CLBP (8 F, 12 M)	Analysis according to Kvale and Giorgi
Bowman (1991)	Interviews with 15 CLBP (6 F, 9 M)	Analysis according to Giorgi
Walker et al. (2006)	Interviews with 20 CLBP (8 F, 12 M)	Thematic analysis

sion (Krohne and Ihlebaek 2010). People with WAD describe how their whole life situation is negatively affected by the pain on account of impaired physical function together with decreased participation in social and leisure activities (Rydstad et al. 2010).

The informants described experiences of how whiplash patients were left on their own and ignored by the medical expertise (Krohne and Ihlebaek 2010). Other experiences described were that family and friends got tired of them if they described their problems and that employers, physicians and social security officers made demands on them, which they had problems fulfilling. This led them to question themselves (Rydstad et al. 2010). The life situation for persons with long-term WAD is described as chaos in life (Rydstad et al. 2010), with loss of hope and dreams, loss of ability, loss of social roles and feelings of being abandoned by those around them. Rehabilitation could help them to change their self-image and start a process of accepting the consequences of WAD.

Examples of accommodating strategies developed on their own by the informants with WAD were described as a process of trial and error as they received no help from the health care services (Krohne and Ihlebaek 2010). They lowered their level of activities, kept to the training scheme and tried to find a balance in life. Rest in calm surroundings was described as one of the most important strategies; it was used to prepare for events and to regain control over pain after social, mental or physical activities. Exercise was also important, often practiced on an everyday basis. Those who had found a training method with good results used it as "self-medication" instead of painkillers. Regularity, intensity and tempo were important for the desired effect. Social withdrawal was used both in order to provide time to rest and for exercise, but also as a means to avoid pain triggers and maintain good periods (Krohne and Ihlebaek 2010) [Please refer to Table 9.5]

9.3.5 Long-Term Neck Pain

Two studies about the experience of living with long-term neck pain without traumatic injury are included. They are both from primary care settings in Scandinavia.

People with long-term neck pain without traumatic injury described the pain as constant but unpredictably varying from dull to moderate, they also described stiffness, headache, vertigo and numbness in their arms (Ahlsen et al. 2012b; Hunhammar et al. 2009). The physical, psychological and social effects of pain disrupted their lives with varying consequences regarding physical capacity in both private and occupational settings. The search for the control of pain required time and the prioritization of one's own health (Hunhammar et al. 2009).

Strategies used were "Balancing the pain," including adjustments at home and at work like doing a little at a time, accepting help, and adjusting physical training. Informants who used those strategies were mostly confident in their ability to control their pain. "Concealing the pain" described resisting strategies, such as avoidance of letting others know about the pain (Hunhammar et al. 2009). Excessive use of painkillers was another described strategy, used to manage work (Ahlsen et al. 2012b).

9.3.6 Conclusions from Evidence in Patients' Experiences of Living with and Managing Long-Term Pain

There is now an extensive number of qualitative studies on FM and LBP including several hundreds of patients, exploring different aspects of living with and managing long-term pain. There are fewer studies on chronic pain, but they are still those including 140 patients and showing similar patterns. The results from the different studies of each diagnosis confirm and complement each other and provide evidence within the areas studied.

Table 9.5 Description of included studies for experiences of living with and managing long-term pain chronic in whiplash associated disorder and long-term neck-pain

Study	Data collection	Data analysis
Chronic whiplash associated disorder		
Krohne and Ihlebaek (2010)	Focus group interviews with 14 CWAD (8 F, 6 M)	Systematic text condensation with a modified version of Giorgi's phenomenological method
Rydstad et al. (2010)	Semi-structured interviews with 9 CWAD (5 F 4 M)	Analysis according to the principles of the grounded theory method of constant comparison
Long-term neck-pain in primary care		
Ahlsen et al. (2012a, b)	Qualitative interviews with 10 men with chronic neck pain	Narrative analysis
Hunhammar et al. (2009)	Thematic interviews with 12 persons (6 F, 6 M) with chronic neck pain	Grounded theory

There is a lack of qualitative research on whiplash and on neck pain. These few studies cannot yet be considered to provide evidence, but they highlight and provide knowledge with respect to important aspects. Below follows a summary of the evidence:

What was in common for all long-term pain diagnostic groups was that pain was invisible, unpredictable, fluctuating, and hard to communicate. Other symptoms differed: patients with FM stressed fatigue and psychological symptoms, whereas patients with LBP stressed mobility limitations. In FM, LBP and chronic pain, legitimacy was an important issue. The informants with chronic pain experienced a lack of legitimacy; support was lacking both from family and from health professionals. When informants with FM got their diagnosis, it was received with relief as they felt they became credible again. But the diagnosis was also a stigma; they felt that they were not believed or listened to. The informants with LBP preferred the biomedical perspective on diagnosis and treatment; psychological explanations were experienced as if integrity was being questioned. Anger and frustration was commonly described in the meetings with health professionals. For informants with chronic pain the consequences of pain limited and changed every aspect of life, making pain difficult to adapt to. For FM patients the body was the focus of attention and was considered to be an obstacle, a burden or a barrier to everyday life. LBP disrupted every activity in daily life and mobility limitations were common. Informants with chronic pain described the need for appropriate coping strategies for reevaluation of life and to enable pain accommodation. Acceptance was a major help in reevaluating life in FM. Active strategies were an aid in managing daily life. Informants with LBP used strategies such as hypervigilance to painful movements, avoidance, withdrawal, and medication but also tried to live with the pain and assess risks and benefits in choice of activities.

Important aspects to consider in relation to WAD and neck-pain included: patients with WAD stressed hypersensitivity to light and sounds, sleeping problems and cognitive dysfunction; patients with neck pain stressed stiffness, headache, vertigo and numbness in their arms. The life situation of WAD patients was described as chaos in life with a loss of hope and dreams. In good periods, symptoms could be manageable; in bad periods the symptoms controlled life. Important strategies for WAD informants were to find a balance in life, rest in calm surroundings and exercise. In order to manage their work situation, informants with neck pain described an excessive use of pain medication. Other strategies in daily life were adjusting to pain or concealing the pain.

It is recommended that further research of long-term pain conditions is directed towards WAD and other neck pain conditions. In regard to FM and LBP, we suggest that clinicians strive to include the recent qualitative results into their clinical practice.

9.4 Patients' Experiences of Treatment and Rehabilitation

Living with long-term pain often results in numerous contacts with the health-care system; long-term pain is one of the most common reasons for a visit to primary care. The objective of this section is to evaluate and present qualitative evidence of patients' experiences of treatment and rehabilitation. Twenty-five studies with nearly 370 participants dealing with this subject were found. The most common diagnoses were CLBP ($n=104$) and fibromyalgia (FM) ($n=51$), many studies included a variety of different diagnoses such as chronic widespread pain, fibromyalgia, neck and shoulder pain, headache and pain in hip or knee. The MeSH headings used were: qualitative research, qualitative methods, experience, interviews, treatment, rehabilitation, chronic pain, long-term pain, fibromyalgia, low-back pain, back pain, neck pain.

9.4.1 Diagnosis

For people suffering from long-term pain it often take years until a final diagnosis is established. When a diagnosis finally is made, contradictory opinions about prognosis and treatment among health professionals are common and this make patients become irresolute and frustrated (Dewar et al. 2009; Harding et al. 2005).

Receiving a diagnosis was felt to have legitimized the pain and reduced the stigma perceived because of the invisible pain (Dewar et al. 2009; Undeland and Malterud 2007). The diagnosis established the informants' credibility towards physicians, family, friends, employer, and coworkers (Dewar et al. 2009), but there were both positive and negative aspects. For example, informants with FM described that to receive a diagnosis was initially met with relief (Henriksson 1995a; Schaefer 1995) due to the belief that the illness had been validated, that the individual had become credible again (Soderberg et al. 1999) and that the illness was not as serious as feared (Henriksson 1995a; Mengshoel and Heggen 2004; Schaefer 1995). When the informants later discovered limitations in treatment options, respect, understanding, sadness, and despair emerged (Undeland and Malterud 2007; Werner et al. 2004; Werner and Malterud 2003). In the longer term the diagnosis—based on mainly subjective criteria—raised more questions than answers, and uncertainty remained. Also, the status of the diagnosis carried a stigma; the individuals' experiences were frequently dismissed or belittled (McMahon et al. 2012).

9.4.2 Interaction with Health Professionals

The informants wanted the professionals to be well trained, professional, empathic, and attentive. To have a supportive primary care physician who provided sympathy, guidance, and discussion about treatment options was described as important for the pain management (Dewar et al. 2009; Escudero-Carratero et al. 2008; Lempp et al. 2009; Liddle et al. 2007; Slade et al. 2009a; Werner et al. 2004). To be perceived as supportive, it was important that the health-care provider was willing to listen to the patient, believed in them and considered their perspective on discussion about treatment decisions (Dewar et al. 2009; Slade et al. 2009a). A health care provider who collaborated and shared decision making in their care plan was preferred (Slade et al. 2009a). Many described that their physician was supportive, but others described contrary experiences with physicians who were dismissive, hurried and who did not provide information, did not make a proper examination or were hesitant to take them into their care (Dewar et al. 2009; Harding et al. 2005; Lempp et al. 2009; Liddle et al. 2007; Slade et al. 2009a; Werner et al. 2004). When preparing for a visit to their physicians, informants described how they made active efforts to appear credible. They sent letters and earlier medical records in beforehand, they planned how to appear "not too healthy," and they suggested or even begged for medical investigations and referrals (Werner and Malterud 2003). When a cause could not be found or the pain could not be relieved with treatments tried, many informants looked to alternative medicine. It worked for some, while some experienced side effects and the diminishment of positive effects (Dewar et al. 2009; Harding et al. 2005). If patients felt that the physician did not believe them or that their complaints were not taken seriously, this was a reason for dropping out from pain treatment and rehabilitation. Dropouts were more common in nonnative patients than in native. One study has explored the reasons for dropouts of Turkish or Moroccan origin with CLBP in the Netherlands (Sloots et al. 2010). The informants described how they had had other expectations regarding the rehabilitation program. They expected to be provided with a specific medical diagnosis and pain relief as the primary aim of the rehabilitation. When no specific somatic cause could be identified, they concluded that the rehabilitation did not meet their objectives. In Turkey, magnetic resonance imaging (MRI) and referrals to a specialist are more common than in the Netherlands, which might explain the participants' expectations to some extent.

The informants had often got a second opinion from a physician in their country of origin, where they often received a specific somatic diagnosis. It was difficult for the informants to cope with the, at times, contradicting views of the Dutch physician and the physician in their country of origin, which sometimes led them to drop out of treatment. Contradicting views of the origin of pain and aims of the treatments prevented successful participation in pain rehabilitation (Sloots et al. 2010).

9.4.3 Information

People with long-term pain want clear explanations about diagnosis and treatment options. They want supportive reassurance and advice about pain management (Cooper et al. 2009; Dewar et al. 2009; Slade et al. 2009a). The informants obtained information through different sources. Support groups sometimes made it possible to meet experts and share ideas and experiences with peers, although sometimes they were described as "pity parties" (Dewar et al. 2009; Slade et al. 2009a). In pain management programs, information was often provided in the context of group discussions. These discussions were often positively described by the informants; they felt connected and described it as beneficial to be sharing experiences, information, thoughts, and ideas with others in the same situation (Bremander et al. 2009; Gustafsson et al. 2004; Martensson and Dahlin-Ivanoff 2006; Rydstad et al. 2010; Werner et al. 2004). When the discussions supported the informants in reflecting and relating to others, their self-confidence rose and informants described how they could set limits without having a bad conscience (Gustafsson et al. 2004; Martensson and Dahlin-Ivanoff 2006; Rydstad et al. 2010; Werner et al. 2004). When informants with CLBP received individually adapted explanations, they were able to act and take control over their situation. Their life had been ruled by their CLBP and after the intervention they experienced a restored sense of direction in their life, as family members and employees. They became responsible for managing their illness and could control the pain with exercise (Angel et al. 2012). One study exploring the experiences of a web-based intervention illustrated how such interventions might be useful as a motivator and for providing feedback. The informants felt that they could trust the therapist, but also that the feedback sometimes was impersonal or that they did not feel that they were understood. The informants described how the intervention helped them to become more reflective about their thoughts and goals. They learned and accepted how to live with chronic pain and to do things despite their pain (Jelin et al. 2012).

9.4.4 Patients' Involvement and Responsibility

Initially a variety of treatment approaches were often tried in frustrated attempts to get a "quick fix" (Liddle et al. 2007). The most common treatment strategy was pain medication and muscle relaxants. When the informants' symptoms persisted despite medical treatment, they started to question the treatment strategy and turned to other options. Those who began to accept the importance of their own involvement in their rehabilitation seemed more satisfied and less likely to search for a fast solution (Harding et al. 2005; Liddle et al. 2007).

Acceptance of pain and that they had to "live with their pain" were controversial statements. Informants often viewed these comments as an excuse for not determining the cause or equated them with physicians not trying to find a solution (Dewar et al. 2009). For others, acceptance meant that they had become more realistic, stopped to search for relief and that they tried to learn to endure pain (Dewar et al. 2009; Gustafsson et al. 2004; Rydstad et al. 2010; Van Huet et al. 2009). Some informants described how they had gone through a process of grieving over what they had lost, moving on in their life, they acknowledged that although pain persisted, life could be managed (Van Huet et al. 2009).

For successful long-term pain treatment and rehabilitation the person with long-term pain needs to be involved and actively take part in the treatments and planning. To become a part of a positive rehabilitation process it was of vital importance that the person experienced that they were being met with respect and recognition (Gustafsson et al. 2004; Werner and Malterud 2003). When being involved in treatment and rehabilitation, informants with different diagnoses described how their bodily, emotional and social competence had increased as they started to recognize and respect their own internal signals (Angel et al. 2012; Gustafsson et al. 2004; Steihaug 2007; Werner and Malterud 2003; Öhman et al. 2011). As informants took more responsibility for their own rehabilitation the need for individual, specific exercises and advice about lifestyle adaptation became more important (Angel et al. 2012; Cooper et al. 2009; Liddle et al. 2007). When actively involved in their own rehabilitation, informants described important aspects such as awareness of how to manage symptoms and accepting and staying within their boundaries, as well as continuing to exercise for informants with CLBP (Angel et al. 2012; Liddle et al. 2007), with chronic pain (Gustafsson et al. 2004; Steihaug 2007; Öhman et al. 2011) and with WAD (Rydstad et al. 2010).

9.4.5 Team Rehabilitation

Most people with long-term pain meet individual health professionals or pain teams within primary care for treatment or rehabilitation. Pain rehabilitation clinics with interdisciplinary working teams are not very common and only relatively few patients have access to this kind of specialist care. A few studies have explored experiences of this kind of rehabilitation (Ahlsen et al. 2012b; Bremander et al. 2009; Gustafsson et al. 2004; Rydstad et al. 2010).

The informants described how the health professionals in the teams were knowledgeable about, or even specialized in, long-term pain and pain treatment and how this allowed them to feel recognized and secure. The informants felt that they were listened to and understood, it was possible to work with psychological aspects of the pain without feeling that the pain was psychological or imaginary (Ahlsen et al. 2012a; Bremander et al. 2009). To participate in pain rehabilitation at a rehabilitation clinic means reaching treatment goals, but also that the rehabilitation is related to human needs such as reorientation, taking control over one's life, rebuilding one's self-image, connecting with others and getting comfort (Ahlsen et al. 2012a; Bremander et al. 2009; Gustafsson et al. 2004; Rydstad et al. 2010). To many informants, participating in a pain rehabilitation program (PRP) meant that they became part of a process in which their feelings towards themselves changed (Bremander et al. 2009; Gustafsson et al. 2004; Rydstad et al. 2010; Van Huet et al. 2009). This can be described as "A process from shame to respect," where theoretical and practical knowledge of one's body served as a starting point for a new approach towards oneself and the pain. The next step was "Setting limits" by adjusting self-demands, workload and telling others. The last step, "Changing self-image" resulted in improved self-image by changing from boundary to possibility, letting pain rule one's life to taking control over pain and from focusing on satisfying others to taking care of oneself (Gustafsson et al. 2004). Even though most of the experiences described were positive, the participants continued to struggle with adapting to living with long-term pain and suffering from their limitations from pain, and the lack of understanding for their situation in society (Gustafsson et al. 2004; Rydstad et al. 2010). To be in a group was experienced as positive by those who were willing to adopt the concept; for others the program did not meet their individual needs (Gustafsson et al. 2004; Van Huet et al. 2009; Werner et al. 2004).

9.4.6 Strategies

For those who had participated in a PRP, thoughts refocused from pain to self-efficacy and self-management. Cognitive behavioral techniques like avoiding talking about pain were found helpful by some, but some considered them to be "brain washing" (Rydstad et al. 2010; Van Huet et al. 2009; Carroll et al. 2013). For informants who used to overdo tasks, learning how to plan and pace was helpful. For those who used pacing, they could control the amount of time spent depending on the type of task (Rydstad et al. 2010) and in this way manage daily routines (Gustafsson et al. 2004; Martensson and Dahlin-Ivanoff 2006; Van Huet et al. 2009). To develop body awareness and to listen to the body was crucial in finding how to improve capacity and avoid unnecessary flare-ups of pain (Gustafsson et al. 2004; Rydstad et al. 2010; Öhman et al. 2011). For informants with CLBP, the ability to "know their body" was empowering. They learned to differ between good pain (after exercising) and bad pain (aggravated) (Slade et al. 2009a). A training diary could be a support in reaching bodily understanding and help the participants to understand pain patterns and when to increase or limit activity (Angel et al. 2012). Exercise was commonly used among informants with CLBP (Cooper et al. 2009; Slade et al. 2009a), usually when their back was painful (Cooper et al. 2009). They did exercises that made sense to them and fitted into their lifestyle. Informants with CLBP wanted individually adapted exercise programs aligned to their fitness level and previously acquired skills (Slade et al. 2009a). They reported how they lacked confidence in correct exercise performance. It was important that the exercise instructors demonstrated the exercises, observed, provided feedback, and if necessary corrected the technique. Informants with CLBP underlined that they needed supervision and corrections of exercise programs. Follow-ups and reassurance that they were doing exercises correctly supported their self-management strategies (Angel et al. 2012; Liddle et al. 2007; Slade et al. 2009a). If attending group training, it was important that the groups were matched for similar strength, fitness, and technical skills (Slade et al. 2009a).

9.4.7 Conclusions from Patients' Experiences of Treatment and Rehabilitation

The literature presented supports evidence for a number of important aspects concerning treatment for patients with long-term pain. Receiving a diagnosis is important for patients in order to regain perceived credibility, but the diagnosis can also often lead to disappointment when it becomes obvious that there are limitations in treatment options and when some caregivers disbelieve the diagnosis. The informants wish for supportive and competent caregivers who provide information, who listen and respect them and involve them in rehabilitation planning decisions. Many patients experience the opposite, which results in them having to focus on convincing health-care professionals and others on the legitimacy of their pain.

Accurate and individually adapted information increases patients' self-confidence and provides a basis for patients on which to act and regain control of their situation. Patients who are actively involved in their treatment or rehabilitation are more satisfied; they increase their bodily, emotional and social competence, take more responsibility for their own rehabilitation and thus need more individually adapted measures. To become involved is supported by one's own acceptance and by being met with respect and recognition. Important strategies learned to manage daily routines were planning and pacing, knowing and listening to the body, and performing individually adapted exercise programs. To participate in a pain rehabilitation program often helps in reorientation, taking control over one's life and rebuilding one's self-image.

It is recommended that new qualitative studies are done when new treatments or rehabilitation measures—or combinations of measures—are tested. It is proposed that clinicians take advantage of the reported aspects of the qualitative studies presented [See Table 9.6]

9.5 Patients' Experiences of Staying at Work or Not Being Able to Work

In industrialized countries, workers with long-term pain account for significant human, societal and economic costs. The economic impact is due to the costs associated with health care, sickness absence and work disability. Health and workplace

Table 9.6 Description of included studies for experiences of treatment and rehabilitation in people with long-term pain

Study	Data collection	Data analysis
Ahlsen et al. (2012a, b)	Qualitative interviews with 10 men with chronic neck pain	Narrative analysis
Angel et al. (2012)	Interviews with 20 persons with CLBP who participated in individual counseling interventions for CLBP	Text analysis in three steps by Ricoeur
Bremander et al. (2009)	Interviews with 16 persons (13 W 3 M) with chronic pain, after completing of a PMP	Analysis according grounded theory
Carroll et al. (2013)	In-depth interviews with 13 persons (10 M 3 F) with chronic pain in pain rehabilitation	Analysis with thematic analysis
Dewar et al. (2009)	In-depth interviews face to face or by telephone with 19 persons with chronic pain (13 F, 6 M)	Thematic analysis, using constant comparison method to examine categories for differences and similarities
Escudero-Carratero et al. (2010)	Focus group interviews with 21 persons (1 M, 20 F) with fibromyalgia receiving care in the public health system	Content analysis
Gustafsson et al. (2004)	Semi-structured interviews with 16 women with chronic pain. They had participated in a Pain management program 1 year earlier	Constant comparison method according to Grounded Theory
Harding et al. (2005)	Interviews with 15 patients (12 F 3 M) with chronic pain who had attended a hospital-based pain clinic	Thematic analysis and consensus discussions.
Jelin et al. (2012)	Interviews with 7 women with fibromyalgia after participating in a 4-week inter-net intervention after a PMP program	Analysis by systematic text condensation according to Kvale
Lempp et al. (2009)	Interviews with 12 persons with fibromyalgia receiving care at a rheumatology clinic	Data was analyzed with content analysis
Liddle et al. (2007)	Focus group interviews with 18 persons (14 F, 4 M) with CLBP were included. They had received treatment including exercise and advice for their LBP within 24 months.	Identification of main themes.
McMahon et al. (2012)	Narrative interviews ($n = 10$ F)	Narrative analysis
Martensson and Dahlin-Ivanoff (2006)	Focus group interviews with 24 persons with chronic pain who had participated in a PMP in a Primary care setting	A thematic, interpretative analysis inspired by Krueger's method
Rydstad et al. (2010)	Semi-structured interviews with 9 persons (5 W 4 M) with whiplash associated disorder, who had participated in a PMP 1 year earlier	Analysis according to the principles of grounded theory method of constant comparison
Slade et al. (2009a)	Focus groups with 18 persons (9 M, 9 W) with CLBP who had participated in exercise programs for LBP	Analysis according to the principles of grounded theory
Sloots et al. (2010)	In-depth interviews with 23 patients (10 M 13 F) with LBP with Turkisk or Moroccan origin, who dropped out from a rehabilitation program. Also 8 rehabilitation physicians and 2 rehabilitation therapists were interviewed	Coding and analyzed to themes
Steihaug (2007)	Qualitative interviews with 8 women with chronic pain who had participated in a PMP	Data was analyzed by systematic text condensation inspired from Giorgi
Undeland and Malterud (2007)	Focus-group interviews with 11 women with fibromyalgia	Systematic text condensation according to Giorgi and Malterud

(continued)

Table 9.6 (continued)

Study	Data collection	Data analysis
Van Huet et al. (2009)	In-depth interviews with a narrative focus with 15 persons with chronic pain (11 F, 4 M). They had participated in a Pain management program (PMP) 2 or 3 years earlier	A narrative analysis of the experience of living with chronic pain
Werner and Malterud (2003)	In-depth interviews with 10 women long-term chronic pain. The women had previously participated in group-based treatment program	Data was analyzed according to Giorgi's phenomenological analysis
Werner et al. (2004)	In-depth interviews with 10 women long-term chronic pain. The women had previously participated in group-based treatment program	The analysis was inspired by narrative analysis and discourse analysis. The interview-guide was theory based
Öhman et al. (2011)	Diary notes from and in-depth interview with 14 women with neck- and shoulder pain who participated in a Feldenkreis group-treatment	Analysis according grounded theory

strategies to address work disability and sickness absence due to long-term pain are required.

The current evidence-based approach to the occupational management of low back pain is that people stay at work with temporary adjustments if required or are granted sick leave, and then return to usual hours and work tasks. This can be combined with medical care and physical therapy. For those with long-term back pain, multidisciplinary biopsychosocial rehabilitation with an occupational focus is recommended (Franche et al. 2005; Kuoppala and Lamminpää 2008). Work modifications may include changes at the workplace, of equipment and work design, and of organizational aspects of work (van Oostrom et al. 2009). There is also evidence that modified work can reduce sickness absence, increase return to work rates and job retentions and decrease the recurrence of symptoms (Franche et al. 2005; Turner et al. 2008; van Duijn and Burdorf 2008; Williams et al. 2007). A better understanding of the experiences of those struggling to stay at work with pain and knowledge of the facilitators and barriers for work return may help clinicians and employees with their treatment and management approach. Since pain may have a multifactorial origin it is important to consider a number of factors that may influence the outcome.

The objective of this section is to evaluate and present qualitative evidence of barriers and facilitators of return to work (RTW). 21 studies were found dealing with this subject: Sweden ($n=5$), the UK ($n=5$), Canada ($n=4$), the USA ($n=2$), Netherlands ($n=2$), South Africa ($n=1$), Finland ($n=1$), and Norway ($n=1$) including 464 persons with long-term pain conditions. Barriers to RTW were described in 18 studies and facilitators to RTW in 15 studies. The majority of the studies concerned low back pain and some fibromyalgia or chronic pain/long-term pain. The method used was to code the facilitators and barriers found in the articles for the present literature review, and similar areas for both formed themes: "internal," "external," "occupational," and "work" or "meaning of work." Although, some facilitators or barriers are found in both categories, they can be both a facilitator in some studies and a barrier in another or both in the same study. There were more barriers reported than facilitators.

The MeSH headings used were: qualitative research, return to work, low back pain, neck pain, chronic pain, fibromyalgia, facilitators and barriers.

9.5.1 Internal Barriers and Facilitators to RTW and Work Participation

People suffering from pain limiting their work activities described the mayor barriers to RTW as: persistent pain (Dionne et al. 2013; Patel et al. 2007; Shaw and Huang 2005); somatic symptoms, and fatigue (Sallinen et al. 2010; Sjostrom et al. 2011); illness beliefs including fear of pain and fear of reinjury (Baril et al. 2003; McCluskey et al. 2011; Shaw and Huang 2005; Stewart et al. 2012); perceived lack of control (Stewart et al. 2012); perceived inability to perform their pre-injury job (Stewart et al. 2012); despair (Buijs et al. 2009); lack of motivation (Baril et al. 2003); earlier negative experiences, poor self-judgment of work ability, low self-esteem (Magnussen et al. 2007); ability to cope with flare-ups (Coole et al. 2010a); coping with fluctuating symptoms, being "in between" (Glavare et al. 2012); "being over the edge of exhaustion" (Sallinen et al. 2010); activity interference and negative self-perceptions and interpersonal challenges (Tveito et al. 2010). Furthermore, barriers to RTW involved reluctance to use medication (Coole et al. 2009a), self-efficacy for resuming physical activity and self-efficacy for resuming work. Resuming physical activity included eight sub-domains: lift; carry; sit; stand; push/pull; bend; climb; and reach. Self-efficacy for resuming work included pain control (Shaw and Huang 2005). Pain representations were indicators of the type of actions the participants were ready to take to control the immediate or possible consequences of their pain. During the rehabilitation trajectory different pain representations predicted return to work (Coutu et al. 2011).

Internal facilitators for RTW were: personal characteristics; adjustment latitude; coping with pain and pain beliefs (de Vries et al. 2011); using cognitive strategies; reducing pain symptoms; effectively communicating about pain (Hansson et al. 2006); being prepared for a bad day (Hansson et al. 2006; Tveito et al. 2010); moving and finding leeway (Hansson et al. 2006; Tveito et al. 2010); motivation (inner drive) changing goals from pain-oriented towards function restoration and RTW (Buijs et al. 2009); and the worker's transitioning from a less mechanistic to a more functional view of health (Coutu et al. 2011). Furthermore, facilitators for staying at work were: enjoying life; taking care of oneself; positive thinking; setting limits; using pain as a guide; using creative solutions; learning and being knowledgeable; being able to walk a "tightrope." The grieving process was a prerequisite for managing the struggle to stay at work and was influenced by social support (Löfgren et al. 2006).

9.5.2 External Barriers and Facilitators

The mayor external barriers to RTW were: the lack of access to information or support groups (Dionne et al. 2013); lack of collaboration between stakeholders (Dionne et al. 2013; Patel et al. 2007; Soeker et al. 2008); lack of collaboration with and understanding from employer (Buijs et al. 2009; Dionne et al. 2013; Glavare et al. 2012; Patel et al. 2007); lack of support from employees (Glavare et al. 2012); lack of recognition by others involved in the return-to-work process (Stewart et al. 2012); lack of support from a rehabilitation team (Glavare et al. 2012); lack of education in disability management and inadequate workplace policy (Soeker et al. 2008); the tardiness of the health care system (Buijs et al. 2009; Dionne et al. 2013); the impact back pain might have on their job security and work capacity in the future (Coole et al. 2010a); how back pain was viewed by their employers and coworkers (Coole et al. 2010a, b; Soeker et al. 2008); distrustful attitude of the medical professionals (Soeker et al. 2008); lack of client centeredness (Soeker et al. 2008); inefficiency of insurance companies (Soeker et al. 2008); lack of support from social security authorities, unsuitable economic arrangement (Magnussen et al. 2007); an unsupportive society (Soeker et al. 2008); and previous medicalization in health care (Buijs et al. 2009). Furthermore, barriers were found concerning work restructuring (Liedberg and Henriksson 2002), changes in the labor market and commuting between home and work causing additional strain on their life situation (Liedberg and Henriksson 2002).

External facilitators influencing RTW reported were: understanding from the employer (Dionne et al. 2013); protocolled communication (e.g., information exchange among health-care providers and a graded activity program) (Buijs et al. 2009; Dionne et al. 2013) in which professionals individualized support, the participants' sense of involvement in their rehabilitation process, coaching in a real workplace and the support from a multi-professional team, were all considered to be facilitators during the process of RTW (Glavare et al. 2012). Further, the beliefs and attitudes of managers and employees, the impact of health on work, moral aspects of absence and attendance at work, and the absence of management policies all influenced the RTW process. These issues require careful consideration of the rights and responsibilities of both employees and employers (Wynne-Jones et al. 2011).

9.5.3 Occupational Barriers and Facilitators

Occupational barriers reported were: the impossibility of a gradual RTW (Dionne et al. 2013); the inflexibility of the actual work (Tveito et al. 2010); receiving little work-related help from occupational health in modifying jobs (Coole et al. 2010a, b); the lack of adjustment of working hours, work tasks or the work environment (Liedberg and Henriksson 2002); and perceived lack of workplace accommodations (Stewart et al. 2012).

Informants reported on occupational facilitators for RTW: improvement of the work environment and conditions of work (Baril et al. 2003; Coole et al. 2010 b; Dionne et al. 2013; Sjostrom et al. 2011); a gradual return to work (Dionne et al. 2013); flexible working hours, possibilities to take a break, and a modified job adapted to own capacity (Coole et al. 2010b; Sjostrom et al. 2011; Soeker et al. 2008; Tveito et al. 2010). Furthermore, injury management strategies, a positive work culture, work placement strategies and having meaningful/satisfactory work experiences (Soeker et al. 2008), coworker support (Baril et al. 2003), extent of control over working hours and duties, peer support, and own beliefs and attitudes concerning working with back pain are other known facilitators (Coole et al. 2010a, b). The ability to return to or remain at work depended on work tasks not including static posture and repetitive movements of the body and the possibility to vary work posture (Liedberg and Henriksson 2002).

9.5.4 Personal Barriers

Possible personal barriers for employability were age and education (Soeker et al. 2008).

9.5.5 Work Barriers

Barriers to RTW were when a person was not able to fulfill the work requirements (Sjostrom et al. 2011), not being able to meet role expectations (Shaw and Huang 2005), experienced a lack of meaning and satisfaction in work, the poor matching of worker and work (Soeker et al. 2008) and perceived uncertainty about the future (Stewart et al. 2012).

9.5.6 Meaning of Work

16 motivators and 52 success factors for staying at work with chronic pain emerged from interviews in a study by de Vries et al. 2011. Motivators were categorized into four themes: work as a value (job-satisfaction, self-realization, social status), work as therapy (distraction from pain, an energizer, structure in life, social contacts), work as income generator (financial needs), and work as a responsibility (feeling indispensable, loyalty to colleagues) (de Vries et al. 2011).

9.5.7 Conclusions from Patients' Experiences of Staying at Work or Not Being Able to Work

In the literature presented, some of the factors have been well studied and can be considered to provide evidence for RTW, but not all. Internal barriers are somatic symptoms and self-efficacy.

Illness beliefs and coping strategies are important both as barriers and facilitators. Information, collaboration and support are important both as barriers and facilitators. An important external facilitator is also the patient's involvement in the rehabilitation process. Occupational facilitators are improving the environment and working conditions and a positive work culture. Both barriers and facilitators are the possibility of a gradual return to work, the level of flexibility in the work situation and ergonomic factors. An important barrier is lack of support from occupational health care. Work barriers are, for example, when the person does not manage the work demands or experiences a perceived uncertainty about the future.

It is recommended that qualitative studies on RTW are carried out in more countries. Many of the facilitators and barriers to RTW that have been presented can be valuable considerations not only for clinicians but also for insurance officers, job center officers, and employers' personnel departments [See Table 9.7]

9.6 Health Care Providers' Experience of the Meeting with Patients Suffering from Long-Term Pain

For improved understanding of the complex problems with the caring process of patients with pain, it is relevant to include studies of the health care providers' experiences and attitudes. MeSH headings used were: qualitative research, qualitative methods, experience, interviews, treatment, care, health care provider. Only a few qualitative studies were found, so the material provides no basis for evidence, but it does raise some interesting issues for consideration.

Physical therapists in the UK play an important part in the management of nonspecific low back pain (NSLBP), dealing with approximately 11 million consultations a year (Clinical guidelines for the physiotherapy management of persistent low back pain 2006). Guidelines for the rehabilitation of patients with persistent NSLBP highlight the importance of practitioners encouraging patients to remain at work and stay as active as possible, with a key focus on self-managing their condition (Clinical guidelines for the physiotherapy management of persistent low back pain 2006). However, physiotherapists often do not follow the guideline advice (Jeffrey and Foster 2012). Tension between the recommendations to stay active and patient expectations to be prescribed rest can make guideline adherence challenging where the priority of practitioners is to maintain a working partnership with their patient (Dahan et al. 2007). Based on this background, a study was performed aimed at understanding more about how the personal experiences and feelings of physiotherapists might influence their decision making when treating patients with NSLBP (Jeffrey and Foster 2012). Three linked themes emerged: (1) physiotherapists believed that NSLBP has an underlying biomechanical and recurring nature, (2) the physiotherapists' attitude toward managing NSLBP was to empower patients to exercise and self-manage their pain and functional problems, and (3) the physiotherapists experienced feelings of tension between the advice and treatment they felt was best for their patient and the patient's own beliefs and attitudes. It is concluded that the experiences and feelings of physiotherapists treating patients with NSLBP include conflict between their pain beliefs, attitudes and working partnership with the patients.

Psychosocial risk factors are known as yellow flags and have been suggested to be associated with the development of chronicity and disability in LBP patients. General practitioners' (GP) identification and management of psychosocial yellow flags in acute low back pain were explored (Crawford et al. 2007) in a study with purposively selected GPs. In New Zealand, a Guide to Assessing Psychosocial Yellow Flags in Low Back Pain was developed by the Accident Rehabilitation & Compensation Insurance Corporation together with the Ministry of Health, as was the New Zealand Acute Low Back Pain

Table 9.7 Description of included studies for Barriers and Facilitators of RTW in patients with work-disabling chronic pain

Study	Data collection	Data analysis
Baril et al. (2003)	A combination semi-structured interviews ($n=16$) and focus groups ($n=9$) of workers as a part of a wider study. Three Canadian provinces and a variety of workplaces were included	Analysis took a social constructionist perspective. An Open coding system was used and meta-codes were analyzed
Buijs et al. (2009)	Semi-structured interviews with a sample of 20 (9 male, 11 female) LBP patients referred to multidisciplinary back pain care.	The constant comparison method was used to identify themes. Theoretical themes were related to the themes found
Coole et al. (2010a)	Semi-structured interviews with 25 (12 Male, 13 F) employed LBP patients referred to multidisciplinary back pain rehabilitation.	Thematic analysis, a partly theoretical and deductive perspective was taken, a literature review formed the interview framework. Coding, constant comparisons method, themes identified
Coole et al. (2010b)	Semi-structured interviews with 25 employed patients (13 F, 12 M) who had been referred for back pain rehabilitation	Thematic analysis, using constant comparison method
Coutu et al. (2011)	Semi-structured interviews with 16 workers (10 M and 6 F) referred to a 12 week work-rehabilitation program. Three interviews during rehab and 1 month after discharge	The interview-guide was theory based. Content analysis was performed with open coding and selective coding was performed
de Vries et al. (2011)	Semi-structured interviews, 21 subjects (9 M, 12 F) who stay at work despite CMP	Data was analyzed according to thematic analysis
Dionne et al., (2013)	Two focus-group interviews with back pain suffers who had returned to work ($n=9$) or had not returned to work or recently returned to work ($n=10$)	Content analysis
Glavare et al. (2012)	Interviews with 11 informants (8 F and 3 M) suffering from long-term musculoskeletal pain	Constant comparison method of Grounded Theory
Hansson et al. (2006)	Interviews with 21 city-dwellers and 12 rural dwellers in all 33 (F and M), suffering from spine related pain (SRP) and sick-listed to some degree	Coding, categories, co pared and transformed categories into concept of the illness flexibility model
Liedberg and Henriksson (2002)	Interviews with 39 F with fibromyalgia, 19 still working and 20 who had stopped working	Coding, categorization, sub-categorization
Löfgren et al. (2006)	Twelve working women suffering from fibromyalgia, participated in rehabilitation 6–8 years earlier. Data collection using; 10 diaries, 3 focus groups and thematized interviews	Emergent design, analysis according to Grounded theory
Magnussen et al. (2007)	Focus-group interviews with 12 F and 5 M being disability pensioners with back pain	The study was anchored in hermeneutic epistemology
McCluskey et al. (2011)	Interviews with 5 disability benefit claimants suffering from nonspecific back pain for a Condition Management Program	Interviews were analyzed using template analysis, i.e., categorizing qualitative data thematically
Patel et al. (2007)	Semi-structured interviews with 38 unemployed patients (15 M and 23 F). The mean duration of work absence was 5 years	Open coding was used and emerging themes were identified. Using thematic framework approach, thematic matrices were developed to help classify and organize data in relation to key themes, concepts and categories emerging
Sallinen et al. (2010)	Narrative interviews 20 F with fibromyalgia of which 6 worked full time, some part-time and some had disability pension	The data was stepwise analyzed applying the ideas of Polkinghorne and Labov and Waletsky

(continued)

Table 9.7 (continued)

Study	Data collection	Data analysis
Shaw and Huang (2005)	4 focus groups ($n = 28$) who had returned to work less than 6 months ago after occupational LBP. In the second phase semi-structured interviews with 23 patients absent from work due to OLBP receiving physiotherapy treatment to restore physical functions	Content analysis was used. An iterative process followed leading to major themes and subcategories pertaining to return to work
Sjostrom et al. (2011)	Semi-structured interviews ($n = 10$) (7 F and 3 M) who had attended a rehabilitation program 6 years ago for long-term pain in back and neck	Manifest content analysis
Soeker et al. (2008)	Semi-structured focus-groups ($n = 26$) of patients having participated in back rehabilitation	Using method described by Morse and Field. Coding, categorization and development of themes
Stewart et al. (2012)	Semi-structured interviews ($n = 18$) with subacute back pain off work 3–6 months	Modified exploratory Grounded Theory
Tveito et al. (2010)	Five focus groups ($n = 38$) with workers with LBP.	Constant comparison method of Grounded Theory
Wynne-Jones et al. (2011)	Interviews with 18 employees (10 F, 8 M) with musculoskeletal pain and 20 managers from two large public sectors organizations encompassing a large variety of occupations	Data was analyzed thematically using Nvivo. Main themes and subheadings were identified

Guide. The results showed that the relationship between the GP and their patient was described as being of key importance in the identification and management of any symptoms, particularly if psychosocial components were present. The guidelines were seen as an artificial, mechanistic approach to medicine; they were viewed as highly structured, categorical, and prescriptive, subjugating clinical judgment by reducing medicine to algorithms. GPs did not use the Guide to Assessing Psychosocial Yellow Flags in Low Back Pain or the related screening questionnaire to identify psychosocial risk factors in their patients with LBP.

Another study examined GP's attitudes to managing back pain as a biopsychosocial problem in the UK (Breen et al. 2007). The five emergent themes were generally negative and dominated by concerns about doctor–patient interaction. They included: feelings of frustration; mismatched perceptions in the doctor–patient relationship; problems with relation to time; challenges and discord between stakeholders in the process (e.g., over sickness certification); and a lack of resources for education, awareness and local services to which to refer. Psychosocial aspects of the actual care process were rarely raised. A desire to avoid conflict in the relationship with patients explained much of the problem of implementing evidence in general practice.

A systematic review of qualitative studies (Parsons et al. 2007) explored how practitioners' (and patients') beliefs about the cause of pain and their expectations of treatment influenced the process of care for chronic musculoskeletal pain. Themes identified included: (1) beliefs about pain; (2) expectations of treatment; (3) trust; and (4) patient education. It is concluded that both GPs and patients want clear and straightforward communication and to be respected. However, conflicts existed within many other aspects of the consultation. To tackle the challenges identified, it is suggested that changes may also have to occur at an organizational and system level.

Table 9.8 Description of included studies for experiences of health care providers

Study	Data collection	Data analysis
Jeffrey and Foster (2012)	Semi-structured interviews with 11 physiotherapists (5 F, 6 M) in clinical practice	Analysis by hermeneutic phenomenology
Dahan et al. (2007)	Focus group interviews with 38 (17 F, 21 M) family physicians	Analysis by a continuous iterative process using an editing/organizing style and immersion-crystallization technique
Crawford et al. (2007)	Semi-structured telephone interviews with 11 GPs	Inductive, thematic analysis
Breen et al. (2007)	Telephone interviews with 21 GPs	Thematic analysis
Parsons et al. (2007)	Review of 15 studies	Thematic analysis

9.6.1 Conclusions from Health-Care Providers' Experience of Their Meetings with Patients Suffering from Long-Term Pain

Important aspects to consider are caregivers' priority to maintain a working partnership with their patients with LBP; GPs were reluctant to follow guidelines on psychosocial yellow flags. The guidelines were seen as an artificial and mechanistic approach to medicine. A desire to avoid conflict in the relationship with patients explained much of the problems of implementing evidence in general practice. Also, for the physiotherapist there is tension between the recommendations to stay active and patient's expectations regarding being prescribed rest, which challenges guideline adherence. More studies are recommended in this area about health care providers experiences and it is suggested that the complex process of developing and introducing guidelines for clinicians is further improved [See Table 9.8]

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Qualitative Evidence on Psychological Trauma

10

Marla J. Buchanan and Patrice Keats

10.1 Overview of the Chapter

Psychological trauma has been a burgeoning field of research since the inception of Posttraumatic Stress Disorder (PTSD) as a diagnostic classification in the 1980 Diagnostic and Statistical Manual for Mental Disorders (APA 1980). Over three decades of scientific inquiry into traumatic stress has influenced theoretical approaches, clinical practice, and research methods in this field. In this chapter we address the question: “What is the qualitative evidence on the topic of psychological trauma?” We begin by defining posttraumatic stress according to the *DSM-V* (APA 2012) and provide prevalence rates, followed by a review of the qualitative research in various domains of trauma such as disasters, refugees, military, physical and sexual violence, and first responder groups. The literature on cancer and motor vehicle accidents were thoroughly reviewed, however we found very little evidence of qualitative research in these domains. A decision was made to not include these topics in this chapter as there was not sufficient evidence to provide a strong analysis. We provide recommendations for knowledge transfer strategies and conclude with a discussion of possible future directions for qualitative trauma research.

10.2 Definition of Terms and Prevalence Rates for Posttraumatic Stress Disorder

Posttraumatic stress is a serious psychological condition that can have chronic and debilitating effects on human functioning as a result of exposure to a single or multiple traumatic events. Although 50–90 % of the population in America may be exposed to traumatic events in their lifetime, most individuals do not develop PTSD (Breslau 2009; Kessler et al. 1995). Published prevalence rates estimate that 7.8–14 % of the US population has a diagnosis of PTSD; women are twice likely to develop PTSD than men (Breslau 2009; Foa and Feeny 2013; Kessler et al. 1995). The types of traumatic events are too numerous to name, but most important is the criterion that the traumatic event was experienced or witnessed as involving actual death or serious injury to self or others and that the person’s response involved intense fear, helplessness, or horror (APA 2012). The three diagnostic

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symptom domains are intrusive imagery, hypervigilance, and avoidance behaviors. There are several comorbid symptom categories that usually accompany a diagnosis of PTSD such as generalized anxiety, depression, substance misuse, and panic attacks.

10.3 A Systematic Review of Qualitative Trauma Research

In order to discern the current qualitative evidence in trauma research, we conducted a review of several trauma journals and qualitative health journals. We also searched databases in trauma organizations (www.istss.org; www.apa.org) and indexes (ISI Web of Knowledge Social Science Citation Index, psychArticles, psychINFO, PubMed, and Web of Science), using the subject terms "posttraumatic stress," "posttraumatic stress disorder," "trauma," and "psychological trauma" with qualitative filters—"qualitative research," "qualitative study," and "qualitative research study." In the journals that we reviewed, we excluded book reviews, theoretical or conceptual manuscripts, reviews of the literature, memoirs and biographies, and quantitative research studies. Our analysis included only empirical research studies that used a qualitative research method to investigate topics on posttraumatic stress. We also included mixed methods research if a qualitative component was included in the study. We now present the qualitative evidence on psychological trauma within the following topic domains: disaster trauma, the trauma of refugees, military trauma, physical and sexual violence trauma, and the trauma of first responder populations.

10.3.1 Disaster Trauma

Disaster response has been a burgeoning field of inquiry over the last two decades. The history of the study of disaster began with the Geneva Convention and the work of the International Committee of the Red Cross in response to the devastation caused by WWII and the holocaust. However, in Canada and the USA disaster mental health "focuses on the mental health needs of those directly affected by disaster, of disaster relief personnel, and of those indirectly affected by disaster (secondary victims). The field can be broadly divided into three areas: preparation, direct services, and research" (Jacobs 1995, p. 544). In his report on a national plan for disaster mental health, Jacobs (1995) comments: "Disaster mental health is a young and burgeoning field; hence, it is critical that researchers study and evaluate the impact of disaster, the needs of those affected, and strategies for management and intervention" (p. 544).

Since Jacob's recommendation almost 20 years ago, research on disaster mental health has expanded from responses to war conflict to natural, human-made and technological disasters. Several historical disasters were responsible for the development of national plans to address mental health concerns in the wake of a disaster. In our review of the literature the following qualitative studies on disaster trauma were found: *the Asian tsunami of 2004* (Ekanayake et al. 2013; Jensen et al. 2013), *the 2010 earthquake in Haiti* (Ghose et al. 2012; Raviola et al. 2012), *a train crash in Sweden* (Forsberg and Saveman 2011), *wildfires* (Cox and Perry 2011), *tornados* (Miller et al. 2012), and *hurricanes* (Dass-Brailsford et al. 2011; Putman et al. 2012; Rivera 2012). These qualitative studies describe the conditions post-disaster, the experiences of disaster survivors, the coping strategies employed by survivors, and the management of disaster relief, in particular, the provision of mental health services. To address the need for effective interventions for disaster mental health, National Disaster Response Teams have been developed and training in Critical Incident Stress Management and Psychological First Aid are now standard practices for first responders and disaster personnel. The Sphere Project (Batniji et al. 2006) was launched by NGO's in response to criticism of aid provided during the Rwandan conflict. This handbook provides standards for mental and social health during disaster and conflict crises and involves assessment through 12 intervention checks (Batniji et al. 2006). Additionally, the American Psychological Association has a web page in their help center on *Disasters and Terrorism* that is an excellent resource: (http://www.apahelpcenter.org/articles/topics.php?id=4).

Research on disasters has commonly been studied using quantitative research methods. As in the other domains of psychological trauma, very few qualitative studies have been conducted on the psychological trauma resulting from disaster events. In our systematic review of the disaster literature, we discovered three studies investigating the risks to mental health relief workers/humanitarian aid workers (Agazio 2010; Sweifach et al. 2012; Wang et al. 2013). These three studies were exemplary with regard to the rigor of their qualitative research design and are presented for their contributions to knowledge in disaster trauma.

Agazio studied the challenges faced by 75 army nurses in humanitarian and wartime missions using a "descriptive qualitative design" and employing telephone interviews that were thematically analyzed. In this study, we learn about the environmental challenges for humanitarian aid workers dealing with extreme weather conditions, from the heat, dust, and sandstorms in Iraq and Afghanistan to the mud and cold in Bosnia. Agazio also reports the difficulty in providing treatment when there are language barriers and no infrastructure for providing health care in host countries due to lack of supplies and equipment. "The pace, difficult environmental conditions, threat level and brutality of the injuries all took their toll on staff" (2010, p. 173). In this study we learn the importance of effective training and preparation before deployment in order to handle the breadth of care needed in conflict and disaster areas that are environmentally challenging.

Sweifach et al. investigated social workers' personal responses to disaster work using a focus group design to understand post-disaster reactions in this population. They recruited 102 social workers from three different countries (the USA, Canada, and Israel) and conducted 14 focus group interviews that were analyzed using grounded theory's constant comparative method. They found that most respondents:

> […] experienced dynamic tension between grasping the disaster from a professional perspective, while attempting to assimilate the disaster within themselves […] expressing difficulty in reconciling their own personal and professional cognitions, emotions and behaviours, and maintaining professionally focused feelings/thoughts/composure, while others expressed little difficulty […] Respondents did seem to indicate that in general, personal needs and emotions should not play a role during disaster response; however, a fail-safe model to assure this, does not exist.
> (2012, pp. 7–8)

This struggle between the personal self as a victim of a disaster and the professional self is made apparent in this article as both identities are completely involved in the disaster experience (Sweifach, p. 8). Implications for professional practice are notable and the ethics of care both to self and other are also significant.

Wang et al.'s (2013) study of the 2008 Sichuan earthquake in China using semi-structured interviews with 25 local relief officials (e.g., health care workers, teachers, and social workers) using a thematic analysis provides insight into the coping strategies used by local relief workers and how these workers' own traumatic bereavement, housing and financial difficulties and work–family conflicts were the main causes of their traumatic stress. Local relief workers differ from provincial or national disaster responders, as "they are also disaster survivors and are likely to be suffering from trauma and loss" (p. 207). There are competing demands from the community and the personal demands from family members. This study provides a detailed account of the perceived sources of stress in local relief workers professional duties and their personal and family life. They describe their coping experiences as: finding meaning and purpose in life through relief work; receiving support from coworkers; suppressing and avoiding their grief through distractions; having a greater appreciation for life; being optimistic and making up for loss by moving forward in their lives. The authors point to the necessity to attend to the immediate grief and loss of workers, as they may be at risk for delayed or prolonged grief if their bereavement is not addressed. They recommend that managers of disaster response be flexible in the work schedule so that relief workers are also able to attend to their personal and family needs. Self-care should always be part of the mandate of disaster response to prevent worker trauma post-disaster.

From these three exemplary studies we learn that post-disaster care needs to be available to disaster relief workers and volunteers. This care needs to be provided by professionals trained in posttraumatic stress and secondary traumatic stress interventions. Further, preparation through education and training of local relief workers is essential in the prevention of posttraumatic stress from disaster response work. Sweifach et al. (2012) recommend that:

> Agencies ought to implement strategies that strengthen the ability of personnel to better navigate through issues inhibiting best professional practices during and after disasters, such as emergency drills that incorporate worst-case scenarios, and include psychological debriefing; employing a buddy system in which co-workers are paired together in case one worker becomes impaired; in-service trainings that review and test disaster protocols; and conducting exercises that are designed to strengthen resilience to primary and secondary trauma.
> (Sweifach 2012, p. 8)

The qualitative evidence in these studies is helpful in the administration of disaster relief and can assist in the development of the management of mental health risks to national and local disaster responders. Given the descriptive accounts provided by participants in these qualitative studies, we can learn how to effectively function in challenging settings. From their experiences, we are able to develop effective coping strategies and resources for individuals and teams responding to natural and human-made disasters. We also learn lessons on how to maintain a balance in responding to client needs and personal family needs simultaneously during a disaster. There are many quantitative studies in the research literature, however, they do not provide a contextualized view of those experiencing disaster events. Without an understanding of the local context, interventions and disaster response efforts are hampered. Qualitative research evidence informs us that disaster experiences are complex and varied and that western interventions cannot be assumed to be useful across all settings. In their discussion of the Sphere Project, Batniji and colleagues (2006) recommend that social interventions need further qualitative research:

> These include mass communication in disasters; family re-unification; misuse of the classroom to incite hatred; community consultation to guide decision-making; and recording, recognizing and addressing rights violations as part of the aid response […] A fundamental question that needs further assessment is whether (non co-morbid) PTSD is associated with impaired daily functioning in non-Western, resource-poor settings […] Through research, social scientists may play a key role in promoting socially appropriate mental health responses and contribute to a more balanced interpretation of the biopsychosocial clinical model.
> (Batniji et al. 2006, p. 1861)

The field of disaster trauma warrants much more research. We are just beginning to understand the importance of context in disaster response. We need to build a better understanding of how religion, ethnicity, culture, age, and gender, for example, affect one's response to disaster and the effects of these factors on one's resilience. We also need to investigate the experiences of children in disaster zones and the experiences of survivors of multiple disasters.

10.3.2 Refugee Trauma

> Today's wars, whose main casualties are civilians, often occur within the confines of a country, pitting country-men, friends, and neighbors against each other. Tensions and violence commonly arise between neighbouring ethnolinguistic or religious groups, and it is not uncommon for a government to wage war against a segment of its own population.
> (Magid and Boothy 2013)

As of 2011, there were an estimated 26.4 million internally displaced persons and 10.5 million refugees around the world (UNHCR 2013). Almost half of the world's refugees are children.

In a review of the trauma literature, five qualitative studies emerged that report on the traumatic experiences of refugees and asylum seekers.

The first study is a 2013 study of posttraumatic growth among 12 Tibetan refugees residing in India. Hussain and Bhushan (2013) interviewed the participants using an interpretive phenomenological method. The major themes found were: "positive changes in outlook toward the world and people, realization of personal strengths, and the experience of more intimate and meaningful relationships" (p. 204). The authors explain that Tibetan culture and religion provide "intrinsic resources for coping and thriving" (p. 206). This phenomenological study provides understanding of how participants make meaning of their lives and provides information about their process of developing posttraumatic growth within the specific contexts of their lives. Most research on posttraumatic growth is conducted with western populations and little research exists on non-western populations. The results of this study are very useful to clinicians working with refugee populations.

Simich et al. (2010) conducted a mixed methods design using a survey of 220 Sudanese refugees in Ontario and Alberta in Canada, followed by in-depth qualitative interviews with 30 community members in three sites. Their qualitative results reveal how "meanings of home emerged as a key concept linking social support, resettlement, and mental health" (p. 199). The authors note that mental health practitioners and other health care providers need to take into account the qualities of home that are lacking in Sudanese resettlement experiences and that social support is a necessary component for successful resettlement in Canada and to the mental health of this refugee population.

Maier and Straub (2011) studied the experiences and treatment expectations of 13 traumatized migrants and asylum seekers from Bosnia, Kosovo, Turkey, Iran, Afghanistan, Cameroon, Sudan and Chechnya. Using a qualitative generic research design and a content analysis, they found that "most participants had no clear or defined expectations concerning appropriate treatment" (p. 232). The authors discuss the issues of language barriers that lead to misunderstandings about the nature of health concerns as well as gaps in respective concepts of illness and mental health treatment. They state that most refugees do not ask for psychological help because they are unfamiliar with this form of treatment and they may be suspect about this form of health care (Maier and Straub 2011). However, once informed and given the opportunity to receive psychological services, the migrants in this study supported the idea of psychological treatment. Maier and Straub recommend specialized training of counselors to work with this population as well as financing for the availability of interpreters.

Somasundaram (2010) investigated the displaced and interned Vanni civilians during the civil war in Sri Lanka. The author interviewed a large sample of people in the internment camps as well as health care providers and NGO's. We learn from first-hand accounts the massive destruction and horror experienced by civilians. The author provides a rich in-depth description of the mental health of internally displaced people and the meaning of their collective trauma—the violent destruction of home, family, village and community. This study explains the importance of international interventions that are context-sensitive in the resettlement and reparation phases of rebuilding community.

Thomas et al. (2011) examined the mental health of 24 refugees who resettled in Nepal. In-depth individual interviews, focus group interviews and a photovoice method were used to understand coping strategies and resilience amongst these refugees from Pakistan and Somalia. The main finding on active coping revealed that refugees seek support through primary relationships. The authors highlight the importance of the provision of legal and social networks in refugee resettlement and recovery from traumatic stress.

These qualitative studies make a significant contribution to knowledge in the development of appropriate interventions and understanding of the breath of refugee trauma. Almost all of these studies were conducted in internment camps with researchers living among their interviewees.

These researchers give voice to the silenced and provide contextual meanings to the experience of collective trauma. We learn first-hand the experience of what it means to lose one's community and traditions as well as the complications of cultural bereavement. Their findings provide important recommendations for clinical practice and health care at an international level. Since the general medical practitioner (family physician) was the most trusted health care contact, it is imperative that family physicians in resettlement countries have skill in assessing posttraumatic stress symptoms. Also important is knowledge about valuable resources such as the Inter-agency Standing Committee (IASC 2007) *Guidelines on Mental Health and Psychosocial Support in Emergency Settings* that emphasize the importance of cultural sensitivity, local ownership, and religious contextualization. The guidelines recognize that the best support comes from within the community itself.

10.3.3 Military Trauma

In this section of the chapter, we review the qualitative evidence on military trauma (e.g., veterans, soldiers, peacekeepers, spouses of military personnel). The qualitative evidence we found covers the effects of war-related trauma with these populations over the last decade.

Most of the qualitative evidence on military trauma describes the experiences of military personnel who have been diagnosed with PTSD due to traumatic events while serving their countries. This evidence is significant for psychologists working with returning soldiers, as they need to be informed about their personal experiences in order to implement appropriate treatment plans for their clients. Shaw and Hector (2010) employed phenomenological interviews with ten male military members who had recently returned from Iraq and/or Afghanistan. The overall thematic structure reveals that psychologists working with returning soldiers need to help their clients explore what their deployment meant to them and how they derive meaning from it. As the new form of insurgency warfare grows (war that makes it difficulty to discern enemies from civilians), the experiences of soldiers in these contexts require expanded knowledge by health care providers. The authors state that qualitative research provides this contextual knowledge.

Ellison et al. (2012), using a participatory research design and thematic analysis, gathered the perceptions of 29 veterans about the educational barriers of Vets with PTSD. This study is very informative for outreach and support services for Vets. The authors describe the barriers to services and the personal experiences of veterans who struggle upon release from their service to get the information they need to make a healthy adjustment back into society. This study provides important suggestions for veteran transition programs. In a similar study, Sayer et al. (2009) employed semi-structured interviews with veterans who were deployed in military conflicts that ranged from the Vietnam War to Afghanistan. They investigated factors that influence treatment initiation and help-seeking strategies. Lack of knowledge about PTSD and an invalidating sociocultural environment following a traumatic event were the main barriers to seeking treatment. As such, "[t]he findings suggest that facilitators located within the health care system and veterans' social networks can lead to help seeking despite individual barriers [...]. Understanding how and why veterans initiate treatment for PTSD is particularly crucial" (Sayer et al. 2009, p. 240).

Burnell et al. (2011) interviewed 30 veterans who were deployed during a time between WWII to Iraq in 2009. They asked the veterans to share their own moral evaluation of their deployment. Using a thematic analysis, they found that the deployment experience is "mediated by the cultural atmosphere in which the conflict takes place" (p. 36). The authors point out that PTSD is not a timeless, universal or cross-culturally valid construct. Mental health care providers need to take into account the complexity of responses to traumatic events and to explore with clients the personal meaning of their experiences.

The last two studies focus on veteran's spouses and family members of soldiers with PTSD. The first study by Sherman and Fischer (2012) examined the perspectives of health care providers, veterans and family members regarding family education in community-based outpatient facilities. Five health care providers and 49 family members participated in qualitative interviews that were analyzed using a content analysis. Veterans Affairs have mandated family consultation, education and psychoeducation since 2008. Very few families, especially those living in rural areas, receive psychoeducation or support. The three main barriers found in this study were distance (travel costs, child care, work release time), group issues (confidentiality in a small community, personal conflicts), and embarrassment/shame for family members and veterans with PTSD. The findings point to the significant issues facing veterans and their families living in rural areas.

Hayes et al. (2010) identified and measured assessment batteries to examine the wellbeing of spouses of veterans with PTSD. The strain on veterans' families who are the main sources of support in dealing with the PTSD of their family member is a serious concern and "[t]he potential for intimate partner violence is greater when the veteran has PTSD" (p. 826). Using a panel of experts and focus group interviews to determine appropriate measures on the well-being of spouses supporting veterans' recovery, the authors found important implications in terms of the family burden, health and mental status of spouses, effects of alcohol and substance abuse of veterans and their spouses, marital and parental conflict, marital satisfaction, role discrepancy, self-efficacy (a changed person) and social support (because of strain, no time for family, friends or social networking). As the authors state, "[f]ocus group interviews yielded valuable input on the domains of experience and key questions that should be included in an assessment battery designed to assess well-being and areas where assistance is needed" (p. 838).

In the only qualitative study on Canadian peacekeeping soldiers, Ray (2009) conducted a phenomenological study on the experience of contemporary peacekeepers healing from trauma. She interviewed ten soldiers who had served in Somalia, Rwanda and the former Yugoslavia. Three main themes were discovered that describe participants' process of healing from PTSD: "the centrality of brotherhood and grieving loss of the military family; the centrality of time and the body in healing from trauma; and the military response as betrayal and creating trauma from within" (p. 55).

> All of the peacekeepers expressed a sense of betrayal by their home-front government, politicians and their military family. Upon their return home, the response of stigma by the military and subsequent release as the response to their suffering created further betrayal and trauma from within their military family. All the peacekeepers in this study felt that they were more affected by the negative reaction from their military family than from the trauma itself.
> (Ray 2009, pp. 60–61)

The author recommends that more Operational Stress Injury Social Support (OSISS) groups be established throughout Canada. She further suggests that there needs to be more training in compassion and self-compassion training within the military among those who provide services to peacekeepers and veterans with PTSD.

Qualitative research studies provide an in-depth richly contextualized understanding of the experience of trauma and healing from trauma from the perspectives of the survivors. The qualitative studies on military trauma point to key areas for future research. Most of the samples in the studies above were conducted with white male military personnel; we need to know more about the experiences of women soldiers and soldiers from other ethnic groups. We also need to know more about the experiences of children whose parent has PTSD due to military trauma. The current breath of knowledge from the findings of qualitative research is very small—more research on the topic of military trauma is warranted. We are just beginning to understand the meaning of these experiences.

10.3.4 Sexual Abuse Trauma

Sexual abuse comes in many forms (e.g., forced sexual intercourse, unwanted sexual touching or threats, incest, child molestation, drug facilitated), and is perpetrated on anyone from any type of cultural population, young or old, female or male. The impacts of these types of assaults are varied and widespread with research focusing on many aspects of this violating crime. Because of the pervasiveness of sexual abuse trauma, it is often accompanied by physical abuse as noted in many of the studies we reviewed (e.g., Clum et al. 2009; Jager et al. 2010; Ungar et al. 2009). Due to the large number of qualitative studies on sexual abuse trauma that include physical abuse, we focus here on our learning from the sexual abuse literature in general.

Also, of note, we excluded mixed method studies in this section. We concur with Creswell and Zhang (2009), in their attempt to clarify some of the ambiguity around mixed methods approaches noting the studies they reviewed were "not called mixed methods, do not use explicit systematic mixed methods procedures, and have not been analyzed to use as models for designing mixed methods research on trauma topics" (p. 612). In the sexual abuse literature, we saw how "qualitative data" (interviews) were used to enhance quantitative findings or qualitative data was quantitatively analyzed (e.g., Deering and Mellor 2011). Thus, we focus solely on studies that used clear qualitative methods in their methodological descriptions.

Researchers have used qualitative methods in the field of sexual abuse for a number of reasons. Some studies used qualitative methods to develop quantitative measures (e.g., Giraldo-Rodríguez and Rosas-Carrasco 2013) in order to study sexual abuse phenomena in more depth for new information, meanings, and understanding. One author (Ullman 2005) described her transition from quantitative to qualitative methods in order to study female advocates and clinicians who provided services for sexual assault survivors. She was interested in the possibilities for depth of knowledge and the inductive theory-building qualitative methods can offer. Additionally, a number of authors discussed the best qualitative methods to use in the field and the best ways of using those qualitative methods to study abuse (e.g., Hall 2011 discussed a constructivist, narrative, feminist perspective to study women surviving childhood maltreatment; Morrow 2006 wrote about feminist collaborative research with sexually abused women; Sorsoli and Tolman 2008 discussed a narrative "listening guide" method analyzing interview data about sexuality and sexual abuse). Teram et al.'s study concerned with counselors developing research sensitivity when working with survivors suggested integrating grounded theory and participatory action research methods to promote the possibility of empowering sexual abuse survivors to voice their perspectives on how to best meet their needs and inform professional practice in the area.

In terms of the specific qualitative methods used in this field, we found that the three most common, in this order, were phenomenology (e.g., interpretative phenomenological analysis, hermeneutical-phenomenological, existential phenomenology), grounded theory, and narrative methodologies (e.g., life story construction, critical narrative, narrative content analysis). Although focus group methods were noted in some studies, they tended to be used in research in international settings or for topics that involved cultural issues (e.g., Moreno 2007; Williams et al. 2012). There was only one actual ethnographic study; it explored the experience of numbing emotional pain for African American women (see Ehrmin 2001). Other random qualitative methods included a cross-case analysis looking at patterns of adolescence dating violence (Martsolf et al. 2012), the content analysis of therapy transcripts and participant diaries (Lev-Wiesel 2006), and analysis of "free listing" and "key informant" interviews (see Murray et al. 2006).

From the review of sexual abuse literature citing qualitative methods, we noted a very wide variety of topics in the area, with the most common topics being some aspect of *childhood sexual abuse* (CSA) (e.g., Stige et al. 2013, on help-seeking among women who suffered childhood trauma; Isely et al. 2008, on how clergy-perpetrated CSA affects adult men survivors; Kisanga et al. 2010, on legal system perceptions of CSA) or *domestic violence* (e.g., Band-Winterstein and Eisikovits 2009, on intimate partner violence [IPV] over a life span; Davis

2002, on the inner resources of abused women; Hogan et al. 2012, on counselors' experiences of working with male victims of female-perpetrated domestic abuse). Additionally, researchers looked at many different populations affected by sexual abuse; for example, Puerto Rican addicts (Hardesty and Black 1999); homeless adolescents (Haldenby et al. 2007); romantic partners of CSA survivors (Del Castillo and Wright 2009), and pregnant mothers (Coles and Jones 2009) to name just a few. Researchers also explored the experiences of service providers for sexual abuse and domestic violence survivors such as nurses' experiences of, and role as health care provider for, women experiencing IPV (Häggblom and Möller 2007); the impact of vicarious trauma on professionals involved in child sexual abuse cases in Malaysia (Nen et al. 2011), and professionals involved in high-profile CSA controversies such as "practitioners and/or academics in the fields of psychology, social work, psychiatry, sociology, and law" (Mildred 2004, p. 102).

From these and other studies reviewed, we note specific contributions to the field in understanding therapeutic issues around sexual and physical abuse (e.g., sexual abuse experiences, issues arising, effectiveness of treatment programs); impacts on individual and family life; health care issues that arise for survivors and service providers; coping and resilience; and the effects of prevention and treatment programs. Although most studies we reviewed had smaller numbers of participants (an average of about 30 with 88 being the largest group and four being the smallest) and the results are not generalizable to the greater population, some important insights were reported.

The most common research topic was in the area of CSA and the impact on family relationships. Researchers found that abuse has a strong developmental impact that creates systemic problems throughout life (Isely et al. 2008), with abused participants struggling to trust others or to give and receive love (Roberts 1999). This gap creates significant problems for families; especially when it came to the processes of motherhood. From the moment some abused women conceive, they report how their partners are sexually coercive, failing to understand or accept pregnancy and its nuances (Shamu et al. 2012). There are also impacts for service providers when assisting survivors of CSA to cope with medical care related to perinatal examinations (Coles and Jones 2009) and other types of sexual and reproductive health care (Ackerson 2012). When children are born and raised by CSA survivors, mothers may sometimes feel repressed emotions arise when they see their young children's innocence at a similar age to when they were abused as children (Erdmans and Black 2008). Some daughters found their mothers (CSA survivors) to lack maturity and struggled with feeling affectionate towards their mothers, or differentiating from them (Voth et al. 1999). If there are repeated patterns of sexual or physical abuse in the family, children's disclosure of abuse becomes more risky and difficult especially if they witness the same abuser assaulting their mother (Alaggia and Turton 2005). Researchers noted the importance of children disclosing abuse (i.e., non-disclosure leading to self-destructive behaviors, greater risk of teen pregnancy) and the need for them to have a receptive and supportive audience so that protection can be given (see; Alaggia and Turton 2005; Erdmans and Black 2008; Lev-Wiesel 2006). This protection is also critical to prevent adolescents from being silent or complacent to dating violence (Martsolf et al. 2012). According to Ungar and colleagues (2009), there is a high rate of non-reported abuse in youth due to their fears of the negative consequences of disclosure. This leads to the second most common research area in the sexual abuse literature: the processes and efficacy of therapy.

There are a number of studies looking at the participants' experiences of therapy and the developments that take place in the process. The most prominent finding in these studies is the importance of survivors telling their story and the different ways that researchers have conceptualized the processes around disclosure from participant experiences (see Del Castillo and Wright 2009; Hirakata 2009; Martsolf and Draucker 2008; Nehls and Sallmann 2005). For example, Del Castillo and Wright discuss three types of experiences in the process of disclosing CSA to a romantic partner to emphasize the risks survivors take in telling a partner about their history: struggling in private about the disclosure; the experience of disclosing, and the aftereffects of disclosure. As shown above, the risk of disclosing is lessened with the presence of a receptive audience. Researchers have also explored the types of therapeutic conditions necessary in a strong alliance because prolonged periods of self-reliance are common before help-seeking takes place (Stige et al. 2013). For example, Hirakata (2009) names a number of factors participants in her study emphasized for a safe and trusting relationship where the therapists:

> (a) reciprocate a sense of trust and confidence in their clients, (b) allow periods of conflict that provide an opportunity for clients to experience interpersonal tension in a healthy and reparative manner, and (c) simply be there for clients in a way that communicates a sense of support and commitment to the clients' reparative journey [… and] having their therapist (a) challenge old patterns and beliefs; (b) know them in a manner that extended beyond words; and (c) model a new way of being that enabled them to better connect with themselves, others, and the world.
> (Hirakata 2009, p. 309)

Alliance is also emphasized for families of children who have disclosed abuse, with a specific emphasis on building an alliance with the caregivers so that they are able to support the child in the process of therapy (see Jensen et al. 2010).

Another aspect of the therapeutic process is the qualitative study of selfhood and identity. For example, Hardesty and Black (1999) found that motherhood provided a grounding identity and lifeline for some women who were challenged by poverty, marginalization, and abuse. Saha and colleagues (2011) found that through the therapy process, participants moved from articulating a traumatized self to a more enduring sense of self. In another study where Spermon and colleagues (2013) were studying child maltreatment in relation to interventions and training, they specifically noted the importance of supporting the development of a positive selfhood.

Qualitative studies have also investigated how abuse survivors cope with their experiences of abuse. Highlighting a few studies in particular, Clum and colleagues (2009) looked at CSA survivors' coping in relation to their sexuality; Draucker (1999) explored how women used practical everyday tasks to cope with family violence; Darlington (1996) investigated both physical and mental *escape* as important aspects of coping; Wang and Heppner (2011) conceptualized a model for coping to support culturally appropriate interventions for survivors from collectivist contexts; and Williams and colleagues (2012) explored *transactional sex* as a survival strategy used mostly by girls in Rwanda to cope with adversity and its implications in terms of child protection.

In terms of health issues and abuse in particular, there are qualitative contributions to the literature showing a clear link between HIV/AIDS infection and domestic violence (Clum et al. 2009; Moreno 2007; Murray et al. 2006; Shamu et al. 2012). These studies all emphasize education about disclosing an infection, debunking some of the myths and superstitions about HIV/AIDS that create the grounds for infection of young girls specifically, and working in culturally appropriate ways to reduce the stigma and stereotypes about the disease.

There are also a number of studies looking at perpetrators of sexual and physical abuse crimes. For example, Bletzer and Koss (2012) are interested in the outcomes of restorative justice and noted the importance of remorse and empathy during an apology when perpetrators had increased knowledge about their victim/survivor. Other research has looked at perpetrator characteristics in both male (e.g., Moulden et al. 2010) and female abusers (e.g., Flinck and Paavilainen 2010; Gannon et al. 2008). Qualitative researchers also investigated the experiences survivors reported from specific types of perpetrators such as clergy (Isely et al. 2008) and teachers (Moulden et al. 2010). There are also a number of studies looking at the effects of participating in the legal system and its failings when persecuting the accused (e.g., Kisanga et al. 2010).

Future considerations for gathering qualitative evidence for sexual abuse trauma should include researchers writing clearer descriptions and more elaborate explanations of their methodological approach, as it was less common for us to see a thorough overview of procedures or explanations of methodology. For example, Coles and Jones (2009), and Isely et al. (2008) described their qualitative method as a "thematic analysis" without a framework for how they approached, understood, or decided on the themes they developed from their interview data. Also, there were very few studies that looked at program evaluation or treatment efficacy from a qualitative perspective, although many of the studies we noted in this section focus on implication for practice as part of their conclusions (e.g., policy/program change for studies done in international settings in the developing world, studies related to cultural aspects suggest cultural considerations for practice). Finally, there were vary few studies of men as survivors of physical or sexual abuse and this area can certainly be expanded.

10.3.5 First Responders and Trauma

As noted in some sections above, professionals on the frontline have multiple challenges when working with survivors or victims in a traumatic context and have a much higher risk (5–40 %) of developing psychological distress, PTSD, and other types of psychopathology than the general population (Thompson and Wild 2012). Generally, these first responders are professionals who arrive first at the scene of an emergency, conflict, or disaster and can provide some kind of service related to the crisis including prehospital care (Shakespeare-Finch 2012). For example, nurses arriving to a disaster event would need to determine "where to begin their relief efforts and what skills are going to be required" (Yin et al. 2012, p. 265). Professionals in this category are most commonly medical personnel (e.g., doctors, nurses, paramedics), firefighters, police, and soldiers. More recently, journalists and photojournalists have also been recognized as first responders on the scene to report these types of events and who face considerable risk for traumatization as a result (Newman and Ochberg 2012).

The vast majority of studies on first responders use quantitative methods, with some beginning to use a mixed methodology approach. For those studies that use only qualitative methods, the research designs vary considerably and it is rare that researchers offer a clear description of their methods or rationale for their approach. Individual interviews (with some type of content analysis) and focus groups were most common formats for gathering data. There were a very small number of researchers who used textual data such as participants' written accounts (e.g., Jonsson and Segesten 2003; Wolf and Zuzelo 2006) or workplace observations (e.g., Keats and Buchanan 2013; McGibbon et al. 2010). The common topics researchers explored include the professionals' experiences of stress, traumatic stress, and coping with some studies focusing on specific events (e.g., Sloand et al. 2012, looking at nurses experiences in the recent Haitian earthquake), or specific subgroups of the profession (e.g., Menendez et al. 2006, looking at New York City firefighters and their spouses). Below we outline the qualitative evidence we gathered from the studies in this trauma-related area of first responders.

Medical professionals were the most highly studied group of first responders for qualitative researchers. First, the medical profession has recently recognized physicians' stress more formally and discussed it in relation to the pressures physicians feel as a result of acute patient care (Meier et al. 2001). Meier and colleagues (2001) described the risk factors and effects of vicarious traumatization and secondary trauma with a suggested model for self-regulation and encouraging physicians to "take an active role in identifying and controlling those emotions" (p. 3007). In a more recent study, Woolhouse et al. (2012) asked family physicians about the emotional impact of patient care related grief (e.g., sorrow, isolation, joy), experiences recounting patients' death or tragedies, and coping strategies (e.g., developing different practice styles, relying on teamwork). In a similar vein, Hadfield and colleagues (2009) explored physicians' experiences of working with patients who self-harm in emergency units and noted how they attended to the harm to patients' bodies, and either expressed or silenced their own values and beliefs about patients' behaviors. All of these studies incorporate the doctor–patient relationship and the necessity of self-care around stress affects.

Second, the nursing profession has done much work on understanding the aftermath of nurses' responses to traumatic events involving patient care (e.g., McGibbon et al. 2010; Wolf and Zuzelo 2006). From qualitative studies (e.g., phenomenological, grounded theory, narrative), we note some specific areas of research related to nurses' work such as dealing with women who have been violently assaulted (e.g., Gates and Gillespie 2008; Häggblom and Möller 2007; Maier 2011), nursing children after a disaster (Sloand et al. 2012), dealing with organ donation (Regehr et al. 2004), or in the aftermath of a terror attack (Somer et al. 2004). These researchers note how difficult these events are for nurses, sometimes leaving them feeling hopeless, incompetent, isolated, unsafe, or experiencing burnout. Most studies emphasize the organizational culture and hierarchical structure of the medical profession as being key factors in nurses' experiences of stress. Strong teamwork between peers and supervisors; appropriate care for patients; and organizational changes were all highlighted as helpful in coping with traumatic events.

Finally, within the emergency medical services, professionals such as ambulance drivers, paramedics, and emergency medical technicians experience traumatic stress. Specifically, researchers have explored aspects of traumatic stress for professionals who work in ambulance services such as looking at occupational stressors (Mahony 2001), the meanings and effects of traumatic events (Jonsson and Segesten 2003), and how workers cope with resuscitation attempts on patients in traumatic events (Davies et al. 2008). These studies also point to organizational issues as a barrier to coping leaving the professional to develop more personal aspects of coping such as expressing feelings in a safe environment, supporting one another after a critical incident, taking brief time-outs, and accepting their own limitations in the work. Regehr (2005) notes the spouse and family as important coping resources for these professionals and suggests adding programs to enhance family relationships into organizational support systems. Finally of note for these professionals is a study by Halpern and colleagues (2009) who looked at the repercussions of debates around critical incident stress debriefing for EMT professionals. Without clear emotional support after a critical incident, workers are left feeling vulnerable and stigmatized if there is no affective intervention for assistance. These researchers suggest that supervisors and front-line workers be educated to recognize these types of events and responses, and then act supportively to the professionals involved.

Police officers are also an important profession of first responders. Although there are few qualitative studies in the field, there are some important findings generated through a number of the research projects we found. Policing is a male-dominated profession and, as such, researchers have noted that officers tend to speak less often about traumatic situations and their effects with each other (Backteman-Erlanson et al. 2011; Tehrani and Piper 2011) and more often with a close family member or friend (Evans et al. 2013). Interactions with fellow officers tend to be more on the level of black humor rather than emotional talk (Evans et al. 2013; Shakespeare-Finch 2012). One study (critical incident technique) of officers on police teams investigating Internet child exploitation showed the importance of collegial relationships and organizational supports, such as stress inoculation, to assist coping with this traumatic material (Burns et al. 2008). Finally, there were a number of unpublished doctoral dissertation studies using qualitative methods to explore police or police services and traumatic stress. For example, Ferguson (2005) explored the trauma effects of police officers' working crime scenes; Troxell (2009) investigated the experiences of 9-1-1 telecommunicators; Picore (1997) looked at women officers and stress; and Pickens (2011) studied coping strategies from critical incidents in law enforcement.

Firefighters are also included in the first responder group. Reviewing the literature for qualitative studies, we only found two published papers. De Soir (2012) and colleagues looked at the disaster-related experiences of both fire and emergency medical professionals. Using a phenomenological approach, firefighters reported more concern for threats and exposure to death than medical personnel likely due to the differences in their training. In addition to the shock of the magnitude of the event (the 2004 Ghislenghien gas explosion in Belgium), they were affected by the death of colleagues, the involvement of friends and family, and their exposure to burn victims (over 150 people hospitalized with burns). Menendez and colleagues (2006) studied the effects on spouses and families of firefighters after the 2001 attacks on the World Trade Center in New York using focus groups. They found women depending on each other to cope with the emotional impact of the event and being more vigilant in helping family members manage the impacts.

Finally, qualitative studies of journalists and photojournalists who report and photograph trauma, disaster, and conflict show similar struggles to those found in other organizations of first responders. Most qualitative studies we found looked at the trauma effects for journalists in and after their work (Keats 2012; Keats and Buchanan 2011, 2013). These professionals were shown to be resilient and resourceful with a unique set of coping strategies such as managing well with frequent exposure to the abnormal and unusual, yet reacting strongly to more common events where they could personally identify the circumstance as similar to their own life situations (Keats and Buchanan 2011). They also had similar issues found in other first responder groups such as anxiety, depression, PTSD, lack of communication about trauma events among peers, organizational difficulties related to workplace stress, and lack of help-seeking (Buchanan and Keats 2011). Much work has been done to support news workers in recent years through the development of the Dart Center for Journalism and Trauma (see www.dartcentre.org) which offers a myriad of resources, peer support, and training for students, working journalists, and journalism educators. For example, Dworznik and Grubb (2007) explored trauma training in journalism programs in order to prepare students for their own emotional reactions as well as those of witnesses and traumatized survivors they would interview or photograph on the job.

10.4 Knowledge Transfer Strategies

How can qualitative evidence about trauma issues be translated to or influence health policy and practices in the field of traumatic stress? *Knowledge translation* (KT) is defined by the Canadian Institutes of Health Research (CIHR) as a dynamic and iterative process that includes *synthesis*, *dissemination*, *exchange*, and *ethically sound application of knowledge* to improve the health of Canadians, provide more effective health services and products and strengthen the health care system. Using this definition, we outline below issues arising regarding the dissemination of qualitative research findings.

It is common for qualitative researchers to disseminate the results of their studies through conference presentations and publications in peer-reviewed journals. It is also common for researchers to present their qualitative findings in other more creative and accessible formats that are tailored to the specific audiences interested in, and influenced by, the questions explored. For example, media formats such as books, pamphlets, and photography have been used to translate topics like self-care and resources available for journalists, and films that translate knowledge about treatment for soldiers and veterans have been produced (see the films “War in the Mind” at http://www.judyfilms.com or “The Difficult Return” by M. Balfour at Griffiths University, Australia). Research participants have been part of a research team who develop and present research findings at academic conferences or public performances (e.g., women prisoners’ productions from a CIHR grant on prison health in Mo Korchinski’s YouTube video “The Revolving Door” at http://www.youtube.com or visit the website designed by incarcerated women at http://www.Womenin2Healing.org). Other examples include vicarious witnessing in concentration camps (see http://www.ccfi.educ.ubc.ca/publication/insights/v13n02/articles/keats/index.html) and artistic displays of drawings, paintings, or sculpture that show the impact of interventions that developed out of research work into domestic violence and sexual abuse.

Qualitative research is also leading the way in welcoming knowledge users—or stakeholders—to engage in the full research process through action-based research. Through methods such as collaboration, action-orientation, and co-production participants are highly involved in helping to shape relevant research questions, connecting with potential participants, collecting and analyzing data, and participating in disseminating the findings to their peers and other interested and influenced parties.

According to Ciliska (2012) there is a clear hierarchy in evaluating quantitative studies in the literature as the "best evidence" in health research. This hierarchy moves down the ladder from systematic reviews of randomized controlled trials, through such evidence as randomized controlled trials; systematic reviews of nonrandomized or cohort studies; cohort studies; case control studies; case studies; case reports; ideas, editorials, opinions; and animal research, to in vitro (test tube) research as the final type of literature on the ladder. She notes specifically how this ladder does not include qualitative research and contends that this is because qualitative evidence "answers questions about experience or meaning" which has its own parallel hierarchy (albeit one that she does not define). She also notes that queries about answers to qualitative research questions have been misclassified in PubMed under the rubric of *health service research* and therefore, not a likely place where most people would look for qualitative answers.

Finally, Murphy et al. (2011) emphasize the importance of qualitative research in providing information that is essential in fully informing people involved in making health policy decisions. Specifically, they mention how the findings from qualitative research can be useful: findings can include such information as richly descriptive data from different perspectives (e.g., providers, clients) about health-related interventions (and their implementation); effects of health-related programs; experiences of different populations; or the meaning and experience of environmental factors such as diversity, culture, and context. This type of evidence-based information is a critical contribution for informing the planning of health-related programs and interventions for diverse population groups experiencing traumatic stress.

10.5 Future Directions

The value of qualitative research is well known in the social and human sciences (Creswell et al. 2011; Denzin and Lincoln 2005). Qualitative research brings "real world" issues into the clinical setting, assisting practitioners working with trauma survivors. It brings in-depth understanding and has the potential to illuminate the complexity of personal experience. As Creswell and colleagues report for the Office of Behavioral and Social Sciences:

> A salient strength of qualitative research is its focus on the contexts and meaning of human lives and experiences for the purpose of inductive or theory-development driven research. It is a systematic and rigorous form of inquiry that uses methods of data collection such as in-depth interviews, ethnographic observations, and review of documents. Qualitative data help researchers understand processes, especially those that emerge over time, provide detailed information about setting or context, and emphasize the voices of participants through quotes. Qualitative methods facilitate the collection of data when measures do not exist and provide a depth of understanding of concepts […]. (Creswell et al. 2011, p. 4)

Bessel van der Kolk and Christine Courtois, world-renowned traumatologists, contend that "omitting or marginalizing qualitative research may impede scientific progress" (2005, p. 6). We agree that there is an urgent need to promote the benefits of qualitative evidence to the field of traumatic stress studies. This text is a beginning, and hopefully trauma journals will reconsider their mandates on publishing only quantitative studies. Now is the time for qualitative researchers in the field of trauma to give serious consideration to producing a qualitative journal on traumatic stress studies to address the inequitable balance of quantitative knowledge over qualitative evidence. As this chapter confirms, there is much to learn from qualitative research about psychological trauma.

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11

Qualitative Evidence and the Development of Sexuality Education Materials: The Case of Family Planning New Zealand

Melanie A. Beres and Frances Bird

What do young people need to know about sex and sexuality? How can we help young people navigate potential risks associated with sex? When and how do we teach young people about sexual pleasure? The answers to these questions vary widely depending on the location and context within which one is situated. An examination of abstinence-only teaching coming out of conservative Christian values teaches that young people need to know that sex is for marriage, that there are a lot of dangers and risks associated with sex, both physically and spiritually, and the pleasures of sex are to be discovered within the bounds of marriage. In other contexts, a risk-reduction approach is taken. From this perspective, young people need to know the biology associated with sex and sexuality, how to make choices around contraception, how to prevent sexually transmitted infections (STIs) and how to negotiate their sexual boundaries with their partner(s). Within a comprehensive view of sexuality education, a holistic approach is taken, which is concerned with the physical, social, emotional and spiritual approach to sexuality education. Biology, contraception and prevention of STIs still play a role, but are part of a broader focus on working with young people to explore their values and attitudes, and develop knowledge and skills, about sexuality and relationships. Within this approach, desire and pleasure are acknowledged as positive and enjoyable aspects of sex.

Family Planning takes a comprehensive approach to sexuality education. In this chapter we discuss how evidence from qualitative research provided the necessary foundation to create a shift in Family Planning's programming from a risk-reduction model to a comprehensive approach to sexuality education.

11.1 Family Planning

Family Planning, a not-for-profit, nongovernmental organization, started running clinical and advocacy services over 70 years ago. The organization has provided sexuality education programs in schools and in the community for over 35 years. It also currently provides clinical training for doctors and nurses, education training and support for teachers, health and community workers in New Zealand and the Pacific. The programs offered by Family Planning are developed within the organization and designed to serve the unique needs of the New Zealand population.

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Public outreach is achieved through social marketing campaigns and events for the wider community. Almost all of its public health work in schools and the wider community is funded through Vote Health (tax) money via the central government's Ministry of Health.

Since December 2011 it has been compulsory to teach sexuality education in New Zealand schools from years 1 to 10 (ages 5–15) in all English-language schools. Family Planning is the largest external provider of school-based sexuality education in New Zealand. It is also the largest provider of sexual and reproductive health resources, sexuality education teaching materials and teacher training.

To meet the standards set by the Ministry of Health (2014), resources are required to be "technically accurate" (p. 5) and information provided to the public is required to be accurate and "knowledge-based" (p. 19). Staff are required to deliver "evidence-based, quality health promotion services" (Ministry of Health 2014 p. 22). An over-arching program logic model underpins all Ministry of Health public health and sexual health service contracting, and all contracted Family Planning health promotion and education services. Program logic identifies the desired outcomes, and maps the service provisions likely to best meet the outcomes, based on a range of what is currently considered best-practice and evidence. In other words, the Ministry requires that Family Planning justifies the content and delivery of its education programs and resources based on evidence demonstrating the effectiveness of the approaches within their programs.

Consistent with the World Health Organization definition of sexual health (WHO 1986), Family Planning takes a holistic approach to sexuality education. Their sexuality programs seek to equip young people with the knowledge, skills, attitudes and values they need to determine and enjoy their sexuality—physically and emotionally, individually and in relationships. They view sexuality within the context of emotional and social development (IPPF 2010). Therefore, they enable learning about the emotional, social, physical, biological and spiritual aspects of growing up: relationships; sex; human sexuality; and sexual and reproductive health. It goes beyond biology and involves young people in expanding knowledge, exploring attitudes and developing skills in order to lead fulfilling and healthy lives, to have enjoyable relationships and to take responsibility for their sexual and reproductive health and well-being.

11.2 Qualitative Evidence in Sexuality Education

Family Planning uses several sources of evidence to create their programs. Qualitative evidence, alongside some quantitative research, has been instrumental in the development of the content of their programs as well as designing effective delivery. This chapter focuses on how qualitative evidence has shaped the content of sexuality education and health promotion materials. The most significant impact of qualitative research has been in shaping the overall philosophy and approach to sexuality education. In Part 1, we detail how qualitative evidence provided the catalyst for a major change in the focus of sexuality education from a risk-reduction model to a comprehensive approach to sexuality education that includes a focus on pleasure and agency. In this section, we outline two factors that have influenced this shift: the turn toward a social constructionist view of sexuality in the social sciences; and research with young people detailing their experiences and desires about sex and sexuality education. This shift was the result of a growing body of research and the introduction of new theoretical ideas to understand sex and sexuality. In Part 2, we describe how particular qualitative research projects have directly impacted the development of specific Family Planning resources and teaching tools. While qualitative evidence has been instrumental in many different areas, we examine four in particular: (1) understanding complex sexual decision making processes; (2) recognizing the need for a program; (3) directing the development of resources; and (4) developing resources for small unique populations.

11.3 Part 1: Shifting Paradigms

State sexuality education in New Zealand had its roots in moral education, and Family Planning originally focused on education about contraception, and the anatomy and physiology of sex, "leading to an appreciation of the nature of sexual desire" (Smyth 2000). By the late 1980s and beyond the focus was broader, and included other aspects of sexuality. The urgency of Human Immunodeficiency Virus (HIV), along with sexually transmitted infection (STI) prevention, and prevention of unplanned teenage pregnancies has dominated public health discourse and approaches since that time. Sexuality education at Family Planning has experienced a major shift over the past 10 years. This shift, alluded to earlier, expanded the scope of sexuality education beyond describing the biological components of sex and risk reduction and toward more comprehensive education. While the roots of the shift rested in theoretical interventions from the 1980s, qualitative research taking up these developing theories demonstrated that the theoretical ideas were useful for understanding sexuality education and made them accessible to practitioners and educators. It is not possible to detail the entire bodies of qualitative work here; instead we focus on a few key ideas that have been instrumental in shaping sexuality education. We highlight the theoretical ideas that formed the basis for this change and subsequently describe some of the qualitative literature that translated these theories into implications for practice.

The theoretical roots of the bodies of research integral in shaping sexuality education today rest at least partially in the writings of Michel Foucault. Foucault's work sheds light on previously uninterrogated aspects of sexuality. Of particular relevance to sexuality education is Foucault's concept of discourse (Foucault 1972, 1978a).

In his work on the history of sexuality, Foucault emphasized the socially constructed nature of sexuality (Foucault 1978a, b; 1986). He draws attention to the way that understandings about sexuality are socially, culturally, temporally, and politically contingent. In other words, the way sexuality is viewed today is not the only, the best, or most natural way to understand sex and sexuality. It is but *one* way. Other cultures and other societies today and throughout history view sexuality very differently.

To further understand how sexuality is located within social and temporal spaces it is important to bring in Foucault's earlier work on discourse and power. Discourses are sets of statements that represent assumptions about the social world (Foucault 1972). These assumptions highlight latent level concepts: beliefs or ideas that are not often thought about; ideas that are taken-for-granted "truths" about the social world. In any social context, there are multiple competing discourses, but there are always dominant discourses that represent the ubiquitous social beliefs about a particular topic. In addition, there are always competing discourses: alternative ways of understanding the social world. For example, one of the most dominant discourses that shapes the understanding of sexuality in many Western cultures is the male sexual drive discourse (Hollway 1984). The male sexual drive discourse rests on the belief that men have an insatiable sex drive and are forever in search of sex. Within the male sexual drive discourse heterosexuality is constructed to satiate this drive. Women are thus positioned as gatekeepers, as responsible for "keeping their heads" and making responsible sexual decisions (in terms of when and where to have sex, and also in terms of ensuring that the sex is "safer").

Discourses open up particular spaces for action and make some decisions and actions seem more readily available than others. For example, the male sexual drive discourse opens up space for male-initiated sex. Within this discourse men's sexual drive is viewed as natural and insatiable. This belief can shape whether or not a young woman agrees to have sex. She may, for example, see it as her job to have sex with a man because of his perceived sexual needs.

One of the challenges of working with post-structural theories, like Foucault's work, is that they often work at the abstract level and it can be difficult to find their practical implications. This is where a body of qualitative research has been instrumental. Here qualitative researchers stepped in and engaged with the theory to find more practical implications. For example, (Jackson and Weatherall 2010; Weatherall and Jackson 2004) conducted observations of sexuality education delivery in schools and focus groups with students in those classes. The data were collected prior to 2004 and analyzed using discourse analysis. They identified a number of discourses present in both the teaching of the classes and in the way the students talked about sexuality education. The strongest discourses were those of victimization and the coital imperative. The discourse of victimization emphasizes the dangerous and/or risky potential in sex, at the expense of discussions of pleasure or other positive outcomes of sex and sexuality. The coital imperative is a term used to describe the implicit definition of sex referring exclusively to penile vaginal penetration without any consideration for alternate forms of sex and pleasure (Jackson 1984). These two discourses were found to dominate teaching practices and student's views of about sexuality education.

Another researcher working at the level of discourse is Louisa Allen. She conducted a large-scale qualitative study including ten focus groups with 78 students and interviews with 81 high school students about their experiences in sexuality education (Allen 2005). A discourse analysis of the data revealed that students were operating with a different set of discourses than were school administrators and teachers. The most striking difference was that young people were constructing themselves as sexual subjects; they saw themselves as sexual people with desires and the possibility of experiencing pleasurable sexual relations (Allen 2007). At the same time, young people perceived that adults set the agenda for sexuality education based on their own goals of behavioral change and risk reduction (Allen 2008). They described this education as inadequate as it did not equip them for understanding themselves as sexual beings and did not deal with, for example, issues such as abortion or teen pregnancy (Allen 2008). As part of her research described above, participants were also asked to do two card sorts. They were given a stack of cards with various topics that are often covered in sexuality education. The participants sorted topic cards into piles related to how well the topics were covered in their sexuality education and a second sort based on what they want their sexuality education to cover. The sorting exercises formed the basis for discussions about sexuality education. Results suggest that students wanted to know more about making sexual activity enjoyable and about abortion and teen parenting. The students were critical of sexuality education that focused exclusively on negative consequences and negative aspects of sexuality and had a lot of questions about the positive and pleasurable aspects of sexuality (Allen 2008).

Through the research of Jackson and Weatherall (2010) and Allen (2008), Family Planning was able to make a number of changes to their programming. This research contributed to the shift toward more comprehensive education programs, inclusive of a pleasure and relationships focus, and no longer focused only on STI and pregnancy prevention. In response to the identification of the coital imperative, activities were developed to help young people to understand that a range of behaviors could be pleasurable and fulfilling. For example, in Year Nine, the activities "Values About Sex" and "Reasons Lots Do" reinforce the message that sex should be wanted and pleasurable and "Sex etc." affirms that sex is more than penis-vagina intercourse (Family Planning 2013a, b). The Year Ten activity "Hot Bods" focuses on coloring parts of male and female bodies that may be erogenous zones and pleasurable to have touched (Family Planning 2010a).

Family Planning also began to incorporate a greater focus on pleasure throughout their programming. For example in Year Ten (14–15 years old) there is an activity called the "Pleasure Package" (Family Planning 2010a). In this activity, students think about what they want from a pleasurable sexual experience. Students are given space to think about the setting (where and when the activity might take place and ambiance), the ideal partner (in terms of the type of relationship and/or qualities in a partner) and activities that they might enjoy. This activity has multiple purposes. It provides students with an opportunity to think about and articulate their own values and desires in a safe environment. Students learn about how they think about pleasure while also thinking about broader issues (like setting and relationship context). It encourages students to see themselves as agents in their own sexuality and opens up possibilities for them to create the types of relationships and experiences that will fit for them.

When researchers and practitioners work at the level of discourse they tap into unrecognized assumptions about sex and sexuality. These assumptions and beliefs are often so strong that they play a large role in shaping sexual decision-making. Addressing these beliefs indirectly and directly can open up alternative spaces for action or present other available decisions. By analyzing how participants talked about sexuality education, Allen (2005) and Jackson and Weatherall (2010) were able to identify the discourses deployed by the participants, and tap into underlying assumptions and beliefs. Through this analysis we learn that sexuality education can at times come from a discourse of victimization that highlights the dangers of sex (Jackson and Weatherall 2010). This is in contrast to the way young people see themselves as sexual actors (Allen 2005). As a result of the research described above, Family Planning shifted their focus from risk reduction toward exploring ideas around pleasure in the classroom.

Another branch of research utilizing discourse analysis to understand sexuality education was built on Michelle Fine's articulation of the missing discourse of desire. In the 1980s, Michelle Fine (1988) conducted an ethnographic study of a high school in New York. The research included classroom observations of hygiene classes, analysis of students' fictional and autobiographical writing and interviews with 55 students. Through her analysis she identified what she labels "the missing discourse of desire" (p. 29) to describe how sexuality education fails to acknowledge sexual desire as part of adolescents' experiences. Fine's original paper describing the discourse has been cited well over 1000 times, with many qualitative researchers taking up the discourse and identifying its use in a variety of contexts. So, while the original work is contextually contingent, the subsequent body of work demonstrates the usefulness of the concept across a wide range of social contexts.

One such researcher who built on Fine's work was Deborah Tolman, who conducted a qualitative study interviewing adolescent girls to talk about their experiences with sexuality education (Tolman 2002). Her findings suggest that, unlike boys, adolescent girls are not taught to be active and desiring subjects and that "teenage girls continue to be denied entitlement to their own sexuality" (p. 7). She argues that the development of this subjectivity is important for young girls to become "healthy" sexual adults. However, while boys are granted sexual subjectivity and encouraged to develop their sexual selves, girls are left as the mediators of boys' sexual desire and thus cannot have sexual desire of their own:

> A gendered perspective on adolescent sexuality offers more explanation for what is behind the urgency of resisting girls' sexual desire: Girls' lack of desire serves as the linchpin in how adolescent sexuality is organized and managed. To the extent we believe that adolescent sexuality is under control, it is adolescent girls whom we hold responsible because we do not believe boys can or will be. (Tolman 2002 p. 15)

Tolman's (2002) work uncovers how romance and sex are gendered. Women and men are expected to play certain roles when it comes to sex. Men are supposed to be desiring subjects while women are in a position of mediating and controlling those desires. Here, Tolman brings together Fine's (1988) work on the missing discourse of desire with Hollway's (1984) work on the discourses of heterosexuality. Based on qualitative interviews with both women and men, Hollway identified three main discourses that govern heterosexuality. The most ubiquitous and prevalent discourse is the male sexual drive discourse. As mentioned earlier, this discourse presumes that men are insatiable sexual subjects are forever in pursuit of sex. Women are positioned within this discourse as the objects through which male sexual desire is, at least temporarily, satiated.

By putting the discursive work of Fine (1988) and Hollway (1984) together, Tolman (2002) describes how young women are positioned within their sexuality education. Family Planning picked up this work and added exercises to their education programs that challenge assumptions about men and women's roles during sex, and also challenged the underlying discourses related to sexuality. For example, in the activity "Reading the Rules," Year Ten (age 14/15 years) students identify how societal expectations of gender roles and heterosexuality are learned through a range of socialization processes (Family Planning 2010a). Students discuss how we are socialized, draft a stereotypical romance story, identify the recurring stereotypes and rewrite the stories with the characters going against norms and stereotypes. Following this, students identify possible outcomes for people who do not fit in with norms and stereotypical behaviors, and reflect on their learning from the lesson.

The purpose and effect of the abovementioned activities go beyond challenging gender stereotypes. Challenging stereotypes builds tolerance of difference. These exercises also challenge dominant discourses that shape sexuality and in so doing open up alternate spaces for action, producing, for example, narratives of desiring young women or young men who are not always interested in sex. Drafting alternative romance stories gives students tangible alternatives to the standard romantic "script." These types of exercises give young people permission to make sexual decisions that challenge or transgress heteronormative discourses that shape sex, like the missing discourse of desire and the male sexual drive discourse.

Jackson and Weatherall (2010) also noted the emphasis on *information based knowledge*, which students found descriptive but lacking in depth. They argue that this leads to a knowledge–practice gap with students knowing about, for example, safer sex practices but not following them in their own practices. Family Planning has responded to this critique with a greater emphasis on teaching and practicing skills, its teacher professional development program, teaching resources, and direct delivery of education programs.

The poststructuralist turn in the social sciences has had a tremendous impact on the delivery of sexuality education in New Zealand. Qualitative research embedded within this paradigm has impacted sexuality education. It has shifted the focus from a risk aversion, biological focus toward a comprehensive model of education. It has done this in two ways: firstly, it has contributed to a student-centered approach to sexuality education that focuses on issues of desire and pleasure in addition to biology and risks associated with sex; secondly, the social constructionist view of gender and sexual relationships has challenged dominant discourses associated with sex.

11.4 Part 2: The "Nuts and Bolts"

In the first part of the chapter we discuss how evidence derived from qualitative research has built on a theoretical change in the social sciences to create a shift in the focus and goals of sexuality education. In this second part we move to discuss how qualitative evidence from individual studies has impacted the programming created by Family Planning in more direct ways. For example, Weatherall and Jackson (2004) noted the emphasis on providing *information based knowledge* in the programs in their study. Students recalled definitions and explanations about STIs and contraception, which they found descriptive but lacking in depth. As previously noted, Jackson and Weatherall argue that an emphasis on information in programs leads to a knowledge–practice gap with students knowing about, for example, safer sex practices but not following them in their practices. What is implied, although not articulated, is that the programs lacked skills components where students could link information based knowledge to the development of skills such as critical thinking, and practical skills such as communication and negotiation.

Family Planning has responded to this critique with a greater emphasis on teaching and practicing skills, within its teacher professional development programs, the lessons and activities it provides for teachers' use, and direct delivery of education programs. Below are other ways that Family Planning has incorporated evidence from qualitative studies.

11.4.1 Reflecting Complex Decision-Making Processes

Making sexual decisions is complex. Often advocates for sexual health focus on a risk model of sexual behavior and attempt to educate about risks in an attempt to promote healthier sexual behavior (Davis 2002). Qualitative research using semi-structured interviews has highlighted the complex nature of sexual decision-making, suggesting that a risk-aversion approach to sexual health promotion is not viable because young people are weighing the perceived risks next to the perceived benefits of having sex (Abel and Fitzgerald 2006; Livingston et al. 2013). An example of this takes place in the development of Family Planning's program about alcohol and sexuality.

Research coming out of a risk model of sexual behavior, which is largely quantitative, is clear that consuming alcohol prior to sexual activity decreases the likelihood that a condom will be used, increases the likelihood of contacting an STI and that alcohol is often used in cases of acquaintance rape (Boden et al. 2011; Krebs et al. 2009). This research does not account for the complex decision-making processes that young adults go through.

Recent qualitative research has shed light on how young adults make decisions about their alcohol use prior to sexual activity. This qualitative research (see Abel and Fitzgerald 2006; Beres and Farvid 2010; Livingston et al. 2013) suggests that at least some young adults are aware of the risks of using alcohol prior to sex; yet also perceive benefits to using alcohol. For example, results from 15 focus groups with adolescent women suggested that alcohol was perceived by this group to facilitate social interactions and excuse unsanctioned (or taboo) behavior (Livingston et al. 2013). These young women reported that people who want to engage in sex may choose to drink alcohol to make it easier to initiate sexual activity. Follow-up interviews with young people in a variety of contexts suggested that they perceived the risks as more distal than they did the benefits associated with sexual activity (Livingston et al. 2013). Similarly, in an interview study of adolescents, findings suggested that participants perceived that the risks to their reputation or relationship if they did not participate in sex were greater than the risks of catching an STI (Abel and Fitzgerald 2006). The risk of STI infection seems remote when compared with the possible social benefits to the use of alcohol. In another study, researchers interviewed young women in two countries about their casual sex experiences. A discursive analysis of their interviews suggested that, for many participants, drinking alcohol allowed them to feel less guilty about engaging in casual sex (Beres and Farvid 2010).

As a result of the qualitative evidence described above, Family Planning developed exercises that provide students with the opportunity to work through their ideas and perceptions of alcohol use before they are in that situation. For example, in one activity the facilitator starts with the question, "Why do some people choose to drink alcohol and what influences how much they drink?" Once students have brainstormed, facilitators "explain that although some people may drink alcohol to gain what they believe to be positive effects, it can still have negative effects on a person's wellbeing" (Family Planning 2013a p. 91). Students are then given a sheet to fill in with the possible negative consequences of alcohol consumption for various aspects of well-being including physical, emotional, mental, and spiritual well-being.

In other exercises, students are presented with scenarios that reflect the decision-making process uncovered in the research described above. For example, an exercise called "Status Update" (Family Planning 2013a) builds directly on the Livingston et al. (2013) study described above. In the exercise, students are presented with possible Facebook updates from peers looking for advice. The scenarios highlight possible situations involving alcohol, including someone getting aggressive after drinking, or a guy always "hitting on" the most "wasted" girls at a party (Family Planning 2013a). One scenario in particular highlights the issues of balancing of perceived benefits and risks highlighted by the research described above:

> I've started going to parties and hanging out with my friends more. People say that the best place to have sex is at a party after you've had a bit to drink because it's less embarrassing but I don't want to be out of it either. How can I make sure my first time is special?(Family Planning 2013a p. 43)

Exercises like the two presented above are scenarios that were described by participants of the Livingston et al. (2013) study. Family Planning used the examples given in the research to develop realistic scenarios. These exercises give students the opportunity to work through the decision-making process described by Livingston and colleagues in a facilitated environment without the immediate pressures that might be present at a party or when they are talking with their friends. When students are faced with decisions about alcohol and sex they will have already put thought into their own values and ideas and may have a better sense of how the possible negative consequences relate to the perceived positive effects.

11.4.2 Recognizing the Need for a Program

One main public health-related reason for the development of sexuality education and sexual health promotion programs is to decrease the rates of negative health outcomes and increase positive health outcomes, whether they be individual or social. Quantitative measures of rates of infections, teenage pregnancy and violence are used as evidence of a need for sexuality education. Young adults are often targeted by policies related to sexuality education precisely because of the high rates of negative sexual outcomes (like infections). Quantitative measures of negative and positive outcomes can only tell part of the story. Sometimes understanding the need for a program is not about rates of infections, unintended pregnancies or violence, but comes from an understanding of how young people manage and negotiate the unexpected outcomes such as unintended pregnancies; and how they can demonstrate respect and care for other people, a key underlying concept in sexuality education in The New Zealand Curriculum.

One clear example of this relates to teaching about abortion. When it comes to the subject of abortion, high abortion rates are generally used as a rationale to increase teaching about contraception. Yet, there is also a need for teaching about abortion directly. Recently, Family Planning developed a resource for teaching abortion content in schools based on qualitative research suggesting a need for such a program. In 2007, the director of health promotion for Family Planning attended the Global Safe Abortion Conference—Whose Right, Whose Choice, Who Cares? What was particularly compelling about the research presented at that conference was that researchers reported that their participants did not know much about abortion, and that the young women they interviewed faced with unexpected pregnancies had not thought about their views on abortion prior to getting pregnant, or about what they would do in the event they became pregnant (MIS and IPAS 2009). Lee and colleagues (2004) outlined the benefits of an education program that would allow young people, both men and women, to learn about abortion and to think about their own values in relation to abortion before they may be faced with a pregnancy and have to decide whether to obtain an abortion.

The need for programs about abortion also came directly from students themselves. As part of the study described earlier, Allen (2008) conducted focus groups with high school students about their experiences and opinions about sexuality education. Students clearly wanted comprehensive education about abortion. They said abortion was rarely mentioned and that, when it was mentioned, the emphasis was on how abortion was wrong. Students wanted to hear a more balanced approach to abortion and have the opportunity to develop their own thoughts about it.

In 2010, the *Teaching about Abortion* program was developed for teachers to use with young people between the ages of 14 and 18 (Bird 2010). It was developed as a direct result of hearing the experiences from the conference, and the research findings mentioned above. It prompted a New Zealand-based quantitative research project to identify gaps in the knowledge of Family Planning clients. The teaching materials and information booklet for young people subsequently created give students information and skills to negotiate an unintended pregnancy and to support and respond to peers who may have unintended pregnancies. The teaching materials combine fact-based learning about abortion with opportunities for students to work through their own ideas and values related to abortion. The development of the resources is described in more detail in the section below. Without the qualitative research discussed above, this program would not have been developed at this time.

11.4.3 Direct Development of Resources

One of the strengths of qualitative research is that it allows participants to describe their lives in their own words. Descriptions presented by participants are then useful for developing resources for sexuality education that reflect the language and experiences of young people. The Family Planning *Teaching About Abortion* (Bird 2010) program was heavily influenced by several studies including one by Lee et al. (2004). Lee and colleagues conducted a mixed methods study with young women who became pregnant in their teens. Of particular interest here are the interviews that were conducted with young women who chose to have an abortion and young women who chose to continue with the pregnancy. They asked the women how they made the decisions around their pregnancy.

The study was used by Family Planning to craft an exercise for young people to consider their own views on abortion including exploring the reasons why someone might choose to have an abortion, or why someone might choose to continue the pregnancy.

The second theme of *Teaching About Abortion* is dedicated to exploring values around abortion (Bird 2010). The students are asked to brainstorm reasons why women might seek to have an abortion. The facilitator can bring up other issues the students may not consider, with many possible reasons listed in the resource guide. The list included in the resource guide was developed partly through the Lee et al. study and includes reasons such as: “want to study,” “can’t afford a child,” and “can’t tell parents.” This exercise aims to create an understanding of the complexity of decision-making for women faced with unintended pregnancy, and to create empathy for young people who may be faced with such a decision. To encourage students to think through the decision-making process even more they are given scenarios to work through. Some of the scenarios here were developed from stories out of the Lee et al. study. For example, one scenario involves a “pregnant 15 year old school girl with a steady boyfriend. Family members are religious and do not know she is having sex” (Bird 2010). The students are asked to think about what the girl would be worried about, what would she want to consider and what her options would be. These scenarios again create empathy for the decision process and have the potential to help prepare those students who may be faced with a decision about an unintended pregnancy. By using scenarios that come out of qualitative research, the program is built to reflect actual, rather than imagined, situations.

11.4.4 Developing Resources for Small, Unique Groups

Previous research shows that targeted sexuality education and health promotion is more effective than programming aimed at the general population (Noar et al. 2007). Qualitative evidence can and has contributed to the understanding of unique contexts of particularly small populations. To this end, Family Planning New Zealand routinely uses its own research to understand the unique needs of small populations, or groups where there is little other research. One example is the development of programs for young Māori men.

New Zealand has a small, yet diverse, population. Like many indigenous populations, the sexual health outcomes for Māori in New Zealand are poorer than the general population. Targeted and relevant programming is essential for Māori in New Zealand and the Ministry of Health has requested that programs specifically improve Māori health outcomes and reduce Māori health inequalities. Family Planning conducted focus groups in order to better understand the unique needs of young Māori men. Results from the research suggested that cultural taboos often meant that issues related to sex were seldom discussed in the home. These men also suggested that peer influence would be helpful to encourage them to use condoms (Hager 2005).

The results from the focus groups were used to create a training workshop for Māori health promoters and health workers providing programs for young Māori men (Family Planning 2005). The workshop included content on cultural taboos in this area, such as the point that sex was rarely discussed in Māori homes. Participants were advised that the lack of discussion about sex should not necessarily be interpreted as an indication that young men did not want to discuss issues related to sexuality, but that they might not have the language and tools to do so. It was therefore important to first give them those tools.

As a result of this work, and of the recognition that targeted educational programming is more effective, Family Planning regularly uses Māori language and models in their health promotion campaigns. For example, the *Tiakina tōu whakapapa* (Taking care of our present and future generations) is a poster series to show positive male role models for men (Family Planning 2010b). These men were directly involved in the delivery of workshops for young Māori men within a specific program developed for Māori young men, and the posters were designed by the young men as part of the program.

The Māori men in the focus group research said it would be easier for them to start using condoms and changing their behaviors if their peers did the same. The visuals in the campaign serve to present young Māori men engaging in positive sexual behaviors, and were developed as a form of modeling of behavior. Family Planning used this information to develop the *It's about Mana* campaign. This campaign builds partially on Māori cultural concepts to make it relevant to young Māori men. The word "mana" is a Māori word that can be loosely translated to mean "honor" in English. Mana is recognized by non-Māori speakers in New Zealand and has been incorporated into the general New Zealand lexicon. The campaign uses many models whose appearance may be read as Māori. Captions for the posters include "we're going to wait until we're both sure we're ready" and "I thought we were both really up for it then she kind of just lay there so I backed off." The combined use of the word "mana" with visuals understood by Māori men is expected to help them model these behaviors of their "peers."

11.5 Discussion

In this chapter, we outline a number of different ways that evidence from qualitative research has been used to develop sexuality education. At its core, qualitative research has been fundamental to the major shift in sexuality education from focusing on risk aversion and describing biological processes toward valuing the social and emotional aspects of sex, respecting young people as active sexual subjects and providing them with opportunities to work through the complex social aspects of sexuality. In addition, qualitative research has provided evidence that has highlighted the need for specific programs, described the unique needs of small populations, and has shaped specific exercises and educational materials.

Two different aspects of the impact of qualitative evidence are highlighted. The first part of the chapter addresses the broad shift in approach to sexuality education and the second part describes more specific and direct forms of evidence used to develop educational materials. It is important to note that these two sections are not distinct from one another. Instead, the work described in the second section is embedded within the theoretical turn described in the first section.

This shift is an epistemological one, meaning that it is a shift in the forms of knowledge that are valued by researchers and practitioners. Inherent in the shifts described in this chapter are shifts in the understanding about what is important to know, in order to understand sexuality. Sexuality education focused on sexual "facts" (biology, rates of STIs, and risks) is inherently limited in its effectiveness because much of how sexuality is negotiated and social. The way forward in sexuality education is to acknowledge and address the underlying sociality of sex; ranging from broad-based discourses that shape cultural assumptions about sex to the situated knowledge of small groups of people. What all the examples discussed above have in common is that they focus on the meanings associated with sex and sexuality. For example, as discussed previously, understanding the meanings associated with adolescent alcohol consumption in relation to sex, provides much-needed context to discussions about the risks of alcohol consumption to sexuality. Challenging dominant discourses is important because the meanings we attribute to sex and sexuality may not fit for everyone. Challenging these meanings has the potential to open spaces for subverting and transgressing these norms in ways that support young people's agency about sex.

In light of the discussion above, we would like to make particular recommendations to educators and researchers in order to facilitate this process. One of the challenges for educators when it comes to qualitative evidence is that the evidence necessary to inform sexuality education is seldom present in one particular research paper or project. Shifts in the underlying assumptions and approaches to sexuality education are not possible to see from reading a couple of pieces of work. Instead, it is the impact of bodies of research from this perspective that come together to suggest changing the focus of sexuality education. This can make it difficult for educators to access this research. Most educators do not have the time to read large bodies of research and to distill out the relevant information. Academic sources may also be filled with jargon that does not make the research easily accessible to those without an academic background. It is up to researchers then to develop ways to summarize large bodies of work and to seek out platforms that make their research more accessible for practitioners and educators.

Ideally, researchers and practitioners would partner together and work as collaborators, with each contributing to the research design, program creation and evaluation. This builds the capacity of both researchers and practitioners to expand their practice and work at the cutting edge. Partnerships across research and practice would ensure that the research conducted is relevant to the community.

When working with qualitative research, it is important for practitioners to be aware of the population and context within which the study was operating. For example, what happens within Māori communities in New Zealand might not be relevant for Latina/o communities in the USA. In the first section of this chapter we describe some theoretical interventions by a small number of authors. Michelle Fine, for example, introduced the missing discourse of desire in 1998. The evidence for the use of this concept to alter sexuality education programs comes not from this one article alone, but from the mass of literature that explored and used the concept across wide-ranging social contexts. Work using Fine's description of the missing discourse of desire (1988) has been conducted with ethnic minority communities (Burns and Torre 2005), across time (Fine and McClelland 2006; Fine 2005), across sexual orientations (Diamond 2005; Ussher 2005), in different countries, and with people with disabilities (Tepper 2000). The plethora of studies taking up Fine's concept help provide evidence for the utility of the concept across social contexts and can provide practitioners with important information about the utility of the concept and how it might vary in different contexts. Without this information practitioners should be mindful about whether or not—and how—the research applies to the contexts within which they are working.

Perhaps the biggest strength of qualitative research, as it relates to sexual health promotion, is that it goes beyond describing a particular phenomenon to providing pathways to address problems or issues identified through the research.

This feature is evident throughout all sections of this chapter. Qualitative research not only provides a picture of how students think about sexuality education, it provides direction about what to change and what to add to sexuality education. For example, qualitative research demonstrated that teaching on abortion was necessary, suggested that students needed the opportunity to work through their own values and ideas about abortion, and also provides stories and quotes that can be used to create relevant and meaningful scenarios or problems for the students to work through. The richness of qualitative data is unparalleled when it comes to supporting practitioners in developing robust and meaningful programs.

11.6 Conclusion

The relevance of qualitative research to practice extends beyond sexuality education and sexual health promotion. Qualitative research is an ideal match for a range of health practitioners including health promoters. It enables the community of respondents to offer their ideas about issues *and solutions,* rather than the researcher providing them with a range of preassembled issues and solutions for agreement or negation. According to the WHO:

> Health promotion is the process of enabling people to increase control over, and to improve, their health. To reach a state of complete physical, mental and social well-being, an individual or group must be able to *identify and to realize aspirations*, to satisfy needs, and to change or cope with the environment […] Health is a positive concept emphasizing *social and personal* resources, as well as physical capabilities. Therefore, health promotion is not just the responsibility of the health sector, but goes beyond healthy life-styles to well-being.
> (WHO 1986)

Qualitative research facilitates the development of health promotion practices by detailing the social contexts surrounding health behaviors *and* providing pathways to solutions, while empowering the subjects themselves.

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12 Qualitative Evidence in Addictions

Lindsey Coombes

12.1 Introduction

In this chapter the contribution of qualitative evidence to what is known about addictions is critically examined. It is argued that there is bias against publishing qualitative research in and for addictions and that there are ideological reasons for why qualitative research is not valued as *evidence*. A critical point in such discussions is the epistemology of method. The way qualitative research is used to inform and critique aspects of the addictions field is explored in relation to drug consumption (focussing on drug use by young people as an exemplar) and distribution (focusing on qualitative research on drug markets). The production of knowledge about drugs is scrutinised in terms of the processes of problem construction and the often taken-for-granted knowledge that informs or shapes them. Broader questions about the science and ideology underlying drug use related interventions (using harm reduction as an exemplar) are also considered. Examples of quantitative, qualitative, and mixed methods research questions are compared and contrasted in the chapter and the notion of transdisciplinary research is examined as a possible solution to the ontological and epistemological differences between researchers. It is demonstrated that the addictions field has been slow to implement evidence to inform best clinical practice and that qualitative research provides an insight into why this might be the case. Suggestions for future research, policy, and practice in defined evidence-based addictions interventions are made.

Throughout the chapter, the question of what is meant by *evidence* in general and *qualitative evidence* in particular in the addictions is alluded to. *Evidence* is especially difficult to define and has been characterised by theorists in a number of ways, e.g. the truth or falsity of something, or its *probability*, *likelihood*, or *warrantability* (Miller and Fredericks 2003). As is discussed later on in the chapter, these different characterisations mean that the concept of evidence is contested by different users of it. Additionally, it is not immediately obvious how qualitative data becomes evidence for a claim and there are several models in existence to explain the process (Miller and Fredericks 2003). Detailed discussion of these issues is beyond the scope of this chapter, but it is important to note that these theoretical concerns are not merely academic as they impinge on the credibility of the qualitative research paradigm and underpin some of the problems explored in relation to evidence based practice in the addictions field that are discussed below.

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12.2 Evidence in the Addictions Field

12.2.1 Historical Background

Most historiographers of addictions research agree that Lindesmith's (1947) study of opiate dependence and withdrawal is the start of modern qualitative research in the field (Feldman and Aldrich 1990). In this study, Lindesmith adopted a symbolic interactionist perspective and demonstrated that the experience of addiction had a social rather than a merely physiological basis. Following Lindesmith's seminal work, the concealed nature of many drug use behaviours and subcultures was further developed through a series of what are now considered classic ethnographies of addictions (Agar 1973; Becker 1953; Jackson 1978; Preble and Casey 1969; Preble and Miller 1977; Spradley 1970; Sutter 1966). The focus of such research was to *make sense* of the social world of drug use from the perspectives of drug users. Popular perceptions of drug users as passive or deviant were challenged through these studies and purposeful and active meanings in drug use within the context of the drug user's lifestyle were established (Becker 1963; Feldman et al. 1979; Hughes 1961).

Since the early qualitative studies in the addictions field there has been an increasing acceptance of the use of qualitative methods as a means of understanding and responding to drug use and misuse. Ethnographic analyses of populations marginalised on the basis of race/ethnicity, gender, and/or social class have emerged in recent decades (Bourgois 1995; Bourgois and Schonberg 2009; Maher 1997; Maher and Dixon 1999; Moore 2004). For example, early methadone treatment programmes for opiate-addicted women were shown to be characterised by limited space, inadequate facilities, overt voyeurism and sexism, and lack of gender-specific services in qualitative research undertaken by Rosenbaum (1981). More recently, Moore (1993) highlighted the manner in which drug use and related harms are influenced by historical and structural factors such as economic and class distinctions. Adler (1985) and Pearson's (1987) research on neighbourhoods in the north of England suggested a close local relationship between heroin abuse and neighbourhood levels of social deprivation and unemployment. Epidemics of HIV/AIDS infection among injecting drug users during the 1980s created the need to better understand the social contexts of risk behaviour so as to control HIV transmission. In addition to these studies, qualitative research began to be used to inform the development of policy and community interventions during the 1980s and 1990s (Atkins and Beschner 1980; Brooks 1994; Feldman and Aldrich 1990; Hughes 1977).

In recent years, there has been recognition of the importance of qualitative methods in the addictions field, particularly in relation to mixed methods research (Bourgois et al. 2006; Clatts et al. 1999; Grund 1993; Koester 1994). This new interest in qualitative research reflects awareness of the need for methodological and analytical research approaches capable of untangling the complex environments in which actions, diseases, and policies interact (Rhodes and Moore 2001a, b). Such approaches have also opened the way to the production of more reflexive accounts of the relationship between qualitative researchers and their subjects. Reflexivity entails focussing on the politics inherent in the representation of research data and in being interested in how wider social forces (whether historical, social or economic) shape the everyday realities lived by drug users.

The topics investigated using qualitative research in the last 67 years are almost limitless, and the range of methodologies employed is increasing all the time. For example, Coombes and Wratten (2007) used phenomenology to illuminate the experiences of mental health professionals working with people who have a dual diagnosis. Oksanen (2012) has used narrative analysis to examine rock autobiographies describing a wide variety of legal and illegal substances and risky behaviour used by rock artists. Martin and Stenner (2004) and Fraser (2006) have used discourse analysis to how participants first came to use heroin and how methadone treatment is reported in newspapers respectively. Murphy et al. (2010) employed grounded theory to explore the experiences of racially and culturally diverse young mothers whose own mothers' misused substances two decades ago in inner city, urban neighbourhoods in the USA. It will be interesting to see how qualitative research continues to develop over the next seven decades.

12.2.2 Qualitative Evidence in the Addictions Field

This brief historical discussion has illustrated the gradual acceptance of qualitative research as a valid form of evidence in the addictions field. In a recent influential book on drug policy, Babor et al. (2010) mention qualitative research in relation to the production of evidence. They say "[…] a variety of methodological approaches have been used to assess the impact of drug policies as well as the effectiveness of policy-relevant prevention programmes, treatment strategies, and related efforts" (p. 98). They go on to add that qualitative research is an appropriate methodological approach. However, it is interesting to note that, perhaps unconsciously, qualitative research is placed at the end of a list of research methodologies starting with experimental studies.

There is much debate about the concept of *evidence* and *the evidence base* in the addictions field. As well as the conceptual problems mentioned in the introduction, the usefulness and relevance of such terms to both policymaking and practice has been questioned. The term *evidence-based practice* is used frequently in the literature, yet largely relates to only one type of evidence, namely research. In reality, a variety of distinct pieces of evidence and sources of knowledge inform policy and practice, such as histories and experience, beliefs, values, competency/skills, legislation, politics and politicians, protocols, and research results (Elliot and Popay 2000; Sibbald and Roland 1997). Because of this, the term *evidence-influenced* or *evidence-informed* practice or policy has been introduced in the addictions field and elsewhere to reflect the need to be context sensitive and to consider use of the best available evidence when dealing with everyday circumstances (Hayward et al. 1996; Nutbeam 1996; Sackett et al. 1996). A key challenge to those working in the addictions field is to better contextualise evidence for more effective policymaking and practice.

Consensus regarding the best procedures for identifying practices with sufficient empirical foundation to be considered *evidence based* has not yet been reached in the addictions field. For example, some have argued that evidentiary value should be based on a hierarchical model of research evidence (Lohr 2004). An alternative view is based on systematic reviews and meta-analyses as exemplified by the Cochrane Collaboration (Clarke 2007; Walshe and Rundall 2001). Yet others have proposed highly specified criteria that reflect the number and types of trials required to establish a treatment as *evidence based*, e.g. the American Psychological Association's Division of Clinical Psychology 1995 (Chambless and Hollon 1998). Critics of these approaches to selecting interventions for use in practice have argued that interventions established through efficacy research are unlikely to generalise to "real world" settings (Garfield 1996; Seligman 1995). Also, for reasons considered next, such approaches tend to exclude data obtained through qualitative research in the addictions field.

Taken as a whole, the addictions field is dominated by quantitative research (Neale et al. 2005). In a recent survey of the top eight ranked journals in the social science category of the Thomson ISI impact factor (IF) ratings, supplemented by journals of relative high impact in the field of drug use or known to attract social research submissions, it was estimated that 7 % of published papers were qualitative research (Rhodes et al. 2010). But it is not just the quantity of qualitative research studies that are published that is the issue. How is the research that is published *valued* by those in the addictions community?

Whilst it is difficult to generalise across groups as diverse as make up the addictions field, it is possible to discern some messages about how qualitative research is regarded. For example, Babor et al. (2010) comment:

> Researchers can complement quantitative research methods such as social surveys with qualitative studies, such as ethnographic interviewing, participant observation, case studies, and focus group

> discussions. As long as researchers apply standard scientific principles of confirmation, refutation, causal inference, and generalizability, qualitative research can provide an additional different form of evidence that can inform drug policy development. (pp. 99–100)

Qualitative researchers working in the addictions field would have no difficulty in accepting the proposition that qualitative research delivers evidence that can edify health providers, societal stakeholders and drug users in the addiction policy field. What is more contentious though is the inference that the proper place of qualitative research is secondary to quantitative research and that it should be appraised using quantitative criteria.

12.3 The Epistemology of Method and the Addictions Field

A critical point in this discussion concerns what is often referred to as the *epistemology of method*. Often, researchers' choice of a method will be between quantitative or qualitative or mixed, without any reference to our assumptions regarding the way of understanding and interpreting how we know what we know. A detailed analysis of the epistemological debates that have taken place regarding the correct approach to knowledge production is not possible here, but one effort to resolve what has been called *paradigm wars* is worth consideration, namely the call for *pragmatism* (Hammersley 1992; Johnson and Onwuegbuzie 2004). The pragmatist position, which sits comfortably inside narratives of evidence-based medicine, implies that differences in the epistemology of method are exaggerated as well as unconstructive. In the field of addictions, McKeganey (1995), for example, has argued for reconciling differences between quantitative and qualitative methods in addictions research, suggesting that *divides* are *unhelpful*, and that *methodological identity* should not be preserved at *the cost of greater understanding*.

Many qualitative researchers would contest this view and would argue that pragmatism as a solution to differences in epistemological method is insufficient. Qualitative research approaches are a commitment to illuminating how power, context, and objectification shape knowledge in relation to addiction (Bourgois 1999). Qualitative researchers should not have to quash their attachment to interpretivist theory, disguise their epistemological beliefs, or dumb down their analyses. Addiction and addiction science are essentially social and historical constructions (Courtwright 2001; Reinarman 1995), and a key role of qualitative research, through theoretically informed, systematic analyses, is to explore and demonstrate how particular constructions of knowledge, practice, and subjectivity come to be taken as real.

12.4 Use of Evidence by Addiction Workers

So far it has been suggested that traditional evidence based practice has tended to exclude qualitative research in relation to knowledge production in policy and practice. Nonetheless, in spite of these attempts to discount qualitative research, the approach has made several significant contributions in the addictions field. These are briefly discussed under the headings of: drug consumption and distribution (using drug use by young people as an exemplar); production of knowledge about drugs; and the science and ideology underlying drug use related interventions.

12.4.1 Drug Consumption and Distribution

For 2010–2011, the annual Crime Survey for England and Wales data for younger people aged 16–24 showed 19 % saying they had used an illicit drug in the past year—the lowest level since the survey began in 1996. For this age group, cannabis use has fallen sharply from 26 % in 1996 to 15.7 % in 2011, followed by a drop in powder cocaine use from 5.5 % at its peak in 2009–2010 to 4.2 % in 2011. Despite the current media focus on ecstasy, its use among young people has also experienced a recent decline, down from 4.4 % in 2008–2009 to 3.3 % in the latest figures. Legal highs remain as popular as ecstasy among young people, with 3.3 % of 16-to-24-year-olds using them in the past year, but this is a decline since the previous survey showed 4.4 % trying it.

How should these statistics be interpreted? Trends such as those above signal a shift in the use of a drug. But why does the shift occur? Some commentators have claimed that the recent cannabis statistics in England and Wales are evidence that drug policy in the UK is working. The problem with this argument is that, for many critics, it is factors such as the legal reclassification of cannabis, changes in prices, availability of other substances, improvement in living standards, employment status, and changing family structure that are the causes of shifts in drugs trends, rather than drug policy. Yet other critics point to the contradictions and unintended harmful side effects of UK drug policy, which are not seen in headline official statistics (Transformhttp://www.tdpf.org.uk/).

In order to answer the two questions posed at the beginning of the preceding paragraph and to throw light on the issues touched upon in the rest of the paragraph, it is not simply a matter of referring to the facts produced by quantitative research. As Agar (2000) has pointed out, drug trends are the engines that drive planning, intervention and evaluation in the addictions field, whether one thinks of prevention, treatment, or law enforcement. Typically trends are monitored with a *number trail* from the institutions that deal with drug users but, useful as such data may be, well-known problems exist in reading trends from the quantitative record. One such problem is that indicators are typically lagging rather than leading. Another is that institutions that maintain records usually over-represent long-term users from impoverished groups and, in practice, their institutional processes may change the numbers (e.g. arrest statistics fluctuate with policy and shifting police priorities). The final issue is that the numbers do not reveal the changing worlds of use that are needed to interpret them: who is using what drugs, in what ways, in what circumstances—the world of use—plays no role in the indicator data. To account for a statistical trend in drug consumption, information about the lived world of user and use is needed, information that is best provided by qualitative research.

These points are well illustrated in a recent overview of drug research in the UK commissioned by the Joseph Rowntree Foundation regarding cannabis use by young people. Lloyd and McKeganey (2010) reported on five qualitative research studies of cannabis use by young people that focused on: the policing of cannabis as a Class B drug; the impact of change of legal classification of the drug; the domestic cultivation of cannabis; the social impacts of heavy cannabis use and; how young people access cannabis.

Lloyd and Mckeganey (2010) drew a number of interesting conclusions about the trend in cannabis use by young people in the UK. Firstly, they noted that there are some very significant gaps in knowledge of the most commonly used of the illicit drugs in the UK such as skunk and home-grown herbal cannabis, and that the growing fears over the new potency of cannabis have therefore been based largely on anecdote and conjecture. Secondly, they found that there were wide variations in practice in the policing of cannabis that cannot be accounted for merely on the basis of operational or strategic needs, particularly in relation to black and minority ethnic groups and the very different way that young offenders are dealt with. Thirdly, in relation to the domestic cultivation of cannabis, their research showed that there is considerable variation and confusion on the question of enforcement regarding young people's cannabis use. Fourthly, while an increasing proportion of cannabis is grown in the UK, the large majority of young people still have to obtain their cannabis from the illicit market—a market that seems to be able to reach people anywhere in the country. However, young users do not tend to buy their cannabis from a stereotypical older, unscrupulous and unknown "pusher"—they are far more likely to obtain it through friends. Fifthly, a somewhat surprising finding was the number of young people who reported taking cannabis into school and smoking the drug on school premises.

Sixthly, findings suggested that young people with troubled pasts may be more likely to smoke cannabis heavily, and that this heavy use can amplify their problems. Relatedly, there is also the suggestion that professionals working with vulnerable young people may not recognise the potential seriousness of heavy cannabis use. This may relate to their own, very different, experience of smoking cannabis during their youth.

As well as drug consumption, qualitative research has also made important contributions to the understanding of drug distribution. One of the earliest studies of drug distribution focused on the heroin market in New York and described the levels and hierarchies to the market (Preble and Casey 1969). This early qualitative study of the structure of drug markets was built upon by Dorn et al. (1992) in the UK, who identified seven different types of drug trafficking firms. They made two central claims about the structure of the drug market: firstly, they argued that there was no evidence for the large scale organised, top-down hierarchies controlled by "Mr Big"; secondly, the researchers found that the drug markets are constantly fluid and changing. Dorn et al. (1992) did not subscribe to the view of a simple hierarchical organisation, with levels of distribution characterised by the weights, price, and purity of the drugs traded.

From the USA, qualitative research by Natarajan and Belanger (1998) described a number of typologies of the drug market identifying five tasks/roles in drug trafficking organisations: (1) grower/producer; (2) manufacturer; (3) importer/smuggler; (4) wholesale distributor; and (5) regional distributor. As regards organisational structure, they identified four types: freelance, family businesses, communal business, and corporations. In the UK, qualitative research by May and Hough (2004) noted the change in the market from an open street-based market to a closed market, and associated this with the widespread introduction of mobile phones, coupled with community concern about public space. They used the term "retail market" to describe this segment, and distinguish it from the "middle-level" drug markets. Above this retail level, May and Hough (2004) documented two types of distributions systems: the more traditional pyramidal market (prevalent in the 1980s and characterised by highly disciplined and hierarchical organisation); and the fragmented, non-hierarchical entrepreneurial market (characterised by little structure, fluidity, and free enterprise). They noted that they cannot determine which of these two structures predominates. Aspects of the low-level market are described in South (2004) through two qualitative case studies of heavy recreational drug users. The daily lives of these users blur the line between the legal and the illegal and their drug trading is generally as a consumer and "friend of a friend" small dealer.

So far we have considered what Moore (2011) describes qualitative research *in*, or *fo*r, the drug field. That is qualitative research aimed at improving understandings of the addiction field, in this case, drug markets. However, qualitative research *on* the drug field and its underlying theories, methods, assumptions, and ideological bases, has also become the object of critical inquiry. An example of this kind of qualitative research is provided by Dwyer and Moore (2010) through a detailed critical analysis of surveillance and criminological research on illicit drug markets in Australia. They argue that conventional surveillance and criminological research on illicit drug markets is limited in terms of its inadequate methods, limited theoretical models, neglect of sociocultural and political processes, and narrow conception of those participating in drug markets. Given that drug markets and street-based drug marketplaces in particular, have emerged as central public policy concerns internationally, it is important to question whether quantitative approaches provide adequate understandings of these sites.

12.4.2 Production of Knowledge About Drugs

It was suggested in the previous section that knowledge production relating to drugs, drug use and addiction has been dominated by quantitative research and, because of this, many would argue that it is on this knowledge that drug policies and practice is (and should be) based. While this approach has several strategic benefits, it also has two weaknesses. Firstly, it is self-contradictory—according to the advocates of evidence based drugs policy, policy should be based on independence and rationality, yet these are the characteristics that are said to be lacking in drug use and addiction. Secondly, it is epistemologically naive—it tends to take for granted that value-free, objective knowledge about the world can be produced. The quantitative approach to knowledge production assumes that social problems are constituted from concretely real damaging or threatening conditions. In this view, any condition that causes death or disease, shortens life expectancy or significantly reduces quality of life for many people should be defined as a "social problem" (Goode and Ben-Yahude 2009). An example of this is the disease model of addiction, which describes an addiction as a lifelong disease involving biological and environmental sources of origin. Within this model a genetic predisposition is believed to be present.

An alternative perspective to this is the social constructionist position, which argues that what makes a given condition a problem is the process of collective definition of that condition as a problem. Definitions of social problems emerge out of specific sociocultural conditions and structures, operate within particular historical eras, and are subject to the influence of particular individuals, social classes, and so on. Derrida (1993) has asserted:

> There are no drugs in 'nature' […]. As with addiction, the concept of drugs supposes an instituted and an institutional definition: a history is required, and a culture, conventions, evaluations, norms, an entire network of intertwining discourses, a rhetoric, whether explicit or elliptical […]. The concept of drugs is not a scientific concept, but is rather instituted on the basis of moral or political evaluations; it carries in itself both norm and prohibition, allowing no possibility of description of certification—it is a decree, a buzzword. Usually the decree is of a prohibitive nature. (p. 2)

Derrida is pointing to the intrinsically political nature of "drugs". He argues that the term does not refer simply or reliably to certain substances with clear-cut attributes or effects. Instead "drugs" is a political category that includes some substances and excludes others, depending on the politics of the day. For example, until very recently, tobacco was not commonly referred to as a drug.

12.4.3 Ideology Underlying Drug Use Related Interventions

One of the main preoccupations of qualitative research is with the question, "what really going on here?" What is really going on with this substance misuser, with this family affected by substance misuse, with this community where substance use and misuse is occurring? This initial question leads to further questions, for example, how do substance misusers and others in contact with them view their situation? By contrasting different viewpoints of the same situation the qualitative researcher demonstrates that there is not just one reality, one truth, but different and conflicting definitions of reality.

Following on from this, it becomes important to ask what people believe they are doing compared to what they are actually doing. This raises questions about ideologies. Beliefs may be ideological not because they are inherently untrue—often there is a strong element of truth in them—but because they are exaggerations of the truth, or they do not accord with the facts, or they are based principally on belief rather than careful observation and evidence, or they are used to justify the position of the powerful. One of the main tasks of the qualitative researcher is to criticise ideologies by demonstrating how they distort reality and how they serve the interests of the powerful. A good illustration of this kind of qualitative research is Bourgois and Schonberg's (2009) work with homeless injecting drug users.

Bourgois and Schonberg (2009) argue that epidemiologists identified injecting drug users as a potential threat in the spread of HIV in the 1980s. One response to this threat was the emergence of a worldwide health movement known as *harm reduction*, modelled on earlier hepatitis A prevention initiatives for heroin injectors in the Netherlands (Marlatt et al. 2012). The movement advocated non-judgmental engagement with active drug users and hoped to lower the cultural and institutional barriers to medical services. Harm reduction outreach initiatives such as needle exchanges were not based on an abstinence model; rather they were designed to be pragmatic and inclusive (Marlatt et al. 2012).

Despite the radical, user-friendly intentions of harm reduction activists, Bourgois and Schonberg (2009) point out that the movement operated within what they call the *logic of governmentality*. Drawing on Foucauldian theory, they assert that harm reduction functions within the limits of middle class public health discourse committed to educating "rational clients […] free to choose health" (Moore 2004 p. 1549). In short, according to Bourgois and Schonberg, harm reduction became the gentle strand in the disciplinary web that seeks to rehabilitate the poor. Knowledge may be empowering to the middle class, but prevention and outreach messages that target the decision making processes of drug users fail to address the constraints on choice that shape need, desire, and personal priorities among the poor and homeless.

To illustrate this point, Bourgois and Schonberg (2009) described how healthcare providers and outreach workers routinely advised the homeless injecting heroin users in their study never to use injection paraphernalia. Practice at the time of the study regarding injecting drug users in the USA was to provide individuals with bottles of bleach to clean their equipment. But, as Bourgois and Schonberg point out, it is impossible to rinse a used cotton (a filter for drugs like heroin) or cooker (a container used for mixing and heating a drug) with bleach if these are used to inject leftover residues of heroin. Furthermore, they suggest that hypersanitary messages ignore the moral economy on the street. From the perspective of the homeless injecting drug user, sharing injection paraphernalia actually promotes health rather than damaging it. Their top priority is to avoid withdrawal symptoms and that requires them to share publicly and frequently in order to build a generous reputation.

What Bourgois and Schonberg (2009) seek to show in their analysis is that the harm reduction movement's well-intentioned initiative is based on an ideology inadvertently created by a dynamic of unproductive self-blame, which contributed to conventional misrecognition of the relationship between power and individual self-control.

12.5 Kinds of Questions that Can Be Answered in the Addictions Field Through Qualitative and Mixed Methods Research in Contrast to Quantitative Methods

A research question is a statement of the specific query the researcher wants to answer, to address a research problem. They can be expressed in declarative forms, for example, "The purpose of this study is to target co-occurring problems of substance use and intimate partner violence (IPV) using a computer-based intervention, B-SAFER" (Choo 2012 p. 1), or interrogative forms, such as "Which individuals and groups have the most input in decisions about substance use prevention curricula?" (Rohrbach et al. 2005 p. 516). Research questions serve two purposes: (1) they determine where and what kind of research will be carried out, and (2) they identify the specific objectives the study will address. Quantitative, qualitative, and mixed methods research questions in the addictions field are discussed below.

12.5.1 Quantitative Research Questions in the Addictions Field

A quantitative study seeks to learn the what, where, or when, of the research topic. For example, Haddock et al. (2003) stated the following quantitative research question in relation to their RCT of cognitive behavioural therapy and motivational intervention for schizophrenia and substance misuse: "To investigate symptom, substance use, functioning and health economy outcomes for patients with schizophrenia and their carers 18 months after a cognitive-behavioural treatment (CBT) programme" (p. 418). Often quantitative researchers may not state the research question in this form, but instead present a statement of purpose and then one or more hypotheses, for example, "We tested the hypothesis that cigarette smoking would increase the risk for subsequent alcohol and drug use disorders by the young adult years and that the magnitude of this association will be stronger in youth with ADHD" (Biederman et al. 2012).

12.5.2 Qualitative Research Questions in the Addictions Field

In contrast, qualitative research questions need to articulate what a researcher wants to know about the intentions and perspectives of those involved in social interactions. Creswell (2007) noted another aspect of qualitative research that, "Our questions change during the process of research to reflect an increased understanding of the problem" (p. 43). Recent qualitative inquiry has moved toward involving the researcher and participants in the process of inquiry (Flick 2008; Griffiths et al. 1993). In the field of qualitative addiction research, Neale et al. (2007) conducted a study of injecting drug users (IDUs), and used the following qualitative research question: "To examine the nature and extent of barriers to effective treatment encountered by IDUs".

12.5.3 Mixed Methods Research Questions in the Addictions Field

A mixed methods study integrates both qualitative and quantitative studies, so the researcher must be directed at determining the why or how and the what, where, or when of the research topic. Redman (2010) conducted a mixed methods study of a community engagement orientation among people with a history of substance misuse and incarceration with the following research questions:

> The aim of this study was to identify contributors to a community engagement oriented purpose in life among people with a history of substance misuse and incarceration. The theme of community engagement was distilled from the qualitative data using an inductive process of constant comparisons […]. Themes were then aggregated for use in a series of quantitative analyses. Initially, bivariate analyses were conducted to explore the relationships of variables that previous research has associated with community engagement (e.g. demographics, substance use, treatment, socioeconomic status, education, self-esteem, previous civic involvement). (Redman 2010, pp. 249–250)

12.6 Research Designs, Protocols and Techniques that Can Produce Trustworthy and Rigorous Qualitative Research in the Addictions Field

During the 1980s and 1990s, there was increasing recognition within addictions research of the limitations of quantitative approaches (Rhodes and Moore 2001a, b). One consequence was the development of various forms of mixed methods research on addictions in which qualitative research was given increased prominence. These approaches emphasised cross-disciplinary research involving "cross-methodological and analytical dialogue" across research teams (Bourgois et al. 2006). Proceeding in this way, it was hoped that some of the limitations of quantitative and qualitative research could be minimised (e.g. the limited generalizability of qualitative research and the limited depth of quantitative research), and some of their strengths could be reinforced (e.g. the richness of qualitative data and the large samples of quantitative research). According to Rosenfield (1992), transdisciplinary research is the strongest form of cross-disciplinary research since it involves integrating two or more disciplines to produce novel, integrated hybrids of ideas, theories, and methods.

A recent example of the transdisciplinary approach to addiction research is the Addiction and Lifestyles in Contemporary Europe Reframing Addictions Project (ALICE RAP 2013http://www.alicerap.eu/). ALICE RAP aims to help policy makers "re-think and re-shape" current and future approaches to the human and economic costs of addictions and lifestyles in Europe. The initiative will investigate addiction in its broadest sense, including all types of substance problems and internet gaming and gambling. Over 100 scientists from 67 institutions in 25 countries are bringing together cross-disciplinary work into an integrated evidence base for informed policy action. The research programme includes a wide range of different quantitative and qualitative scientific disciplines.

Whilst the aims of cross-disciplinary research are laudable and its rationale is compelling, less attention has been paid to the politics of the approach and in particular how questions of theoretical and epistemological differences between disciplines might be managed and possibly reconciled. This issue has been encountered in earlier sections of the chapter. To achieve Fuqua el al.'s (2004) "[…] higher levels of convergent and discriminant validity […] through the triangulation of multiple methodologies" (p. 146) either the qualitative or quantitative researchers have to "suspend" some of their theoretical and epistemological commitments (Mckeganey 1995). Many qualitative researchers would argue that this usually means discarding their beliefs: such as there is no direct, unmediated access to the objective world; that qualitative data is created intersubjectively; and that there are multiple interpretations of data.

Differences in the epistemology of method discussed above can make truly cross-disciplinary research in the addictions field challenging (Moore 2002). But differences in approach are helpful too. There is increasing acceptance of post-positivism in quantitative research, as well as recognition of pragmatism in much applied qualitative research, and a growing respect for the need to reflect on how research questions and methods relate to epistemological assumptions. Collaborations between ethnography, epidemiology, and mathematical modelling provide examples in the addictions field (Agar 2003; Bourgois et al. 2006; Ciccarone and Bourgois 2003; Moore et al. 2009).

12.7 A Critical Evaluation of Current Qualitative Evidence for Addictions to Inform Best Clinical Practices

In recent years, health and social care organisations and agencies in the developed world have been exploring and adopting best practices (evidence based/informed practices) when delivering services. For example, in the USA, the Institute of Medicine issued the landmark report, *Bridging the Gap Between Research and Practice*: *Forging Partnerships with Community-Based Drug and Alcohol Treatment* (Institute of Medicine 1998). Several tasks were charged to this committee, including the identification of promising research strategies that would help lessen the disparity between research and practice within the field of substance abuse treatment. Among the committee's recommendations to improve implementation of research-based interventions in practice was the development of an infrastructure to facilitate research within a network of community-based treatment programmes and the suggestion for states and federal agencies to develop financial incentives to encourage the inclusion of evidence-based treatments (EBTs) in community-based programmes.

The National Institute on Drug Abuse (NIDA) responded to these needs in a number of ways. One method of promoting greater diffusion of EBTs was publishing treatment manuals for several different approaches including: cognitive behavioural treatment (Carroll 1998), the community reinforcement approach plus vouchers (Budney and Higgins 1998), and individual drug counselling (Mercer and Woody 1999). In 1999, NIDA established the Clinical Trials Network (CTN), which has produced several articles demonstrating the effectiveness of different substance misuse treatments in community-based treatment settings (e.g. Petry et al. 2005). In 2001, NIDA worked with the Substance Abuse and Mental Health Services Administration (SAMHSA) to create the NIDA/SAMHSA Blending Initiative. The general technology transfer strategy used as part of the Blending Initiative includes: identification of promising CTN and/or other NIDA-funded findings that address gaps in the treatment field and formation of blending teams (composed of representatives of the NIDA research and representatives from the ATTCs), which work closely together to develop training curricula, supervisory manuals, and strategic dissemination plans.

Over the past decade, a great deal of effort has been invested into ensuring that evidence-based practice (EBP) is being utilised in the treatment of addiction. But even with this concerted effort, the implementation of effective addictions treatment interventions into the “every day” clinical setting has been minimal (Amodeo et al. 2011; Bradley et al. 2004; National Institute on Drug Abuse 2004; Rawson 2006; Sloboda and Schildhaus 2002). It has been shown that evidence-based programmes and practices take time to develop and mature. Some researchers have suggested that implementation of even the most successful interventions rarely exceeds 1 % of the target populations (Ginexi and Hilton 2006). Others have found that it takes at least a year for a new programme to be imbedded into an organisation (Bradley et al. 2004; Orwin 2000). The Institute of Medicine estimated that it may require about 17 years for a new technology to make its way into widespread clinical use in medicine (Chaffin and Friedrich 2004). Although the Institute of Medicine was referring to the field of medicine, the timeframe estimated for a substance abuse treatment organisation to adopt a new programme or practice needs to go well beyond a few months of training that may often be considered sufficient by implementers to transfer a new intervention into practice (Amodeo et al. 2006).

Why are frontline workers in the field of addiction treatment so slow to implement evidence-based practice? Qualitative research on the topic provides some clues. In a recent study from the Center for Addictions Research and Services of the Boston University School of Social Work, Amodeo et al. (2011) carried out 172 qualitative interviews of frontline addiction workers from community-based organisations that had received funding from the Center for Substance Abuse Treatment (CSAT)/SAMHSA to implement EBPs. She focused on four common EBPs in the substance abuse treatment field. Two were individually oriented approaches: *Motivational Interviewing* (*MI*), a brief approach that targets and builds on client motivation to change; and *Cognitive-Behavioural Therapy* (*CBT*), a theoretical approach that uses a variety of present-focused techniques to identify and modify triggers for substance abuse, especially clients’ thought patterns, and to reinforce sobriety-related activities

The other interventions focused on the broader environmental level. These were: (1) *Adolescent Community Reinforcement Approach* (*A-CRA*), a behavioural approach that aims to replace reinforcers for substance abuse with environmental contingencies (particularly those applied by family members) that are supportive of recovery, (2) *Assertive Community Treatment* (*ACT*), a team treatment approach that delivers comprehensive, individually tailored case management services for clients who suffer both from severe mental illness, as well as substance-use disorders.

The authors of this study found that different barriers to implementation accompanied each type of EBP. Firstly, some evidence-based practices were perceived as burdensome in order to practice. Secondly, some practitioners complained of not receiving sufficient training in order to implement the model well. Thirdly, some practitioners felt there was a conflict between the approach of the EBP and their own philosophy, or the philosophy of the organisation they worked for. Thirdly, practitioners felt that the EBP was inflexible in meeting client needs. Fourthly, necessary resources were not always provided to implement the EBP.

This study identified specific, real-world barriers that have to do with the difficulty of implementing evidence-based practice in community-based agencies through qualitative research. Those responsible for promoting evidence-based/informed practice and for executing it need to be aware of barriers to implementation and find ways to dispel them. Qualitative research has an important role to play in this.

12.8 Direction and Recommendations for Future Research, Policy and Practice in Defined Evidence-Based Addictions Interventions

Qualitative research has added to our understanding of issues in the field of addictions, especially from the perspectives of users and our awareness of how wider social, historical, or economic forces shape the everyday realities lived by drug and alcohol users. It has made major contributions to the addictions field as regards research for, or in, drug consumption and distribution, and strategies and interventions to tackle drug and alcohol use and misuse. In contrast, quantitative research can provide data to describe the illicit drug market, but is less amenable to answer questions of "how" and "why", the raison d'etre of qualitative research. However, more important than this, qualitative research in addictions provides insight into the nature of evidence, knowledge production, and ideology in field.

Based on the discussions presented in this chapter, a number of recommendations for future research, policy and practice in defined evidence-based addictions interventions can be proposed. Firstly, if practitioners are expected to utilise evidence-based interventions, then it should be accepted that addiction journal publishing should not contribute to the marginalisation of qualitative research for, or on, addiction. Secondly, the qualitative researchers in the addictions cannot, and should not, have to suppress their attachment to theory, camouflage their epistemological stance, or diminish the intellectual content of their analyses. Thirdly, policy makers, researchers and practitioners in the addiction field should recognise the key role of qualitative research, through theoretically informed, systematic and grounded analyses, in exploring and demonstrating how particular knowledge production, practice, and subjectivity come to be taken as *real*. Fourthly, cross-disciplinary and transdisciplinary approaches to knowledge production aim to synthesise and integrate different disciplinary approaches leading to new methods or new concepts and ideas and attempt to go beyond the use of multiple approaches to transcend disciplinary boundaries in search of new knowledge. Nonetheless, the integrity of qualitative approaches is also important. Fifthly, evaluation of implementation of evidence based/informed interventions in addictions should include qualitative research and this research should be part of explicit strategies to address barriers to implementation.

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Qualitative Research in Mental Health and Mental Illness

13

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13.1 Introduction

Qualitative research has played a vital role in the mental health field. From its roots in descriptive case studies to current contributions in program evaluation, policy development, and social action, qualitative research has helped shape our understanding of and responses to mental health and mental illness. While quantitative research can be used explore the prevalence and frequency of illness across the population and the impact it can have on rates of social participation (such as employment and levels of education), qualitative research enables us to unpack the lived experience of mental health issues and mental illness from the perspective of those involved. Improved understanding, rich descriptions and critical appraisal of services and systems can contribute to theory development and begin to shift our focus to building a better and more just society. Thus, qualitative research represents an important topic when considering the advancement of evidence-based practice in the mental health field and our evolving knowledge and understanding of mental health and mental illness.

In this chapter we consider qualitative research as it relates to people living with mental illness and mental health issues. We write this chapter from our perspective as qualitative researchers and clinicians in the Ontario mental health field with experience conducting collaborative, community-based research, institutional ethnographies, and policy and program related research. We tend to focus our studies on social determinants of mental health such as employment, income, education, oppression and stigma, and how to create more just and inclusive social structures. Collectively, we are particularly interested in the lived experience of all those involved in the mental health sector—consumers of mental health services, Mad[1] people, service providers,

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[1] By Mad we are referring to a term now used by many individuals to self-identify their experiences with diagnosis, treatment and mental health services. As outlined in the new Canadian Mad Studies reader, Mad Matters (LeFrancois et al. 2013), Mad may refer to a movement, an identity, a stance, an act of resistance, a theoretical approach and a burgeoning field of study. There are many ways to take up a Mad analysis, and they may be informed

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and family members—as well as the impact that social and structural issues can have on people's lives and the services they might receive. We have considered mental health and mental illness in the context of the workplace and employment opportunities, social assistance and social policy, community participation, and the impact of oppression and stigma.

We begin this chapter with acknowledgement that people living with mental illness are among the most marginalized, stigmatized, and oppressed groups in society (Krupa 2008; Pescosolido et al. 2008). However, people living with mental illness form a diverse and heterogeneous population that has been defined in different ways, grounded in the lived experience of all those involved. Mental health and mental illness are largely invisible, but can have significant implications for individuals, families, and communities. The experience of mental illness can be acute, continuous or episodic, fluctuating between periods of health and illness over time in rather unpredictable ways. Often, the lived experience is less about the clinical manifestation of symptoms and disease associated with mental illness, and more about the social factors and responses that pose challenges to daily living and functioning in the community.

We also begin this chapter standing in particular theoretical places, for qualitative research always makes clear its philosophical position(s) at the outset. A far cry from the positivist stance that drives the quantitative quest for neutrality and truth so common in much research, our positions often demand instead that we embrace subjectivity, look for multiple "answers" and assume that there are many ways of knowing. They shape our questions, our research methods, as well as what constitutes evidence. Indeed, we cannot provide an overview of what we "know" about mental health in this chapter without making clear the various theoretical lenses that birthed that knowledge. To that end, we must make clear that those lenses are largely influenced by critical and social theories of disability (e.g., Abberley 2004; Beresford and Wallcraft 1997; Devlin and Pothier 2006; Rioux and Valentine 2006), critical social work approaches such as Anti-Oppressive Practice (Baines 2007), critical approaches to power (Bourdieu 1990; Foucault 1980; Giddens 1984; Oliver 2006) and social constructionism (Blumer 1986).

What all of these positions share is the tradition of critical theory, a lens that "assumes the play of power in society as opposed to claims to objective knowledge through 'scientific' approaches" (Lather 2004, p. 760). For more than 40 years, critical theorists have contested scientific approaches and paradigms that enshrine objectivity and prioritize "prediction, explanation and verification" over "description, interpretation and discovery" (Lather 2004, p. 760). The most recent of these approaches has been the evidence-based focus in health sciences, with its premise that "if healthcare professionals perform an action, there should be evidence that the action will produce the desired outcomes" (Holmes et al. 2006, p. 181). However, those working in the critical theoretical tradition and who are mindful of this play of power in health research ask, "what constitutes evidence?" and who has the power to decide "when or how one piece of evidence shall count […] while another is denigrated or excluded altogether?" (Holmes et al. 2006, p. 182). Similarly, they have long questioned notions of bias and quality (Moss et al. 2009). Indeed, most qualitative researchers working in this tradition believe "that knowledge is unavoidably shaped by the preconceptions of the knowers" (Moss et al. 2009). Because we cannot hold to the notion that objectivity is possible, rather we may judge quality based on: whether a study seeks to deconstruct the play of power that affects how health is known; whether a study promotes the multiplicity of what Foucault names as subjugated forms of knowledge (such as Mad knowledge for instance); how well a study promotes post colonialism and the privileging of local knowledge; how detailed is the description in an inquiry; how a study interrupts standard ideas of expertise; how it fosters democratic practices; and how well it demonstrates the reflective competence of the researcher (Moss et al. 2009).

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by multiple ideas from Anti-oppressive social work practice (AOP), Intersectionality, Queer Studies, and the Social model of disability for instance.

And so, it follows that from this deeply theoretical position, in this chapter we consider how quality qualitative research in the mental health sector has evolved over time, including promising directions for critical future work. We have chosen work that is always reflective, deeply descriptive and democratic, and seeks the insurrection of subjugated knowledge (Pease 2002). Our stance on qualitative research and what constitutes evidence has emerged from our local (Toronto, Hamilton, Northern Ontario) work and experiences, and our belief that qualitative research can be used to promote social action. Throughout this chapter we will provide examples that represent the range of studies that we have conducted and encountered in our work as mental health researchers and clinicians that contribute to the existing and emerging knowledge(s) in the field.

13.2 Qualitative Research in the Mental Health Sector: An Historical Perspective

Qualitative case studies, interviews, and observational studies form the foundation of many theoretical and practice approaches in mental health and psychiatry. For example, Freud's approach to psychoanalysis was grounded in qualitative case studies with his patients (Rothgeb 1971; Streiner 2008). In addition, Goffman's seminal studies of patients in psychiatric institutions formed the basis of our understanding of the medicalizing of mental illness (Goffman 1961) and stigma as a spoiled identity (Goffman 1963). These early contributions to the field highlight the prominent role that qualitative research has made to our evolving understanding of mental health and mental illness.

The rise of behaviorism in the twentieth century, however, prompted a focus on quantitative research (Peters 2010). In psychiatry, there was an effort to establish credibility through conducting research from a biomedical perspective, thereby focusing on experimental studies from a positivist perspective with large sample sizes, objective measures, and reliance on statistical approaches (Joseph et al. 2009; Streiner 2008). Indeed, most psychiatric journals stopped publishing case reports and there were few articles utilizing qualitative methods (Streiner 2008). The few that were published were primarily descriptive in nature and generally explored the treatment or the course of mental illness. The rationale for these studies was the scarcity of research and knowledge in the area, suggesting that qualitative research was limited to pilot or exploratory studies. There were, however, some dissenting voices, arguing for the importance of understanding the lived experience of mental illness and how this can inform research and practice (Lord et al. 1987; Strauss 1989).

A review of publication trends in general medicine and psychiatry from 1990 to 2000 by Crawford et al. (2003) highlighted the ongoing exclusion of qualitative studies from high impact journals such as the *British Journal of Psychiatry* and *Psychological Medicine*. According to this study, less than 3 % of articles published during this time period included any qualitative methods, with little fluctuation over time. A broader review of several medical and psychiatry databases between 1990 and 2007 found an increase in qualitative literature, particularly since 2000 (Schulze 2008). The review highlighted the fact that published qualitative research tended to focus on patients' and caregivers' experiences of mental health problems, and the lived experience of using and providing mental health services. Since the late 1990s, qualitative mental health research has explored the lived experience of people with mental illness (Church 1995, 1997; Church and Reville 2001; Johnson 1998; Pickens 1999), service providers and family members (Rose 1998; Sveinbjarnardottir and de Casterle 1997). More recently, rather than being limited to pilot or exploratory research, qualitative studies are used to develop an in-depth understanding of complex processes such as how people understand mental illness (Secker et al. 1999), and to develop theories of key concepts such as recovery (Young and Ensing 1999) and social participation among people living with mental illness (Alverson et al. 1995; Bassett et al. 1999; Dougherty et al. 1996; Kirsh 1996; Weiner 1999). Qualitative studies have also been used to highlight limitations in the structure and delivery of mental health services and supports (Rebeiro 1999).

13.3 Approaches to Qualitative Research in Mental Health

Qualitative research in the mental health sector draws on a range of methods and approaches. In our collective work, we have encountered approaches that have been used to make important contributions to the evidence-base and knowledge in the mental health sector or have the potential to do so. These approaches demonstrate how we have moved beyond descriptive case studies that were prominent within our history. They demonstrate how qualitative research is increasingly being used in sophisticated and analytical ways to advance knowledge and understanding of mental health, mental illness, and the related services and systems. While not exhaustive, these approaches provide a glimpse into the innovation of the field.

13.3.1 Phenomenology/Lived Experience

As illustrated throughout this chapter, phenomenology and documenting lived-experience through case studies, personal stories, and narratives is a prominent and influential qualitative approach in the mental health field. Such approaches dominated the early qualitative work in the field, and are still common practice. Zolnierek (2011) reviewed 35 phenomenological studies exploring the lived experiences of individuals with severe mental illness, highlighting key themes related to the experience of suffering, challenges in the mental health system, and desire for community integration. Other review studies have examined the experience of recovery from mental illness (Borg and Davidson 2008), and the process of returning to work following a mental health related sick leave (Noordik et al. 2011).

Deegan (2007) argued for the importance of phenomenological research in informing mental health practice, explaining that clients have expertise by virtue of the lived experience of their disorder and their intimate knowledge of what gives their life value, meaning, purpose and quality. Her qualitative research led to the concept of *personal medicine*, or non-pharmaceutical strategies that individuals use to build personal resilience and prevent relapse (Deegan 2005). Other authors have also noted that the voices and experiences of mental health consumers are often silenced; therefore, to effectively understand, study and treat mental illness, it is important to pay attention to the lived experience over time (Strauss 1989; Zolnierek 2011).

In the mental health field, a number of narrative research studies have been conducted, including studies examining the stories of individuals with psychosis (Gold 2007), those who have experienced trauma (Hall 2011), and older adults with substance abuse problems (Gardner and Poole 2009). Personal stories, whether told through the lens of phenomenology or narrative research, can play a critical role in understanding, communicating, and shaping the experience of mental illness and the process of recovery.

13.3.2 Institutional Ethnography

Institutional ethnography is a qualitative research approach that explores, from a critical social perspective, the social relations of power that shape the day-to-day practices of individuals in organizations (Smith 2006). Starting from individual day-to-day experiences, the critical social lens of institutional ethnography examines the institutional structures and policies that shape these experiences (Campbell and Gregor 2008). One of the key functions of an institutional ethnography study is to uncover power relations and inequities that serve to marginalize or disempower individuals. This function is particularly relevant in the study of individuals with mental health problems and organizations that provide treatment and supports to this population.

There is a growing body of research in the mental health field that incorporates institutional ethnography to advance our understanding of the ways in which institutions shape behavior. For example, a study by Townsend (1998) highlighted tensions in mental health program service delivery that are perpetuated by power structures and social policies both within and outside the organization. In particular, she described key disjunctures between strategies that empower clients to direct their recovery and caregiving processes that perpetuate dependence. Another study by Lane (2011) critically examined the process and system issues involved in the transition of older adults from hospital mental health units into nursing homes. Findings from this study highlight institutional and social forces that factor into difficulties for discharge planning and placement.

13.3.3 Arts-Informed Research

There are a plethora of arts-informed research methods that have been used in the mental health sector. One such broad area of arts-informed research is qualitative visual research which covers a range of methods and practices that involve the use of visual media and technologies at all stages of the research process (Pink 2006). This approach often involves the combination of visual, verbal, and written methods such as in-depth interviewing, field notes or participant observation (Pink 2006). Although relatively new to health research, visual research has had a place in social sciences since the 1920s, with separate branches developing in anthropology and sociology.

Some modalities of visual research include more participatory-based approaches, and some focus on *extraction* or using video to record a specific interaction so that it can be studied in more depth. Haw and Hadfield (2011) argue that video as extraction makes possible a more detailed examination than direct observation, as it allows for repeated showings that can be slowed down, combined with other data sources, and allows for multiple researchers to consider, critique and reflect on the same social interaction. As an example, Poole et al. (2011) created a qualitative video-as-extraction method which, when used with in-depth interviewing and field notes, has dramatically shifted how clinicians understand mental distress both before and after heart transplant. Indeed, this qualitative method has enabled the team to determine that over 88 % of patients experience mental health distress after transplant rather than the 30 % rate often argued in quantitative self-report studies (Abbey et al. 2011; Poole et al. 2011; Ross et al. 2010).

Photovoice is another promising arts-informed qualitative method that has been incorporated into various mental health advocacy initiatives. Photovoice is a grassroots approach to photography and social action, originally developed in 1992 by Caroline Wang who worked with women in rural China (Wang and Burris 1997). It is informed by documentary photography, feminist theory and critical consciousness theory, and involves a participatory process "by which people can identify, represent and enhance their community through a specific photographic technique" (Wang and Burris 1997, p. 369). Photovoice studies have been conducted with a range of populations around the world, including many populations with mental health issues, such as individuals who are homeless (Wang et al. 2000), at- risk youth (Young et al. 2013), new immigrants, and those in the early stages of dementia (Wiersma 2011). Unlike traditional research methods that often require people to be able read, write, or speak in settings that may be intimidating or that fail to accommodate the cognitive, emotional and social limitations that can accompany mental illness, using a camera can free people from the constraints of traditional modes of communication. For example, a study conducted with women who experienced trauma and abuse led to the creation of powerful photographs depicting their struggles and triumphs (Moll et al. 2006). The women decided to display their work in the lobby of city hall and their initiative led to engagement of local politicians in their call to action, and a feature newspaper story. Photovoice offers an innovative way to break the silence that often surrounds the experience of marginalization and mental illness (Foster-Fishman and Nowell 2005).

13.3.4 Discourse Analysis

Discourse analysts Phillips and Hardy (2002) describe a discourse as "an interrelated set of texts, and the practices of their production, dissemination and reception that brings an object into being" (p. 6). Generally, discourse analysis can be understood as an exploration of how that process takes place with a specific focus on language, knowledge and power. Whereas other qualitative methods, such as phenomenology might want to understand the lived experience of mental health, discourse analysis uncovers the ways in which that experience is constructed, by whom and for what purposes (Phillips and Hardy 2002). In a recent overview of discourse analytic psychological studies on mental distress, Georgaca (2013) argued that the main function of such studies has been to highlight how professional forms of knowledge and practice are always socially constructed, using discursive resources for particular and not always positive effects. Similarly, critical discourse analysis, informed by the theoretical ideas of Foucault, was adopted by Poole (2011) in her analysis of the discourse of mental health recovery in Ontario. She found that there was not just one discourse on recovery but five, all constructed and used for different ideological purposes. The varied discourses created confusion for users of mental health services, as well as differing and often negative social effects including cuts to service, exclusion of the most marginalized and cracks in the consumer/survivor movement(s). In short, discourse analytic studies demonstrate the power of words to do, to make, and to change mental health and its study.

13.3.5 Participatory Research

In line with the critical tradition that seeks to re-center subjugated or local knowledge creation, people with lived experience have increasingly been included in all phases of the research and programs of research, from guiding the research problems and questions to identifying the key informants. Furthermore, people with lived experience are sometimes employed as research staff in qualitative studies to contribute to data collection and data analysis. As an example, a qualitative study on housing among people with mental illness (Kirsh et al. 2011) employed two peer research assistants to conduct the interviews with residents. Although this can occur in other forms of research as well, employing interviewers with lived experience can be particularly advantageous because participants might be more comfortable sharing intimate details of their experiences if they are speaking to an interviewer with a shared history. Researchers with lived experience can often provide critical insight during the analysis that can help shape the findings in meaningful and important ways. For example, in a qualitative study by Rebeiro et al. (2001), the consumer researchers provided valuable and insightful input during the data analysis phase, yielding results that would not have otherwise been possible.

Community-based participatory research (CBPR) is an example of a participatory qualitative method that places the research lens at the local level (Twohig 2007) and integrates knowledge gained with interventions, policy and social change to improve the health and quality of life of community members (Israel et al. 2005). CBPR reflects a valuing of community-driven, interdependent collaboration and helps to ensure that the individuals, providers, and decision-makers involved in rehabilitation services are positioned to inform the process and products of the study. CBPR methodology is also well-suited to enlisting partners and facilitating collaboration, and is useful for the rapid translation and dissemination of the research findings into local practices. Furthermore, CBPR has proven to be a valuable in places challenged by geography, distance, weather, culture, and time, often prohibiting extended immersion in any given community (Rebeiro Gruhl et al. 2012b). For example, CBPR encouraged extensive personal and community investment in a qualitative case study on employment by Rebeiro Gruhl (2011) in northern

Ontario, and this investment is reflected by the community's ownership of the project and of their commitment to change. In fact, the community remained involved on an employment advisory committee for 2 years beyond the end of data collection, and wholly supported the recommendations for capacity building leading to changes in local and regional employment practices for persons with SMI.

13.4 Contributions of Qualitative Research to the Mental Health Field

Qualitative research offers theorists, researchers, clinicians, and decision-makers glimpses of mental health and illness that often defy measurement, and it underscores how illness is expressed within a range of social contexts. While seemingly categorical, mental health and illness are nonetheless idiosyncratic in how they are experienced and expressed—it is a human condition that demands understanding across and between its layers. Qualitative research can help to uncover these layers to improve our understandings. Using different types of data, approaches, methods and theoretical perspectives, qualitative researchers have highlighted, described, and theorized about key social processes, concepts and phenomenon within the mental health sector from different perspectives. In this section, we provide a scan of the existing literature to consider how evidence from qualitative research can contribute to clinical practice, theory, and policy development in the mental health sector. We provide a sampling of how qualitative studies have expanded our knowledge and insight, and contributed to innovation within the mental health field.

13.4.1 Consumer/Survivor Voice: Capturing the Lived Experience

Qualitative research can offer thick descriptions that can deepen our understanding of the lived experience of mental illness. This improved understanding is critical within the mental health sector as serious mental illnesses are largely invisible, highly stigmatized and often poorly understood. Thus, qualitative researchers have used personal narratives to document personal journeys over time, and help us better understand complex processes such as recovery, and as a tool for personal change and advocacy. For example, in a qualitative study exploring the experience of young men recovering from their first episode of psychosis conducted by Gould et al. (2005), participants shared their stories of illness and the role of meaningful occupation in their recovery. The collection of narratives described a common struggle of attempting to rebuild lives in spite of persistent perceived barriers. This research sheds light upon the personal losses and disruptions experienced with the onset of schizophrenia.

Qualitative research can also provide a platform for subjugated or marginalized groups to articulate their lived experience and influence policy and services. The personal stories and narratives used in various forms of qualitative research can be extremely powerful in promoting advocacy and change at the social level by engaging decision-makers in policy and practice around a problem and possible solutions (Davidson et al. 2008). Recent policy reports, including *Out of the Shadows at Last* by the Standing Senate Committee on Social Affairs, Science and Technology (2006) includes many narratives by people with lived experience, family members, and service providers as a means of highlighting the pressing need to take action. Similarly, Stapleton (2010) used personal stories of mental illness and addictions to highlight how government policies can inadvertently work against their own stated purpose. Such stories and narratives can be used to effectively engage and mobilize decision-makers towards needed social action.

In early qualitative studies, people with mental illness were primarily engaged as research participants. Through participants' first-hand accounts of their lived experiences, researchers were able to describe the experience of living with a mental illness from multiple perspectives and across multiple contexts, as well as evaluate the experience of receiving services and ongoing service needs. People living with mental illness benefited from increased understanding of their experiences and by having their stories valued as knowledge. However, they were not directing the research, the questions being asked, or the focus of the analysis and conclusions, and they were not being credited for their contributions to the research beyond the honorarium that they might have received. Of note, however, is the exceptional work of ethnographer Kathryn Church who, since the 1980s, has used a variety of qualitative methods to help people with lived experience, especially consumers/survivors and Mad people, reclaim and direct the research process. In her 1995 book, *Forbidden narratives*, she uses auto-ethnography to detail the historical exclusion of consumers/survivors from knowledge-making and their attempts to become part of mental health policy making at the provincial level in Ontario.

13.4.2 Building Theory

Another key function of qualitative research is building theory and theoretical understandings of concepts, phenomenon, and social processes. This function of qualitative research is particularly relevant in the mental health sector as it allows us to explore and explain key concepts and complex social processes such as stigma and recovery from a serious mental illness (Young and Ensing 1999). In the mental health sector, this process of theory building is particularly important given that the experience of living with mental illnesses has not been well expressed or understood through other research methods.

As an example, Canadian qualitative research has played a vital role in the development of the new field of Mad Studies (LeFrancois et al. 2013). In the tradition of critical theory outlined in our introduction, Mad Studies is an interdisciplinary field that seeks to interrupt dominant discourses around mental health and illness that add to the fear, exclusion, dismissal, pathologization, and oppression of Mad people. And the fears are many, especially for family members of those with mental health issues or professionals long steeped in more traditional approaches to treatment. However, as psychiatry itself now questions its "technological paradigm" (Bracken et al. 2012) and reliance on pathologization (Frances 2013), Mad Studies, informed by participatory, arts-based, narrative, ethnographic, and discourse analytic qualitative approaches, provides possibilities for researchers seeking to reconceptualize the "mad," reclaim their agency, and rework notions of support, well-being, and participation.

13.4.3 Program and Treatment Development

Qualitative research can also be used for program development. It has been argued that decisions about how to best design and deliver services should be guided by research that is sensitive to local context and incorporates the perspectives of providers and recipients of care (Goering et al. 2008). Qualitative methods, for example, can generate insights into cultural values and local learning needs, leading to construction of interventions that are individualized to the unique social context of individuals and communities. Engagement of key stakeholders, including potential service users throughout the process can not only help in program design, but can maximize the uptake of the program that is developed (Goering et al. 2008).

The early work of Lord et al. (1987) underscored the potential of qualitative research to build responsive community services. These researchers conducted a qualitative needs assessment, soliciting what people living with mental illness identified as their most pressing community needs. They learned that securing meaningful employment and developing friendships were the largest unmet needs of this population. Lord et al. summarized the importance of seeking input from people living with mental illness by stating, "in the current rush to improve mental health systems, we run the risk of ignoring the very people and methods which might begin to help frame our understanding" (p. 34).

13.4.4 Program Evaluation

Traditional approaches to evaluation in health and social services have been quantitative, with a focus on tracking efficiency and accountability (e.g., days in hospital, ER visits, number of visits or patient contacts). However, qualitative research is increasingly being used to flesh out the meaning behind the numbers. Instead of simply asking whether or not a program achieves specific outcomes, qualitative questions lead to a more nuanced understanding of how a program works, how it is perceived by service users, and ideas about how it could be improved. Goering et al. (2008), for example, conducted a qualitative study of a pediatric telepsychiatry service that involved engaging service providers and users in multiple remote communities. They were able to generate a richly textured description of the program and capture process and outcome data that helped to shape understanding of the barriers and facilitators to implementation within the social context of each community. They argued that the setting and environmental influences (history, geography, politics, social and economic conditions, and efforts of competing organizations) are often ignored when studying programs, and that these influences are critically important in interpreting evaluation findings and assessing their generalizability. The knowledge and insight gained through qualitative research can enable the development of services that respond to the needs and priorities of those who use and provide mental health services, and build increased accountability within the mental health system.

13.4.5 Mental Health Policy

Qualitative methods can also be used to explore the impact of social structures and policies on the experience of people accessing services and supports. Whereas quantitative methods can be used to highlight outcomes of various policies and service systems, qualitative studies can be used to unravel the underlining values and assumptions that guide the construction of policies, highlight the pathways that lead to specific outcomes and how people experience services and supports regardless of the outcomes. This type of understanding can shed light on specific areas for development and how particular social problems are understood.

Qualitative methods have been critical to positioning recovery as an organizing framework in mental health policy (Davidson et al. 2008). For instance, a community-based participatory research project (Mental health recovery workgroup 2009) brought together both scholars and consumer survivors to explore how recovery policies in Toronto were impacting support and services. One of the first studies of Canadian recovery policy, it highlighted how little impact recovery's promise had changed what was available to people with lived experience. Similarly, a participatory qualitative research team, co-led by recovery researcher Nora Jacobson and community mental health worker Deqa Farah (Jacobson et al. 2010) made clear how many recovery policies and concepts were inherently racist and classist, excluding many racialized people living in poverty and not able to "afford" to hope or pay for key recovery supports.

Qualitative case study methods have also been used to explore how values and assumptions impact policy and the available services and supports. Rebeiro Gruhl et al. (2012a), for example, explored access to mainstream, competitive employment for people with serious mental illness in northeastern Ontario. These researchers learned that the prevailing, dominant discourse in both the mental health and the vocational services sectors was that people living with mental illness are largely incapable of competitive employment and more so suited to volunteer or sheltered work. While studies in northeastern Ontario were identifying promising employment rates based in the data collected by local community support teams for people living with serious mental illnesses, qualitative exploration revealed that competitive employment was being aggregated along with volunteer and sheltered work (Lurie et al. 2007). As a result, few resources were being allotted to support employment among this population despite its prominence with the existing funding models.

13.5 Synthesis of Evidence from Qualitative Research Related to Mental Health and Mental Illness

Our scan of qualitative research pertaining to mental health and mental illness began from our stance on qualitative research and evidence, drawing first on research that we have encountered in our collective work. We searched for studies that would represent the range of existing research and evidence, as well as emerging areas that hold promise for the future. We sought influential papers published since 2000, as well as the work from key qualitative researchers within the mental health field. We also searched the electronic databases CINAHL (Cumulative Index to Nursing & Allied Health) and PsycInfo using keywords such "mental disorder" and "qualitative study" combined with key areas of focus including "stigma," "recovery," "housing," and "employment." From these searches we identified additional papers published since 2000 that used qualitative methods to explore and examine mental health or mental illness, or supports directed at this population. In this section we present an overview of the range of studies using qualitative methods that have been conducted and offer a synthesis of the evidence derived from this body of work.

13.5.1 Recovery

Recovery is a key concept within the mental health field that has been informed by many qualitative studies that have explored the lived experiences of consumer/survivors of mental illness (Deegan 1988). In fact, our scan of published qualitative research in the mental health sector suggests that the concept of recovery is featured prominently in many of the studies, and that qualitative methods have been used to explore the meaning of recovery, the process of recovery, and recovery-oriented indicators or outcomes. These studies have provided a more complete understanding of recovery as both an individual journey and a framework to guide policy and practice in the mental health sector.

Qualitative studies have examined first person recovery narratives to examine the experience of recovery, the process of recovery, and common dimensions of recovery. For example, Jacobson (2001) drew on 30 personal narratives by individuals who identify themselves as recovering or in recovery from the experience of living with a mental illness. This research aimed to provide an understanding of the uniqueness of the recovery process and the common dimensions that cut across individual experiences. Also drawing on first person narratives and how individuals formulate and reformulate their life story, Ridgway (2001) explored common patterns in order to develop a more complete conceptual understanding of recovery to inform theory, policy, and practice. The findings highlight that recovery is an active and ongoing process of overcoming obstacles such as stigma and discrimination, developing a renewed sense of self, participation in valued activities and important human relationships, feeling hope, and a sense of personal meaning and purpose. Borg and Davidson (2008) drew used narrative phenomenology methods to identify recovery in everyday life experiences of people with mental illness. These findings suggest that we need to examine social policies and practices that reward permanent disability status and provide disincentives for engagement in meaningful activities such as employment.

Other qualitative studies have expanded our understanding of key components of the recovery process. The importance of developing a positive and empowered sense of self, hope and optimism have consistently emerged from qualitative studies with individuals who have experienced mental health problems (Borg and Davidson 2008; Cohen 2005; Davidson and Strauss 1992; Kartalova-O'Doherty et al. 2012; Moran et al. 2012; Ochocka et al. 2005; Perry et al. 2007). Mancini (2007) used qualitative methods to document turning points in the recovery process identified by people with mental illness who were also service providers. These turning points were events that were critical in their recoveries and included resisting coercive environments, accepting help and social support, and becoming involved in activism. Similarly, in a qualitative study using hermeneutic phenomenology to analyze recovery narratives, Sutton et al. (2012) identified a range of experiences from complete disengagement to full engagement in meaningful occupations. These researchers also identified turning points where they found hope, "that there was something about the everyday world that was worth living for" (p. 145). These findings suggest that recovery-oriented mental health services should provide opportunities for people to find their place and way of being.

The emergence of a recovery-oriented system of supports and services has been a priority within the mental health field. Qualitative methods have been used to examine this process of reform and consider challenges to implementing recovery in practice. For example, Poole (2011) and Morrow (2013) identified the emergence of the new field/concept of critical recovery in Canada. Driven by participatory action methods and the qualitative methodology known as *World Café*, Morrow's research team found that locally, people were most concerned with the language of recovery, a social justice approach to mental health, social policy and the role of peer workers in recovery (Morrow 2013). Piat and Lal (2012) conducted focus groups with mental health service providers to explore their experiences with and perspectives on recovery-oriented reform. These researchers identified positive attitudes towards recovery-oriented reform, skepticism, and challenges with implementing recovery-oriented practices, due in part to limited leadership, training, and support.

13.5.2 Stigma

Stigma is another key concept in the mental health literature, with theoretical ideas evolving over time. Qualitative research has played a central role in informing the process of comparing, elaborating, refining and verifying emerging theoretical propositions related to stigma and discrimination. The early seminal work by Goffman (1963) on the development of a stigmatized identity was based in part on his observations and reflections on the experience of individuals with a mental illness in mental institutions. Subsequently, other sociological researchers developed labeling theory to explain the process of stigmatization (Link and Phelan 2001). Krupa et al. (2005) suggest that public stigma associated with mental illness includes beliefs about dangerousness and incompetence, which give rise to and perpetuate discrimination.

Findings from qualitative research have informed our growing understanding of different types and dimensions of stigma. Prevalent in the qualitative stigma literature are themes pertaining to the loss of identity, a sense of social exclusion, and strategies for moving forward. For example, Schulze and Angermeyer (2003) conducted focus groups with people living with schizophrenia, their relatives, and service providers. The findings revealed four dimensions of stigma: interpersonal interaction; structural discrimination; public images of mental illness; and access to social roles. These findings show that stigma extends beyond direct social interaction and can negatively affect their life chances and quality of life through structural imbalances as well as negative stereotypes and attitudes. Similar findings were reported by Knight et al. (2003) who used an interpretative phenomenological analysis to uncover both public and self-stigma within the personal reports of events and situations by people with schizophrenia. Forrester-Jones and Barnes (2008) reported on the findings from a qualitative study of the impact of social support in helping people with mental illness develop an identity behind their illness, which enabled more social integration. Furthermore Michalak et al. (2011) considered the impact of internalized stigma on the experiences of people with bipolar disorder who are managing well. The findings suggest that stigma affects individuals' own expectations and self-identity, and describes efforts to move beyond it. Accordingly, self-stigma adds a layer of complexity to self-management strategies.

Qualitative studies have also explored the effects of stigma in specific social settings, revealing the contextual nature of stigma towards people with mental illness. Employment is a particularly important setting to explore the effects of stigma because stigma can act as a barrier to employment, while simultaneously counteracting the effects of stigma by creating opportunities for employers and coworkers to experience people with mental illness as valuable employees (Krupa et al. 2005). For example, Krupa et al. (2009) identified over 500 Canadian documents and conducted in-depth interviews with 19 key informants about work integration among people living with mental illness. A grounded theory analysis informed construction of a guiding framework for intervention to address stigma in the context of employment.

Related to stigma, qualitative research has been used to explore decisions around disclosure. The findings from this work highlights that people with mental illness and their family members often engage in "selective disclosure" (Karnieli-Miller et al. 2013) or "judicious disclosure" (Michalak et al. 2011) by determining what, when, how much and who to share information with about their illness in different settings. Moll et al. (2013) examined organizational policies and practices that perpetuate stigma, silence and lack of support for healthcare workers who are struggling with mental health issues. By mapping the social relations of silence, and the paradoxical consequences of silence for employees and employers, recommendations could then be made regarding disclosure and workplace supports. Drawing on qualitative data, Dalgin and Gilbride (2003) explored disclosure in the context of employment and found that securing an employment position that was well-suited to their strengths and limitations removed the need for disclosure since there was no need for accommodation.

13.5.3 Employment

Findings from qualitative research are quite prominent in the literature on employment among people with mental illness. Employment has been positioned as key indicator of recovery and a priority among people living with mental illness and services for this population (Krupa et al. 2005). Qualitative methods have been used to explore the benefits of employment (Auerbach and Richardson 2005; Kennedy-Jones et al. 2005; Kirsh 2000; Krupa 2004; Shankar 2005) and barriers to employment and the employment support process (Cunningham et al. 2000; Gewurtz et al. 2006, 2012; Henry and Lucca 2004; Honey 2004; Killeen and O'Day 2004), thereby positioning employment as a key issue for mental health services.

Several qualitative studies have focused on the perspectives of people with lived experience. For example, Fossey and Harvey (2010) conducted a meta-synthesis of the employment-related views of people with persistent mental illness, drawing on 20 qualitative studies published between 1998 and 2008. They identified four themes: (1) employment has varied meanings, benefits and drawbacks to weigh up; (2) strategies for maintaining employment and mental health are important and require ongoing, active self-management; (3) diverse supports within and beyond the workplace are helpful; and (4) systemic issues add to the employment barriers. The authors identify strategies for employment services and supports based on these themes and highlight the important contribution that qualitative research can make in developing evidence-based and recovery-oriented employment services for people with mental illness.

Recent qualitative work has also begun to consider different perspectives, beliefs, and assumptions that guide employment efforts in the mental health sector. Kirsh et al. (2010) drew on the methodological principles of constructivist grounded theory (Charmaz 2006) to analyze Canadian documents and data collected from interviews with key informants across Canada. They identified five central perspectives around which the field of work integration for people with mental illness operates in Canada: (1) a competency perspective; (2) a citizenship perspective; (3) a workplace health perspective; (4) a perspective focusing on potential, growth and self-construction; and (5) a community economic development perspective. Understanding these different perspectives on employment among people with mental illness shed light on the emergence of various approaches to address employment within policy and practice. A study by Bertilsson et al. (2013) used qualitative methods to explore the experiences of work capacity among people with mental illness who worked while depressed and anxious. The findings move beyond the standard juridical and medico-administrative perspective to consider the essence of work capacity. The findings highlight the challenges facing individuals with mental illness who either remain in the workplace or are reentering the workplace following a leave for mental health problems.

13.5.3.1 Housing

Housing also represents an important area of focus within the mental health sector. Qualitative research has helped us better understand preferences and approaches to housing support for people with mental illness. In terms of preferences, findings from qualitative studies have highlighted issues related to safety and privacy. As an example, Whitley et al. (2008) conducted a qualitative study to examine the lived experience of residents with mental illness in a small-scale recovery-housing building in an inner city. The findings highlight the ongoing need to address safety and security, and the tension between desires for social connection and privacy.

Expanding these findings, other qualitative studies have positioned housing as a foundation for recovery and a key component of recovery-oriented services. For example, Kirsh et al. (2011) used qualitative methods to interview residents and their service providers to identify characteristics of supported housing for people with mental illness that were associated with valued outcomes. The findings position supported housing as a foundation for recovery and highlights the need for flexibility and choice, safe and accessible neighborhoods, a good fit between individuals and their neighborhoods, access to needed supports and a supportive relationship between residents and their service providers. Similarly, Nelson et al. (2005) also positioned housing as a foundation to recovery and highlighted how it can lead to positive identities, new relationships, and reclaimed resources for living with dignity and meaning, thus suggesting effective housing interventions can have many critical positive outcomes for this population. Similar findings were reported in the evaluation of the pan-Canadian demonstration project, At Home/Chez Soi (Polvere et al. 2013). Drawing on participant narratives to better understand how receiving housing prior to treatment affects engagement and recovery among previously homeless individuals with mental illness, the researchers found that the provision of permanent housing is a foundation for long-term recovery. However, for some, private housing can result in isolation and other adjustment concerns related to ongoing struggles with addictions.

13.6 Challenges to Qualitative Mental Health Research

In this chapter we highlight the many approaches and contributions that qualitative research has made to the study of mental health and mental illness. However, this work has not been without its challenges. Moving forward, we must be aware of these challenges and consider how to best utilize qualitative research to advance knowledge and understanding in the field, in order to contribute effectively to evidence-based practice and decision-making. Here, we briefly highlight some of the most prominent threats and challenges that we have encountered in our work.

13.6.1 Ethics

As with all types of research, qualitative research in the mental health sector presents unique ethical considerations. Although the procedures used in qualitative research do not generally put participants at risk (Baarnhielm and Ekblad 2002), they can raise important ethical problems that require thoughtful consideration, particularly in data collection and presentation of the findings.

In-depth exploration of the lived experience of participants may lead to sharing of very difficult, traumatic stories. In general, the experience of sharing stories may be empowering, however, narrative research conducted with survivors of trauma holds the potential for harm since it involves reactivating the traumatic event, and may prompt individuals to relive the traumatic experience (De Haene et al. 2010). Researchers need to be very skilled in containing the coexisting aspects of both harm and benefit, and carefully balance movement between reiterating and transforming traumatic distress (De Haene et al. 2010). In addition, the confidentiality and anonymity of the participants needs to be respected in all qualitative research, particularly for individuals with mental health problems who are often marginalized, stigmatized, and oppressed.

Institutional research poses additional challenges, particularly if the researcher learns about practices that are illicit, harmful, illegal, or otherwise out of line with one's own values (Moll 2012). A researcher could obtain privileged information in an interview that could be damaging if made public. Moll (2012) discusses the moral dilemmas associated with deciding to expose unethical practices versus one's ethical responsibility to maintain confidentiality and anonymity. In her study exploring how workers with mental health are treated in the workplace, she learned that the stigma and practices of silence in the organization were clearly oppressive at times and out of line with the public mandate of the organization. It was challenging to present the politically sensitive findings to the organization in a way that would lead to positive change and honor the voice of participants who had the courage to share their stories. Research that exposes social structures of oppression must be carefully positioned such that injustices and inequities are presented in a way that does not cause further marginalization of vulnerable individuals.

13.6.2 Backlash Against Personal Stories and Oppressive Methodologies

Although capturing the lived experiences and stories of participants is central to many qualitative approaches used in the mental health sector, there has been some resistance. This resistance has highlighted the importance of considering the ethical implications of using personal stories or narratives within research. For example, the Recovering our Stories campaign in Ontario has been seeking to problematize the practice of using personal stories of "recovery" to promote particular mental health programs, services, or organizations. As outlined on their website,

> Using and sharing personal stories has always been central and important in the history of organizing for change. Psychiatric survivors, consumers, service users get asked to share their story ALOT. But, have you noticed that there is increasing appropriation and commodification of consumers/psychiatric survivors' stories into public displays; a type of "patient porn" where audiences endlessly stare, observe and consume personal and often vulnerable accounts. (www.recoveringourstories.ca)

In response, Costa et al. (2012) describe how the sharing of experiences through stories by individuals who self-identify as having "lived experience" has been central to the history of organizing for change in and outside of the psychiatric system. However, in the last decade, personal stories have increasingly been used to bolster research, education, and fundraising interests. Their work explores how personal stories from consumers/survivors have been harnessed by mental health organizations to further their interests and in so doing have shifted these narrations from "agents of change" towards one of "disability tourism" or "patient porn." They mark the ethical dilemmas of narrative cooptation and consumption, and query how stories of resistance can be reclaimed not as personal recovery narratives but rather as a tool for sociopolitical change.

In qualitative research circles, there is also a growing concern with *sanism* or how particular forms of inquiry and knowledge continue to contribute to the oppression experienced by people with lived experience. Taken up by some of the qualitative scholars who contribute to Mad Studies but who may also take up multiple subject positions including family member (Fabris 2011; Poole et al. 2012), sanism may happen even with the best of intentions or in the most progressive research spaces. Coined more than 30 years ago (Perlin 1992; Chamberlin 1990, 2005), sanist "aggressions" may include low expectations of participants/researchers with lived experience or judgements that such individuals are "constantly in need of supervision and assistance" (Chamberlin 1990, p. 2). Sanism may be the reason for the exclusion of Mad studies in mental health knowledge or the questioning of research carried out by Mad people. However, as sanism also shares its roots with the privileging of objectivity and reason so paramount to the "scientific" and evidence-based traditions, it often masks itself as a neutral discussion of rigor, bias and the ethics of "allowing" mad people to do research with their peers. On sanism, Poole et al. (2012) used community based participatory research to explore sanism's presence and effects in university education, pointing to ongoing rights abuses both in and out of the research classroom for students with mental health issues. Poole and Ward (2013) have also taken up sanism and loss, exploring the explosion of grief "disorders" in the new *DSM V* and what this means for notions and practices of expressing heartbreak.

13.6.3 Availability of Research Funding and Publication Challenges

One of the ongoing challenges to research and evidence-based practice within all areas of health remains the scarcity of funding. Funding is often particularly challenged for research related to stigmatized conditions such as mental illness. The often lower status of qualitative research further compromises the capacity of researchers to secure funding for high quality, large-scale qualitative projects that could significantly contribute to our knowledge base. Historically, prestigious funders have relied on reviewers with little experience or understanding of qualitative research (Cheek 2011; Morse 2003). When evaluated using the rubric for quantitative projects, qualitative research tends to be ranked poorly due to issues related to small sample size, and concerns around reliability and validity.

Related to concerns about funding are concerns about the publication of qualitative studies. As noted at the outset of this chapter, there have historically been biases in high impact, prestigious medical and psychiatric journals against qualitative studies. Even today, qualitative researchers often face challenges getting their articles published in journals. At times, reviewers have little understanding of, or appreciation for, qualitative methods and evaluate the studies based on standards that are more relevant for quantitative studies. However, even more fundamental are the author guidelines which often have strict length restrictions that might limit the amount of critical information that qualitative researchers can provide about their methods and the raw data they can provide to support their findings. These challenges can limit the proliferation and dissemination of important findings from qualitative studies.

One strategy to address these challenges might be to propose mixed methods studies that expand and enhance the contributions and significance of both quantitative and qualitative analyses. Over time, many funders have come to expect mixed methods approaches in large-scale projects in order to cover the spectrum of knowledge required to understand concepts and experiences in mental health and psychiatry (Streiner 2008). Such an approach requires collaboration, shared understanding, and appreciation between researchers who might hold different values and worldviews. However, it could lead to enhanced scholarship and progress in the field. According to Davidson et al. (2008):

> As qualitative methods become integrated more and more readily into mixed-method designs, we will no longer ask: Why do qualitative research? Instead, we will begin to consider when to use qualitative methods, to answer which questions, and with what anticipated results. (p. 143)

Mixed methods are considered to be useful in research in a variety of ways. First, they are useful if they can help answer a research question that a single method cannot. Second, mixed methods can provide stronger inferences due to their complementarity function. And third, mixed methods studies provide the opportunity for presenting a greater diversity of divergent viewpoints (Sandelowski 2000; Tashakkori and Teddlie 2003). According to Morse (2009), the limits of data collection and analysis point to the first purpose of using mixed methods—the identification of gaps or holes that may be corrected by adding other data collection and analytic strategies. Mixed methods may therefore be particularly useful in the field of mental health and illness, given its idiosyncratic presentation and expression.

13.7 Conclusion

Throughout this chapter we have highlighted how qualitative research has influenced evidence-based practice and knowledge development in the mental health sector. From its beginnings in descriptive case studies, to arts-informed methods, and current efforts to push social action and change, qualitative research has had an important influence on the field. One of the most central and basic contributions has been the capacity to feature and profile the lived-experience of mental health, mental illness, and of receiving and delivering services. Through first-hand, contextually grounded accounts, qualitative research has provided a much-needed window into the experience of living with a mental illness and the journey of recovery. This understanding has influenced policy, practice and ongoing research in the field by highlighting critical gaps in our knowledge, not only what works, but how it works, why, and under which circumstances.

Promising developments in the field suggest that qualitative research will continue to be influential, and provide innovative ways for individuals and groups to express and represent their experiences. Such work can continue to push the envelope for much needed social action and change that will contribute to the emergence of a more inclusive and just society, where the focus of services is on supporting individuals as they move forward with their lives, beyond the treatment of symptoms. Furthermore, such innovative research approaches can give a voice to individuals who have traditionally been excluded from research, and can provide for the expression of difficult experiences which are all too common among people with lived-experience of mental illness and mental health problems.

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Qualitative Evidence in Occupational Health

14

Ellen MacEachen and Agnieszka Kosny

14.1 Introduction

Occupational health is a field dominated by epidemiology and clinical studies and there is a relatively sparse qualitative research evidence base. What qualitative research does exist in this field regularly reveals the contested and political terrain of occupational health, where the interests of workers' compensation insurers, employers, health care providers and workers can diverge, each informed by different social, political, and economic systems. Within the field of occupational health, money is at stake. An employer seeks productive workers and workers' compensation insurers cannot offer unlimited access to income support and health benefits. Meanwhile workers seek to avoid injury and can become mired in complex return-to-work (RTW) processes. In many jurisdictions, workers have gained the right to know about the hazards in their workplaces and have a right to refuse unsafe work. However, these rights are infused within broader work social environments, where unequal employer–worker power relations are strongly apparent in growing forms of contingent employment and can diminish workers' agency.

Since the 1990s, workers' compensation insurers across jurisdictions have worked toward a system of early return to work which reduces workers' time on income replacement benefits and places them back in the workplace before they are fully recovered (Frank and Maetzel 2000; Kralj 2000; Purse 2005). This system has led to contestations about employer provision of a safe work environment, worker entitlement to benefits, and the role of health care providers in compensation processes. The qualitative research in injury and illness prevention and subsequent disability management reveals the situated nature of occupational health social relations. This research, which focuses on examining and understanding behavior in social, legal, economic, political, and other contexts, can identify important areas for change and intervention. This chapter provides an overview of qualitative research evidence on key occupational health and safety (OHS) topics that have been taken up by qualitative researchers. Qualitative evidence is based on particular assumptions about the nature of social reality and how it can be known or accessed (Morse 2006). Social reality is understood as context dependent, and actions and behavior are seen as guided by individual and collective interpretations about the meaning of events. In turn, these actions and behavior shape social reality. Contexts that inform

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and guide behavior are varied, and can include institutional norms, cultural trends, economic environments, and political conditions (Pawson 2013; Ritchie and Lewis 2003). For instance, the occupational health laws and policies of a jurisdiction, together with media exposure about active enforcement of those laws, might inform the behavior of workers in relation to accepting occupational risks and reporting hazards. These behaviors, in turn, shape statistics about accident rates, which then condition law reform activities and budgetary allocations for injury prevention. Methods such as naturalistic observation and interpretive inquiry are ideal for providing access to context-dependent social reality. They provide the qualitative researcher with insight into the life world of individuals and groups (such as how and why choices are made) and can display the logic of how processes play out in institutions (such as differences between policy and practice).

Qualitative evidence is gathered by means of systematic empirical research methods ranging from interviews to participant observation to document analysis and that include a form of qualitative analysis such as content analysis, thematic mapping, grounded theory, or ethnography. The search strategy for articles included in this chapter was purposive. That is, the articles were selected iteratively, based on research insights and the expert knowledge of the authors about qualitative research that has been influential in the occupational health research field (Cook 2008). The literature search included Medline, Scholars Portal journals, ProQuest, Scopus, and JSTOR. Searches focused on terms relating to occupational health and safety, return to work, vulnerable workers, and qualitative methods (see Table 14.1).

The studies are published in articles in English language peer-reviewed journals and derive mostly from Canada, the USA, Scandinavia, Australia, and New Zealand. Scandinavian and New Zealand jurisdictions do not distinguish between injuries as work-related or otherwise, and so contestations about injury cause are not a focus for these researchers. This is not the case in North America and Australia, where workers and employers can become embroiled in disputes about whether the worker is entitled to workers' compensation benefits (which provide income support while disabled) or only general health care provided by the state. These are important structural contexts for interpretation of the behavior of various actors.

This chapter is organized in two main sections. We first describe studies of work risk and injury understandings and approaches. How do key players understand work injury risk and what role do they play in accident prevention? How does discourse define risk and consent? We then review research on the return-to-work processes, which come into play once a worker is injured. In most jurisdictions, workers may seek income support benefits and this brings to the forefront a number of actors and processes, each with differing interests and mandates. We devote a special section to problems with this process. Throughout, we distinguish between studies that address state policies and processes, workplace level understandings and activity, and worker level understandings. We also include theoretical contributions to occupational health research that use the broader lens of gender and immigration. What special issues arise when procedures are developed for a certain standard that leads to overlooking of nondominant groups? At the end of this chapter we review the state of qualitative evidence about occupational health and safety, provide suggestions for promising areas of

Table 14.1 Terms searched—combinations and variations

Occupational health and safety	Return to work	Gender	Qualitative
Work risk	Work reintegration	Immigrant	Interviews
Safety inspectors	Modified work	Injured workers	Focus groups
Small business	Occupational health care	Coworkers	Participant observation
Occupational health and safety management systems	Workers' compensation	Vulnerable workers	Document analysis
Non standard work	Health insurance	Occupational rehabilitation	Disability

investigation, and discuss implications for policy and practice.

14.2 Work Risk and Injury Understandings and Approaches

In this section, we provide a picture of qualitative studies of workplace injury and risk understandings and management across three main domains. We discuss studies that focus on the macro regulatory environment. These include enforcement activities by state actors such as inspectors and the set up of laws and policies. We then move to the bulk of research in this area, which considers health and safety at the workplace level and includes worker and management practices. Finally, we consider research at the phenomenological level, which includes workers' understandings of occupational health risk in relation to their sense of vocation.

14.2.1 Macro Regulatory Environment

Qualitative research on macro regulatory processes is scant. An interesting body of qualitative evidence emerging from a mixed-method study in Australia involves interviews with health and safety inspectors about how inspectors understood and addressed safety risks in "nonstandard" work situations such as temporary agency work, home-based work and subcontracting (Quinlan et al. 2009). The study identified challenges with risk-shifting by employers, such as outsourcing leading to deterioration of OHS standards. For instance, a move to tree fellers and logging truck drivers being paid as subcontractors on a piece-rate basis provided workers with economic incentives to cut corners and take safety risks. Further, complex employment situations found with use of temporary agency workers created situations of multiple employer parties responsible for various legal obligations which created difficulties for inspectors in launching prosecutions against employers. Further findings from this study (Johnstone et al. 2011) address the challenge of incorporating psychosocial hazard risk identification into inspectorate activity. Inspectors described difficulty acting on this area because of limited training, deficiencies of regulation and also fears of victimization among workers. This raises questions about how inspectors can deal with complex linkages between psychosocial hazards and industrial relations.

The role of the macro regulatory environment in addressing occupational health risk was addressed in a systematic review of qualitative studies of work and health in small businesses (MacEachen et al. 2010b), which drew attention to the ways that work and health responsibilities in small businesses could be obscured by complex subcontracting chains with multifaceted legal arrangements. A further challenge is that small businesses can lack the knowledge and infrastructure to address workplace risks. The review of qualitative studies raised questions about current regulatory approaches to small businesses across jurisdictions which, instead of actively creating policy OHS for small businesses, tend to simply exempt them from certain standard safety obligations.

Passive management of occupational health was also indentified as problematic in a qualitative study of Ontario not-for-profit agencies that provided care to disadvantaged populations. The study contemplated that not-for-profit employees may lack access to workers' compensation coverage in part because dominant understandings of risky work overlook the ways that empathy and caring work are difficult and demanding forms of labor (Kosny 2009). Indeed, other qualitative researchers have elaborated ways that occupational health regulations are andocentric. That is, because occupational health concepts have been derived from examinations of men's jobs, hazards of women's work have been overlooked in research (Messing 1994; Messing et al. 1993).

A recent qualitative study of how temporary work agencies in Ontario manage occupational health and safety also identified state policy structures that do not adequately protect workers from workplace risks. The study found that the structure of workers' compensation premium rates created a market for employers to outsource their riskier work to temporary agencies (MacEachen et al. 2012b). In turn, these financial rates advantaged temporary work agencies, making agency labor less expensive than "regular" labor in certain types of workplaces, such as warehouses and roofing. The study also identified how, despite the very high accident rate amongst agency workers, temporary work agencies were the only business sector in Ontario not held to account in practice by inspectors with respect to the legal requirement that all businesses with 20 or more employees must convene a joint labor-management health and safety committee that meets quarterly to discuss occupational risks and their management.

In general, more qualitative research on macro regulatory OHS processes is needed, including research on how regulators understand and approach their work. With such research, locations for structural level solutions can be identified (MacEachen 2013).

14.2.2 Risk Management at the Workplace Level

14.2.2.1 Occupational Health and Safety Systems

Most qualitative research on OHS risk management focuses on identifying processes at the level of the workplace. The increasing use of measurable, auditable, and certified occupational health and safety systems (OHSMs) within workplaces in order to prevent worker injuries has been a focus of qualitative enquiry. A strength of qualitative research is its ability to identify conditions and situations that can make an intervention effort useful or not, and for whom. Qualitative research has identified conditions where OHSMs seem to be effective. For instance, an Australian study of a management system in a multinational fast-food chain showed how this approach appeared to control risk among young casual workers, who showed superior knowledge of risk assessment and control strategies (Mayhew and Quinlan 2002). The authors suggest that key to this OHSM success was an environment where all aspects of design were standardied and tightly controlled—from buildings to production processes and training programs— and where health and safety rules were integrated into production tasks and on-the-job training.

Most qualitative research about OHSMs has examined how these systems function in more typical work environments where work processes are not tightly determined and worker discretion is required during the workday. For instance, a fieldwork study of a metal work manufacturing firm in Denmark (Hohnen and Hasle 2011) found that, although items in the OHSM, such as wearing a hard hat, were amenable to measurement and audit, the system could not capture other important conditions that impacted workplace safety, such as staffing levels and work intensification. Further, audit requirements of the new safety system required workers to engage in extra documentation at the same time that they lacked the time for this due to increasing demands on productivity. The authors suggest that an overall challenge is that these new safety systems direct a conceptualization of safety problems as technical and therefore as requiring technical solutions. In turn, this narrow knowledge base of legitimacy overlooks work environment issues and restricts understandings of areas for safety improvement. This consideration of safety logic and its implications is an area that is particularly amenable to qualitative investigation.

Qualitative research has identified how a problem with the current organizational trend to implement OHSMs is that many workplaces require some worker situational judgement, and so these systems can create scenarios where workers are in noncompliance with safety rules. An ethnographic study of an American grain storage facility showed how workers created a "safety counterculture" to avoid injury risk (Walker 2010). The workplace health and safety system was geared to issues such as the wearing of protective equipment, which could be observed and measured. What was revealed through the study was how workers adapted by forming their own safety measures, which were mostly formally invisible and sometimes countered the formal safety rules. For instance, workers disregarded rules about wearing hard hats because they obscured vision. Similarly, they avoided working beside temporary workers who could easily make dangerous mistakes due to their lack of familiarity with the work environment. The current research on OHSMs mirrors similar research conducted in the 1980s following newly legislated "joint labor-management health and safety committees" in Ontario. These committees appeared to provide a way for workers to have a formal role in determining work risk and advising on solutions. Subsequent qualitative research on how workers experienced this new joint committee system (Walters and Haines 1988a; Walters and Haines 1988b) identified issues that are similar to those in current qualitative literature about OHSMs. Studies showed how the hazards that most concerned workers often fell outside of the dominant medical-technical paradigm, prompting workers to not speak up because of concerns that their issues were not legitimate. Strong social discourses about individual responsibility (e.g., being careful, not cutting corners) did not reflect limits to workers' personal control over their environment. Further, workers did not see managers as welcoming worker critique of the safety environment and indeed viewed it as potentially job threatening.

A gendered lens can also illuminate how some hazards fall outside the sphere of official recognition. In the case of nonprofit agencies delivering social service work, organizational language obscured the amount and nature of work that was required to sustain various organizational practices (Kosny and MacEachen 2010). The workers' full spectrum of work was unrecognized, especially in areas such as background preparation, empathy work required for counselling and crisis intervention, and emotional labor requiring workers to curtail their own emotions as they dealt with clients. In this case, workers were unwilling to complain of work conditions because they prioritized the needs of their clients instead. Qualitative studies of health care workers continue to show how health care workers prioritize patient needs over their own health and safety needs (Baines et al. 2012). Gendered approaches to risk were also elaborated upon in a focus group study of young workers (Breslin et al. 2007), which identified how young women complained about health and safety conditions but their complaints were disregarded by their superiors, while young men (and some females in male-dominated work settings) described stifling their complaints in order to appear mature amongst their older coworkers. The study findings suggested that, contrary to the popular discourse that young workers get hurt because they take unnecessary risks, the challenge may lie in creating avenues that lead managers to listen to young workers' concerns.

14.2.2.2 The Role of Discourse in Defining Work Risk

The role of discourse in defining work risk is a repeated topic in qualitative studies (Breslin et al. 2007; MacEachen 2005; Zoller 2003). Although encouraged to inform management of work hazards, workers can find it difficult to articulate their concerns within the discursive boundaries provided by management. A study of how Ontario managers understood and managed the problem of repetitive strain injury among their employees found that managers engaged in some minor preventive efforts, such as improving ergonomic education and supports. However, they were also guided by a discourse of skepticism about the legitimacy of repetitive strain complaints. If workers continued to complain of symptoms, the managers located the problem with the "type" of worker rather than with the work environment (MacEachen 2005). This managerial skepticism about the legitimacy of worker injuries was also a strong theme in a study of young workers' understanding of workplace hazards and injuries (Breslin et al. 2007), in which young workers described not being taken seriously by managers when they reported hazards.

The question of why workers do not make official complaints about poor work conditions is addressed in qualitative studies. A classic reason is worker's job insecurity and lack of power to protect their own jobs. For instance, a study of undocumented immigrant workers in the San Francisco area details how they lived on the margins of society as a "special class." Even when severely injured through work, these workers were weakly positioned to hold their employers to account or claim any compensation (Walter et al. 2002).

Another reason who workers do not protest poor work conditions is ideological. An ethnographic study of workers at an American automobile manufacturing plant tackled the issue of how the "production of worker consent" to workplace hazards is accomplished in workplaces (Zoller 2003). The study showed how workers' commonplace experiences of workplace injuries were excluded from official reporting via normative standards in the workplace. For instance, "good workers" were constructed as those who took individual responsibility for an intense work pace, and their fitness and health. Workers would go to personal doctors to avoid reporting an incident as a work-related injury and workers suggested that colleagues who did suffer from injury or illness "deserved" these problems because of their lack of fitness or carefulness. This ethnographic study was able to show how the hazards associated with manufacturing were naturalized and attention was shifted away from a focus on work process changes that might help workers to withstand work.

14.2.2.3 Nonstandard Workplaces

Qualitative research has also contributed to our knowledge of how injury prevention is managed in nonstandard workplaces. The studies described below of small businesses, flexible software firms, home care workers, taxi drivers, and temporary agency workers tell us a great deal about occupational health understandings and management because they reveal exceptions to norms. It is at the margins that we learn about taken-for-granted assumptions about health and behavior.

Quantitative studies of occupational health interventions in small businesses are sparse, in part because of statistical challenges with small sample sizes per workplace (Breslin et al. 2010). In contrast, qualitative studies have been able to elaborate upon various aspects of occupational health in small businesses. Qualitative studies have shown how small businesses have a strong informal environment, where workers and managers work alongside each other and are familiar with each other's jobs and challenges, and have elaborated how this can lead to specific occupational health and safety risks. Close worker–manager relationships can lead workers to downplay risks as "part of the job" (Eakin 1992; MacEachen et al. 2010b). However, the quality of employee-employer relations could shift this notion. A qualitative interview study found that in conditions of worker–manager labor relations conflicts, workers' risk understandings shifted to blame managers for the situation (Eakin and MacEachen 1998). This then played out in subtle reprisals that allowed workers to exert some control over their environment, such as allowing substandard materials to be shipped to clients.

Unlike workers in clearly defined and standardized jobs, some workers are required to exercise significant discretion and autonomy. In some cases, this becomes enmeshed with occupational health management when managers require that workers create their own ways to protect their health. For instance, an interview study showed how highly skilled knowledge workers in computer software firms were invited to accomplish their work tasks through work flexibility (MacEachen et al. 2008). They could work from the office or at home, and whatever hours suited them. This study revealed a managerial discourse that celebrated this flexibility as permitting a liberating work-life balance for workers. At the same time, managers also described intense work conditions and a strict need for output and observation of deadlines. The study examined how, when workers were "permitted" to work at home, this effectively allowed them to maintain indefinite and very long work hours. It also blurred employer accountability for work hours and injuries.

Many other workers, such as mail carriers, plumbers, and electricians, have nonstandard work environments and this can pose challenges for management of the occupational health environment. This was the focus of conducted study of home health care workers: as health care increasingly shifts from hospitals to the community, questions are raised about the occupational health risks facing providers who deliver their services in clients' homes (Markkanen et al. 2007). A series of interview and focus groups with American clinicians and managers revealed risks prominent in homecare: long-distance driving; being in the field alone; entering dangerous neighborhoods; productivity pressures; and detailed paperwork for medical care insurance that extended the work day long past the client visits. As detailed in previous studies, this study also found that workers hesitated to report occupational injuries. They saw this as detrimental to their image as strong performers, and as leading to time-consuming processes.

The work of taxi drivers and the risks they face is similar in some ways to that of home health care workers. Taxi drivers do a lot of driving, work alone, and face an unpredictable work environment. A study of strategies developed by Ontario taxi drivers to protect themselves from specific hazards of taxi work showed how, through different kinds of "talk"—evaluative, placating, entertaining—they independently and proactively managed their work environment to reduce the risk of being hurt by unruly clients (Facey 2010).

A growing form of work that occurs without a set workplace is that of temporary agency workers. Studies in Ontario and Australia have shown how temporary work agency workers face occupational risks as a result of their inexperience of work site processes, tasks and specific risks in the various workplaces to which they are sent. These workers also face fractured communication with a three-way employment relationship and are generally not socially integrated within workplaces where they are sent for work placements (MacEachen et al. 2012b; Underhill and Quinlan 2011). A particular challenge for temporary work agency workers is that they are spread across worksites (Underhill and Quinlan 2011), which makes collective action difficult to organize.

14.2.3 Risk Understanding and Management by Workers

The importance of workers' positioning within labor relations is underscored by research considering artists and business owner-operators such as farmers and fishermen who use their bodies as a means of production. Qualitative studies have shown how, when work is a vocation, it has an impact on workers' orientation to work injury. For instance, unlike those in a job such as an hourly waged cashier, ballet dancers are heavily invested in their work and this shapes their occupational health experiences. They experience frequent occupational injury, but see their pain and discomfort as sign of vocational commitment (Turner and Wainwright 2003). With their identity tied up in their occupation and the possibility that injury could end a dancing career, dancers both downplay and accept pain and discomfort. Qualitative studies of farmers and fishermen also revealed the importance for occupational health management of understanding vocation, such as when work is a part of one's family history (Lovelock 2012; Power 2008). A study of New Zealand farmers shows how they consider themselves to be the "backbone of their country" and approach work injuries as inevitable and requiring stoicism. The farmers did not use safety technologies if they altered the sensory experience of labor; for instance, earmuffs were not used if they stifled sound and helmets were abandoned when they prevented the feeling of wind (Lovelock 2012). Qualitative studies of Newfoundland fishermen show similar orientations to occupational risk. The fishermen saw fishing as "in their blood" (Power 2008) and, as with the ballet dancers and farmers, the fishermen described stoicism and pain masking as central to their occupational identity.

14.3 When a Worker Is Injured—Return-to-Work Processes

When a worker is injured or becomes ill on the job and the incident is formally recognized by the employer, jurisdictions in most advanced economies require a process of *early return to work*. This generally involves returning the worker to the workplace to modified work before he or she is fully recovered. This process provides cost relief to insurers (state or private) who are responsible for income replacement costs, and rests on an assumption that it is unhealthy for workers to be absent from work for an extended period of time (MacEachen et al. 2007a).

14.3.1 The Influence of State Actors in Return-to-Work Processes

A body of qualitative research explores challenges at the state level with administering initiatives to reduce workers' time on benefits and return them to workplaces. Studies have demonstrated the complexities associated with organizing actors, such as employers, health care providers and insurers, to cooperate and coordinate in work reintegration processes. For instance, in Belgium there are three kinds of physicians (treating physicians, social security physicians, and occupational physicians) and each play different roles. A focus group study showed how, in a context where legislation emphasizes protection of the patient rather than work reintegration, it becomes difficult to coordinate the behavior of the different actors (Tiedtke et al. 2012). The study found that, although the different stakeholders could work toward work reintegration, this was achieved only by pushing boundaries and breaking rules.

The activities of specific key decision-makers in return-to-work processes have been the focus of several qualitative studies. In Sweden, a study of the activities of social insurance officers (Ydreborg et al. 2007) showed how client eligibility decisions were affected by excessive client loads and by the tenure of the officer. That is, older officers based decisions on experience while newer officers were guided by education. This examination of decision-making approaches by gatekeepers of work disability income benefits is an interesting *upstream* area for study and possibly intervention.

In Sweden, significant efforts have been made to tackle work reintegration via the coordination of different parties, using a case approach for each worker with a long-term work absence. Qualitative studies of stakeholder cooperation have illustrated how cooperation is thwarted by each party's focus on their own priorities, which can lead to disagreement about goals. This focus by stakeholders on their own organizational goals undermined cooperation and created mistrust (Stahl et al. 2010). A further challenge was that stakeholders constructed the issues differently (Stahl et al. 2009). For instance, social insurance officers relied heavily on medical status, while physicians took a more holistic view. Further, the new cooperative arrangement created loss of authority for physicians, thereby opening up a new area of contestation. Swedish studies have identified employers as a weak link in this Swedish coordination effort, due to their lack of formal obligation to engage in return-to-work practices (Seing et al. 2012; Stahl et al. 2011). More recent qualitative studies of coordination efforts in Sweden point to improved coordination when more time was allocated to the initiative and the focus was on improving systems rather than solving individual cases (Stahl 2012).

Many state systems offer vocational retraining to workers who, due to the severity of their injury, are not able to return to their former occupation. After retraining, workers are expected to reenter the labor force and their income support benefits are eliminated or reduced. A study of how actors understood their role and coordinated activities within Ontario's vocational retraining program found, as with the case of Sweden, each set of actors to be pursuing their own institutional goals, and lacking a coherent focus on the needs of the workers (MacEachen et al. 2012a). In this case, outsourced private providers worked to push workers through the process, regardless of whether they had acquired the required knowledge, in order to claim financial credit that came with helping to remove a claimant from workers' compensation rolls. Although workers receiving substandard service were aware of their lack of preparedness for the labor market, communication structures and social stigma muted their voice.

14.3.2 Return-to-Work Activities at the Workplace Level

A large body of qualitative research on return-to-work following an occupational injury or illness has focused on workplaces. In the 1990s across jurisdictions, state systems began requiring employers to provide injured workers with modified work until the worker can resume former duties. Employers were also required to coordinate with health care providers, who make determinations about when a worker is ready to engage in return-to-work activities. An early qualitative study of this system (Baril et al. 2003) involved research teams in three Canadian provinces and focused on a range of workplace and regulatory actors. As with the studies of state systems, a conclusion of the study was that coordination of actors to work together on early return to work was difficult. At the workplace level, supervisors could be placed in a role conflict situation when required to provide modified tasks to a worker while at the same time maintaining production quotas. The researchers identified trust and respect as key to coordination; where trust was created there was an ability to clarify goals, exchange realistic information, and search for solutions.

Some qualitative research has focused on how return-to-work is implemented in different work contexts. An interview study of return-to-work in Ontario small businesses found that small business employers faced a conflict between business needs and the requirements of state return-to-work policy, and they managed this by "playing it smart" (Eakin et al. 2003). That is, the employers implemented return-to-work in a way that focused on reducing business costs rather than creating a safe recovery environment for workers. This study also identified a pervasive societal expectation, perpetuated by both injured workers and employers, that workers will try to cheat the workers' compensation system in order to gain illegitimate access to income support benefits. In response to this discourse, small business workers who had been injured at work strove to define themselves as not "cheaters," which ironically perpetuated the discourse that workers may likely be cheaters.

A systematic review of qualitative research studies of workplace-based return-to-work identified numerous communication challenges and barriers between parties and pointed to "goodwill" as a necessary component for successful return-to-work (MacEachen et al. 2006). The synthesis of studies identified intermediary players, such as return-to-work coordinators, as key to the success of the RTW process. For instance, difficulties with setting up appropriate modified work might be alleviated by improved employer contact with physicians. As neither employers nor physicians normally have time to manage this exchange, rehabilitation care providers might facilitate implementation. Subsequent qualitative research has explored the competencies required for success in this intermediary role (Pransky et al. 2010). Another intermediary player identified in the systematic review who could play an enhanced role in return-to-work were supervisors, because they are well situated to monitor day-to-day physical and social conditions of the work return by virtue of their position working alongside the returning worker. A qualitative study that investigated the qualities that workers valued in supervisors in RTW circumstances found that interpersonal aspects of supervision, such as social validation and a nonjudgmental approach to workers' injury, was as important as physical work accommodation (Shaw et al. 2003).

Recent qualitative research of the return process points to the role of coworkers as critical but overlooked actors in return-to-work. Past qualitative studies that had not directly included coworkers in the sampling framework had identified the disruptive role that coworkers could play in the RTW process, such as unwillingness to support the returning worker due to resentment about special accommodation treatment provided to them (Baril et al. 2003; Larsson and Gard 2003; MacEachen et al. 2006; Roberts-Yates 2003). However, research emerging from Sweden (Tjulin et al. 2009) drew attention to a relatively hidden, positive coworker role. A research design based on sets of worker–supervisor–coworker triads in workplaces allowed for a view of the scope of each party's activities and line of vision. Although in workplace policy RTW is normally formally considered an arrangement between the supervisor and the worker, the inclusion of coworkers in the research design showed how coworkers were the party that shaped the sustainability of RTW arrangements, and how both supervisors and the sick listed workers were regularly unaware of the extent of coworker involvement and effort. As sustainability of RTW is a growing concern, with studies showing problematic an on-and-off patterns of return-to-work (Bultmann et al. 2007; Henschke et al. 2008), the role of coworkers in creating sustainable RTW is now a focus of increased attention.

Further Swedish analyses (Tjulin et al. 2011a, b) have detailed the *how* and *when* of the coworker role in return-to-work. For instance, when coworkers expand their role to cover work of the injured worker, they can also have difficulty relinquishing this role when the worker is ready to resume full duties. Also, coworkers can have difficulty adjusting to a returning worker who had experienced significant physical and mental changes during the illness, and was not behaving and functioning as the same colleague that they were before. As well, formal privacy requirements can limit coworker involvement.

The extent of the coworker role in the RTW process was further explored in a focus group study of Ontario workers' experiences of working alongside returning injured workers (Dunstan and MacEachen 2013). This study identified the importance of duration; that is, for a short period coworkers might provide substantial support to an injured worker but this could taper off over time. Further, it showed how tending to workers during their early return could put pressure on coworkers to the extent that they might exit their job. This was the case for a coworker whose employer instructed her to support a worker with a complex mental health problems; she felt both ill-used and ill-equipped. Additional research focused on RTW and the coworker role has described how impediments to coworker support can lie in the quality of the pree xisting worker relationships and in work organization conditions, such as job insecurity and a fractured workforce (Kosny et al. 2013). When a worker's job is on the line, it can be difficult to reach out to support others.

14.3.3 Problems with Return-to-Work Processes

A significant body of qualitative literature examines the unintended and detrimental effects on workers of return-to-work process. A key problem is power imbalances between injured workers and other actors in the system. In this context, workers' compensation system decision-making about claim entitlement in relation to chronic illnesses can be problematic and unsystematic. A study of Quebec actors showed how an adversarial workers' compensation process heightened tension. Employers contested responsibility for injury claims, which led to appeal hearings and lawyers staking out opposing territory (Lippel 2007). Another Quebec study identified how private surveillance agencies were hired by the workers' compensation authority to follow and sometimes videotape injured workers without their knowledge while they were claiming work injury benefits. This study further illustrated the adversarial work injury process and its impact on workers (Lippel 2003). While the workers' compensation authorities saw video surveillance as simply good management practice, workers experienced it quite differently—as intimidation and harassment. For workers, video surveillance created paranoia, depression and withdrawal from daily activities.

Qualitative studies have pointed to how bureaucratic neglect, and a lack of workers' compensation provider focus on workers' needs, can lead to harmful outcomes for injured workers. Australian studies (Roberts-Yates 2003; Sager and James 2005) have detailed how erratic payment of economic benefits, indifferent case managers, stigma associated with a work injury, a general lack of information, disrespectful communication from service providers, and a suspicious response to their injury by the employer can pose difficulties for injured workers. Canadian studies have further elaborated how new immigrant workers can gain only limited access to full workers' compensation services. An Ontario study described access limited by workplace managers providing misinformation to new immigrant workers about compensation rights, poor translations about injury events, and misunderstandings with the worker's compensation adjudicator and the employer (Kosny et al. 2012). A Quebec study showed how language barriers among immigrants limited workers' ability to report a problem or to negotiate when asked to do extra tasks such as overtime (Premji et al. 2008). These studies show how, even when workers have legal access to workers' compensation systems, language and other barriers can limit system access.

In Canada, qualitative research shows how such system processes can pose a "toxic dose" of system problems to workers during the return-to-work process, leading to further injury and diminished ability to reenter the labor force (MacEachen et al. 2010a). For instance, injured workers lost access to workers' compensation benefits due to employers supplying misinformation to insurers about work conditions, incomplete medical reports prompting insurer misinterpretation of worker injury, and complex paperwork that was misfiled because it was incomprehensible to workers. Such problems, which can be revealed through qualitative investigation, would be otherwise quite invisible and not easily accessed by other methodologies such as surveys. Canadian research also shows how workers, when denied workers' compensation benefits due to system complexity, can suffer shame and stigma and become alienated from family and community. A study of injured workers in peer support groups showed how the problem of peers committing suicide was a regular topic, and workers related this to stigma and poverty which is engendered in conflicts with workers' compensation insurers (MacEachen et al. 2007b).

Analyses of the role of health care providers in long and complicated workers' compensation claims have identified a myriad of barriers to workers accessing health care (Beardwood et al. 2005; Kosny et al. 2011). Medical specialists can be inaccessible, especially to rural workers, preventing timely access to specialized care and return-to-work delays. Even when doctors are available, they can sometimes decline to treat injured workers because of the onerous workers' compensation reporting requirements and relatively low payment. As well, a study detailed how medical specialists sometimes declined to treat injured workers because of their former negative experiences with workers' compensation. For instance, health care providers had experiences of carefully providing diagnoses, yet having these overturned by the benefits insurer in favor of a diagnosis provided by an alternate physician (Kosny et al. 2011).

The issue of injury legitimacy has been a theme of occupational health research. A study of women with repetitive strain injury in Australia (Ewan et al. 1991) showed how they experienced a loss of identity, and centered their efforts around "being believed." An ethnographic study of pottery workers similarly identified ways that boundaries about work injury legitimacy were permeable (Bellaby 1990). That is, influenza might be a reason to miss work, but the legitimacy of the absence can be shaped by management assumptions about reasons why the worker caught this illness. For instance, if managers viewed influenza as resulting from poor self-care, then the absence was regarded as less legitimate. Because repetitive strain injury was a particularly contested occupational health injury in the 1990s, and one that was expensive to employers, illness legitimacy became a particular. One qualitative study showed how managers extended their governance to areas such as worker posture while sitting (MacEachen 2005), which also became a locus for managerial questioning of worker self-care (MacEachen 2000) and therefore deservingness of work accommodations.

14.4 Discussion

This chapter has described a range of qualitative research studies on occupational health and safety. We organized the literature into two main categories: research on injury avoidance and risks, and research on the process of getting back to work once an injury has occurred. We drew out studies that consider gender and immigrant status. Much of the research reviewed in this chapter has identified problems with occupational health processes and relationships. In this discussion, we will show how this problems focus creates potential for innovative solutions. It is by understanding how and why processes are not working that we can identify where to revise and improve. In this discussion, we consolidate evidence, offer suggestions for promising areas of future research, and discuss implications for policy and practice.

Qualitative research is valuable because it provides insights into "off grid" issues. That is, items that might not be considered in the academic literature are uncovered through the direct and situated interaction between researchers and participants that comes with qualitative research. As such, qualitative research can yield rich avenues for further study and insights for policy and practice.

One topic that emerged in qualitative studies across the different occupational health and safety topics was worker fear of speaking up about poor work conditions for fear of reprisals or job loss. Studies detailed in various ways how uneven worker–management power relationships, within the broader context of a labor market providing little job security, contributed to an environment of underreporting where workers effectively suppressed their own complaints. As well, a decline of collective worker organization across jurisdictions such as North America and Australia creates an environment where workers cannot easily speak as a coordinated group about occupational health problems they face at work. These conditions pose a problem for occupational health and safety because, when worker knowledge about health risk is not tapped, possibilities for health and safety improvements with workplaces, as well as policy change, are stifled. These conditions can lead to policy-making based on crisis response (for instance, following multiple worker fatalities) rather than on regular and informed discussions among the working community.

Another work and health issue highlighted by qualitative studies was how workers can recognize occupational risk in ways that differ from normative expectations about risk, such as those appearing in law, policy, and safety management systems. For instance, gendered risks in caring work may be invisible to regulators who tend to focus on physical and chemical exposures. Overlooked is emotional labor with difficult clients as well as work overtime incurred when turning away from a client is not a humane option. Similarly, workers can experience rules of workplace safety management systems as perversely hazardous, for instance when bulky safety equipment limits agility or vision. These qualitative studies suggest that workplaces and regulators would benefit from the creation of feedback systems that allow workers to safely speak up about health hazards and from worker input into creating safer workplace safety processes. The potential of enhanced worker representation as a means to reduce workplace injury has been elaborated in recent years by well-established occupational health and safety researchers (Walters and Nichols 2009). Although worker feedback systems exist in Ontario, with formally legislated joint labor-management health and safety committees in all workplaces with more than 20 employees, qualitative studies in this jurisdiction show that workplace power relations do not disappear in this joint forum. Workers can remain reluctant to discuss poor workplace conditions with management. It may be that the focus of policy needs to be shifted away from requiring workers to speak up about hazards and to encouraging employers and policy makers to develop processes that adequately capture workers' concerns about occupational health hazards. To avoid the muting force of uneven workplace power relationships, the creation of forums outside of individual workplaces may provide another venue for workers to voice concerns, for instance to regulators or other parties. Such forums might also provide representation and advice to scattered workers with nonstandard jobs, such as small business and temporary workers. Research on ways to enhance the voice of contingent workers in occupational health and safety management and regulation is much needed.

Qualitative research is well positioned to examine workplace social relationships and how they shape health and safety policy and implementation, not only for workers but also for managers. Although occupational health studies regularly position workplace managers in a position of control over worker health, qualitative studies can consider the limits of managerial control over safety conditions (Baıada-Hireche et al. 2011). For instance, managers are themselves directed by senior managers, and even senior executives can be bound to varying shareholder needs (Thompson and van den Broek 2010). A tempering of notions of managerial control and an understanding of chains of influence would add nuance to occupational health studies.

When considering pathways to improved occupational health and safety regulation, it is also helpful to study the regulators themselves. Too often, policy is considered as a rather immutable background condition. However, policies are created as a result of interaction, politics, economics, and more (Mangurian and Bero 2000). Although the study of Australian safety inspectors (Johnstone et al. 2011; Quinlan et al. 2009) addressed an important state-lever player in OHS, there is generally a lack of evidence about the logic and processes of prevention at the most senior level of state policy and legislation. Researchers interested in policy change and improvement might turn their attention to how key decision-makers arrive at OHS policy.

In contrast to epidemiological studies where the individual is usually the unit of analysis, qualitative study design can consider occupational health at an organizational level by taking account of the interaction between participants' understandings and experiences within the context of workplace environment and social relations. This approach led to the identification of another "off grid" issue: the invisible role of coworkers in return-to-work. Qualitative OHS researchers came across this issue in a study of workplace return-to-work process that captured the experiences of multiple parties around single incidents (Tjulin et al. 2009). Subsequent studies focusing more closely on this coworker role are identifying how we may have been overlooking one of the most important players in maintaining the sustainability of return-to-work processes (Dunstan and MacEachen 2013; Kosny et al. 2013). Many of the qualitative studies included in this chapter suggested that areas for safety improvement are to be found beyond the behavior and knowledge of individual workers. We can learn much about occupational health and safety by examining how work environments are organized.

Qualitative studies are able to identify what occupational risk means to workers and many focus on workers in vulnerable circumstances, such as low wage temporary agency work, who unwillingly face risk. However, some studies have focused on workers who accept occupational risk as a vocational condition, such as farmers and owner-operators who have strong control over their working lives. These qualitative studies draw attention to how the meaning of risk and injury can play a key role in workers' own approaches to occupational health. These studies have implications for the focus of OHS regulators. Where do we draw the line between regulatory prevention and workers' assumption of risk? When employers offer workers "danger pay" for risky work, such as mining, risky work is implicitly linked to worker choice. Qualitative research can help us to better understand the relationship between worker agency and occupational risk exposure: informed and freely chosen or foisted on workers?

Qualitative studies of return-to-work processes show that interparty cooperation is not simply a matter of coordination and education. These studies show that different parties and agencies can care about disparate aspects of the problem and have different entrenched institutional interests depending in part on the nature of the liability faced by their organization. This understanding about meaning and social interaction in coordination processes helps identify solutions that focus on finding better pathways to implementation. For instance Stahl (2012) identifies the need for more time to work out processes and more focus on the process itself and how it will work. A further question that could be tackled by qualitative researchers is that of values. Where do values diverge among key players about who should be returning to work and how and when? An understanding of the relativism of work disability management policy might open doors to new ways of thinking about occupational health management.

A body of qualitative research has examined how state return-to-work policies are implemented at the workplace level and what these work reintegration requirements mean for workplace productivity and social relations. A party involved in return-to-work that warrants further attention is disability managers, who are playing an increasingly important role in efforts to reduce work absence duration. What is the incentive structure for these specialized managers and how does it shape the treatment of workers? Further, qualitative researchers might examine the burgeoning field of disability specialists and work absence managers who outsource their services to workplaces. How do these businesses shape the work disability landscape?

Studies of qualitative research from across jurisdictions draw attention to the need to consider occupational health internationally. Because of global trade, occupational health conditions are interrelated. That is, strong regulation of occupational health in one jurisdiction, such as North America, can lead to risk-shifting. That is, work contracts involving risky work may be moved to another jurisdiction, such as China. Qualitative researchers are well positioned to examine how networks operate, and the impact of supply chains (Walters and James 2011).

In all, qualitative research design allows researchers to apply a variety of theoretical lenses and to understand actions in context. This richness of design, which allows for the understanding of meaning and action in context, has the potential to be expanded in the field of occupational health research. The qualitative research studies reviewed in this chapter suggest that policy and practice would benefit from improved strategies for tapping worker knowledge of health and safety risks, considering work injury prevention and return-to-work solutions within the context of organizational processes, and gaining a relational international perspective on relationships between local occupational health practices and the broader socioeconomic environment.

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Qualitative Evidence in Health Promotion

15

Daphne C. Watkins and Jaclynn Hawkins

15.1 Introduction

Health promotion is the process of enabling people to increase their control over—and improvements to—their health. It incorporates primary, secondary, and tertiary strategies that have the potential to prevent disease, lead to early diagnosis and treatment, and restore healthy functioning (Ferguson and Spence 2012). Health promotion enables people to gain greater control over the determinants of their health, and often incorporates educational and environmental behaviors and conditions that are conducive to healthy living. Health promotion researchers have tried to establish the most effective methods for behavior change for decades. Although early health promotion studies focused on randomized trials in order to provide a strict test of behavior interventions (Sorensen et al. 1996), more recent scholars have identified the importance of using qualitative and quantitative methods in rigorous health promotion research and practice (Crosby et al. 2006; Glanz et al. 2002).

Health promotion is the primary goal of health research and health program planning. Thereby, using qualitative methods in health research and health promotion efforts creates opportunities for understanding health issues in context, and through rich, deeper scholarly inquiries. Likewise, qualitative methods used to acquire such evidence-based knowledge can lead to more tailored and targeted health promotion programs for underserved individuals and communities. Given this, the purpose of this chapter is twofold, as our aim is to examine the scholarly discourse between qualitative evidence and health promotion. Specifically, we examine how qualitative evidence is conceptualized in the current health promotion literature as well as how health promotion efforts have been enhanced by qualitative evidence. This chapter is organized in a way that allows for a broad foundation and operational definition of health promotion to be established early, followed by a presentation of health promotion models, and how health promotion has benefited from qualitative research methods and evidence. We then provide a review of examples from the literature on the various ways that scholars have used qualitative evidence to promote their health initiatives, and then we end the chapter with a discussion about the research, policy, and practice implications for using qualitative evidence in health promotion.

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15.2 What Is Health Promotion?

Increasingly, health promotion is being recognized as a way to meet public health objectives and improve the success of public health and medical interventions. It includes not only instructional activities and other strategies to change individual health behaviors, but also organizational efforts, policy directives, economic supports, environmental activities, mass media, and community-level programs (Crosby et al. 2006). Health education emerged out of health promotion. Health educators saw a need for positive approaches to the overall health of individuals and communities, not simply disease prevention. According to Green and Kreuter (2005), health education "aims at the voluntary actions people can take on their own part (individually or collectively) for their own health or the health of others and the common good of the community" (p. 19), while health promotion encompasses health education and "aims at the complementary social and political actions that will facilitate the necessary organizational, economic, and other environmental supports for the conversion of individual actions into health enhancements and quality of life gains" (p. 19). Health education is more effective when it is supported by structural measures (i.e., legal, environmental) and when the people that will be affected by it are involved.

Often used interchangeably, health promotion is closely related to health education, which includes the actual learning experiences used to facilitate health behavior changes (Glanz et al. 2008). Over the past 50 years, health education and health promotion have evolved into areas of research and practice (and arguably, a prevention science) that have had an impact on communities and target populations at the local, regional, national, and international levels. Similarly, the scope and reach of health education and promotion efforts have gradually increased over the decades. By way of example, the 1960s witnessed health education's influence on single, health-directed acts such as obtaining immunizations. However, during the 1970s, health education efforts changed medical care behaviors through patient education and self-care initiatives. Rapid and increasing responses by local and federal agencies generated interest regarding the mass reach of health education and promotion (as well as issues of equity and social justice) by the early to mid-1980s (Glanz et al. 2002, 2008).

Interests in health education and promotion efforts of the 1970s and 1980s eventually led to questions about how federal entities could respond to organizing efforts by grassroots agencies. Public health officials in the 1970s were not confident that health education could keep up with the changes in public health targets—they seemed to be more complex lifetime habits and social circumstances (Green and Kreuter 2005). However, it was later understood that, with targets similar to these, public health education could significantly improve population health if it collaborated with others and embarked on multiple forces to help address their problems. In this chapter, these multiple forces are illustrated through a discussion about health promotion models as well as the ways that health promotion can be used to address health disparities for target populations.

15.2.1 Health Promotion as a Way to Reduce/Eliminate Health Disparities

For health promotion to be effective it must be designed with its audience and their social characteristics, beliefs, attitudes, values, skills, and past behaviors in mind (Green et al. 2005; Glanz et al. 2002). These factors play a vital role in how health promotion is received by the audience as well as their potential health behaviors based on the information they receive. In order to plan programs that directly impact certain groups, characteristics of those groups must be considered. Potential audiences can be categorized based on their socio-demographic characteristics, ethnic/racial background, life cycle stage, and disease or at-risk status (Green et al. 2005).

Who receives health promotion can play a major role in the reduction and elimination of health disparities. Overall, if certain groups who are disproportionately affected by health disparities do not receive the health information that they need to be made aware of these disparities, then they will continue to engage in unhealthy behaviors and disparities will be neither reduced nor eliminated. For example, if the chance that African American men suffer from undiagnosed and misdiagnosed depression is greater than that of Asian American men, then unless these populations are made aware of this, they will never know about this disparity. Not until African American men are made aware that they are disproportionately affected by this mental disorder can they begin to make moves towards education and treatment of depression. For many groups, such as African American men, the point is that health promotion has to be personal and it has to be relatable.

Health promotion efforts can make essential contributions to the elimination of health disparities by informing the affected groups about their health and quality of life. In many cases, health promotion acts as the bridge between institutions and communities. This bridge leads to a greater understanding of existing disparities and ways in which all entities involved can work toward the elimination of health disparities that infect our communities.

The ways in which health promotion can contribute to the elimination of health disparities are countless. Professionals involved in health promotion are trained to collect and analyze data and identify community needs prior to planning, implementing, monitoring, and interpreting programs designed to encourage healthy behaviors. Of the array of techniques that could be employed by health educators, multiple levels of influence and reciprocal causation can help direct the identification of personal and environmental leverage points for health promotion interventions (Glanz and Rimer 1995; Glanz et al. 2008). The levels of influence, described below and explained from an ecological perspective, can also be discussed as important factors considered by health education as contributors to the current issue of health disparities and also avenues by which health disparities can be eliminated.

Multiple levels of influence have been described by health behavior theorists as related to the five levels of the social ecology model (McLeroy et al. 1988; Stokols et al. 2003). The first level is the *individual level* and focuses on the knowledge, attitudes and behaviors of the target population. The second level is the *interpersonal level* that encompasses the social support systems that have been established by the target population. Social support has been identified as social networks and social support systems (e.g., family, work groups, support groups, peer groups, and friends). The third level is the *institutional level*, which focuses on the social organizations to which the target group belongs. Social institutions and organizations may include churches, worksites, schools, health care settings). The fourth level focuses on the *community* and the relationships among community organizations, community norms, and the mass media. The fifth level is *public policy* and involves local, regional, and national policies that could possibly influence the health behaviors of the target populations.

Reciprocal causation asserts that behavior both influences and is influenced by the social environment (Stokols et al. 2003). Upon examining the relationship that individuals have with their communities, the possibility of reciprocal causation is likely. Since informed changes in health behavior are typically the aims of health education programs, health education can play an intricate role in the reduction and elimination of health disparities among individuals and communities based on the relationship that one has with the other. Reciprocal causation occurs between individuals and their environment. The behavior of the individual both influences and is influenced by the environment (Glanz and Rimer 1995; Stokols et al. 2003). Knowing this, health education can tailor its interventions to programs where both the individual and the environment are encouraged to make positive behavior changes. Recognizing that one can manipulate the other, it is apparent that a combined-methods approach to solving health problems in a community—that is, one that focuses on changes in the people as well as changes in the environment—may be more effective.

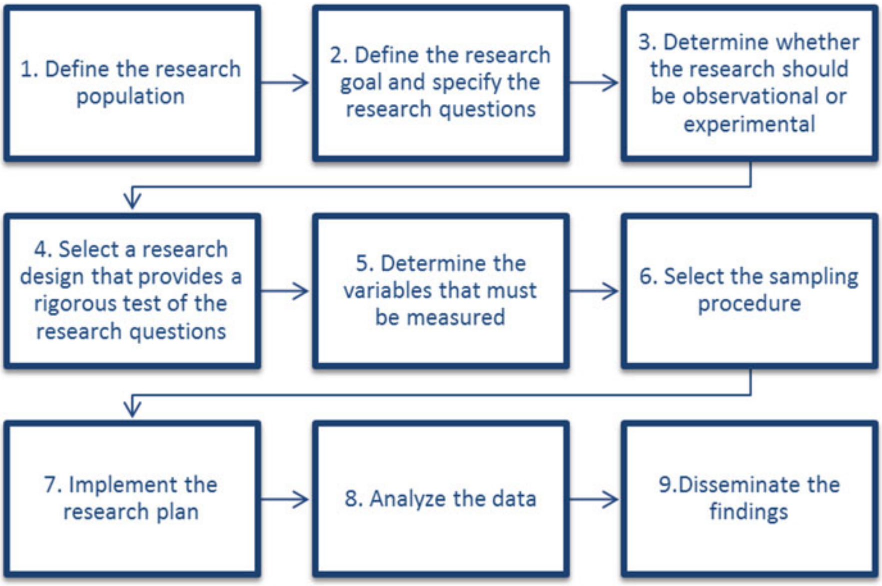

Fig. 15.1 The nine-step model of health promotion (Crosby et al. 2006)

Although the literature offers several models for health promotion planning (Green and Kreuter 2005), we found the nine-step model proposed by Crosby et al. (2006) particularly practical and user-friendly (see Fig. 15.1). According to the authors, the nine steps of health promotion include: (1) defining the research population; (2) defining the research goal and specifying the research questions; (3) determining whether the research should be observational or experimental; (4) selecting a research design that provides a rigorous test of the research questions; (5) determining the variables that must be measured; (6) selecting the sampling procedure; (7) implementing the research plan; (8) analyzing the data; and (9) disseminating the findings. In addition to its simplicity, what is most distinctive about the nine-step model of health promotion is that it provides a roadmap for both the novice and more seasoned health promotion workers to follow.

15.3 Health Promotion Models

Numerous health promotion models employ both standard and condition-specific components. Some of the more popular and widely used models encompass more than just health promotion, and also conceptualize the design, implementation, and evaluation of programs. Despite the various models that exist, we have decided to only discuss two models in this chapter. Guided by their popularity and relevance with regard to public health research and practice, we will first present the PRECEDE/PROCEED model, and then we will present the RE-AIM framework.

15.3.1 The PRECEDE/PROCEED Model

The PRECEDE/PROCEED model is a comprehensive health promotion planning framework often used as the theoretical framework from health program planning to implementation and evaluation (Green and Kreuter 2005). When planning programs, a thorough understanding of the problem and plan of implementation and evaluation is essential. The framework for the diagnosis of the problem will be achieved through the PRECEDE portion of the model and the plan of implementation and evaluation will be achieved through PROCEED. The PRECEDE/PROCEED model is multidimensional. Its genesis is grounded in a variety of disciplines such as social/behavioral sciences, epidemiology, education, and administration. It operates on the notion that health behaviors have multiple causations that must be evaluated in order to assure appropriate interventions (Green and Kreuter 2005). A formative research plan that assesses the needs of the population, plans an effective program, implements the program, and evaluates the effectiveness of the program can be achieved using the nine phases of the PRECEDE/PROCEED model (Green and Kreuter 2005).

15.3.2 The RE-AIM Framework

The RE-AIM framework (Belza et al. 2007; King et al. 2010) is an emerging framework that involves program decision-making by focusing on *Reach*, *Effectiveness*, *Adoption*, *Implementation*, *and Maintenance*. These five elements are critically important for service providers and decision-makers to consider when selecting an evidence-based health promotion program, or when making choices among alternative programs. Each is described below.

Reach is described as the extent to which a program is able to attract its intended audience. It is intended to address who can benefit most from the program and if those individuals will participate. The ability to reach those who are in need is of high importance, as well as if diversity is achieved. *Effectiveness* refers to assessing the measureable objectives of the program to determine the program outcomes. It can help report both the strengths and the weaknesses of the program. *Adoption* helps to assess the extent to which each program is tailored to meet the needs of a particular setting. This includes components such as participation rate and representativeness of the setting. Adoption is similar to Reach, in that both require the use of a "denominator" of eligible individuals or settings to calculate the participation rate. Online resources are available to assist with calculating denominators (www.re-aim.org/2003/commleader.html). *Implementation* (also known as program fidelity) is concerned with whether a program is delivered in the way it was intended to be delivered. Implementation also includes the extent to which a program is delivered consistently by program staff and if (and how) programs are modified over time. Implementation in RE-AIM is often delivered using both qualitative and quantitative approaches (Besculides et al. 2006). Finally, *Maintenance* involves different levels, mainly, the individual and organizational levels. Maintenance addresses the long-term effects of the program on both targeted outcomes and quality-of-life indicators at the individual level. At the organizational level, maintenance refers to the program's sustainability over time.

15.3.3 How Qualitative Evidence Is Used in Health Promotion

Although there is no short, comprehensive definition, qualitative researchers agree that qualitative research is a theoretical and methodological focus on complex relations between (1) personal and social meanings, (2) individual and cultural practices, and (3) the material environment or context (Ulin et al. 2005). Despite purists' claims that qualitative research is not guided by true, empirical science, it has been suggested that, "qualitative research is a field of inquiry in its own right" (Denzin and Lincoln 1998, p. 2). Particularly with regard to in-depth examinations in natural settings, qualitative research methods tend to be beneficial as they help to provide a context through which a phenomenon of interest is examined. Qualitative inquiry remains at the forefront of disciplines, in that its naturalistic paradigm provides the best fit to virtually all phenomena (Lincoln and Guba 1985).

There are certain characteristics of qualitative research that differentiate it from quantitative research. For example, instead of addressing the *what* and *how many* of a phenomenon, qualitative research helps to address the *why*, *how*, and *under what circumstance* do things occur. Qualitative research also seeks a depth of understanding, views social phenomena holistically, provides insight into the meanings of decision and actions, uses interpretive and other open-ended methods, is iterative rather than fixed, is emergent rather than pre-structured, involves

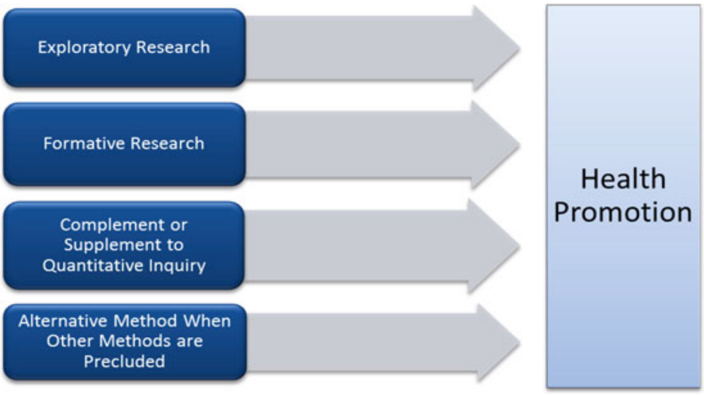

Fig. 15.2 Ways in which qualitative modes of inquiry can be used for health promotion

respondents as active participants rather than subjects, and defines the investigator as an instrument in the research process (Ulin et al. 2005). Salazar and colleagues (2006) offer four major purposes for which qualitative inquiry can and should be used in health promotion research (see Fig. 15.2). These purposes are to: (1) conduct exploratory research; (2) conduct formative research; (3) complement or supplement quantitative studies; and (4) serve as an alternative when other methods are precluded (Salazar et al. 2006). Below, each is discussed more thoroughly.

15.3.3.1 Conducting Exploratory Research

Qualitative evidence is often used to shed light on a topic that has not received much attention or for which deeper exploration has not occurred. Given these needs, the purpose of exploratory research corresponds highly with a qualitative mode of inquiry (Salazar et al. 2006). Exploratory studies tend to occur before descriptive and explanatory studies, thereby not needing an a priori hypothesis to be tested. Given the early and preliminary stages of the knowledge level continuum that exploratory studies encompass (Grinnell and Unrau 2011), for health promotion purposes the researcher would be able to achieve a lot with a small, centralized sample, and explore a topic by focusing the analyses on patterns.

15.3.3.2 Conducting Formative Research

When answering health promotion issues that impact a particular group of individuals or a community, sometimes the decision regarding which methods to use can be challenging to make. In such cases, formative research plans are used first to assess the needs of the population. The formative, qualitative evidence acquired in health promotion research is oftentimes a first step in understanding the complexities of a health condition. Formative strategies can help to collect information about the most pressing concerns of a target group, and offer insight into ways that these concerns can be addressed. Some researchers even take advantage of the natural language that is used by a group and incorporate many of these terms into the next step in the research process for addressing health concerns and developing health promotion materials to improve the social situations of these groups.

15.3.3.3 Complementing or Supplementing Quantitative Studies

A third way in which qualitative inquiry can be used in health promotion is to complement or supplement quantitative inquiry. Oftentimes, researchers will first conduct a qualitative study to obtain depth of the health condition under study, and then they will conduct a concurrent or sequential quantitative study to obtain the breadth of the health condition (Creswell and Plano Clark 2011). This helps the researcher gauge a thorough understanding of the factors that contribute to a particular health condition while also allowing for the use of multiple methods as a way to obtain a multidimensional view of the condition (Salazar et al. 2006). The benefit of doing this is that the qualitative data tends to provide information that, though different from that provided by the quantitative data, is complementary in nature. Researchers agree that using a qualitative and quantitative (or mixed methods) approach can help develop a more complete picture of the issue at hand.

15.3.3.4 Serving as an Alternative When Other Methods Are Precluded

The final mode in which qualitative inquiry can be used in health promotion is as an alternative mode of information gathering when other methods are precluded. Salazar et al. (2006) present situations when researchers may be limited in the type and nature of the inquiries that they make for evaluating programs. One example offered was that of a Louisiana jurisdiction that prevents students in the state of Louisiana from being tested, quizzed, or surveyed about their personal practices and beliefs. While limiting with regard to what can be surveyed, researchers may still have options to qualitatively evaluate students' perceptions of a sexual abstinence program via semi-structured interviews with principals, teachers, and peer mentors (Yoo et al. 2004).

When using qualitative evidence for health promotion purposes there are certain theoretical and conceptual points of reference to keep in mind (Salazar et al. 2006). Since qualitative methods highlight how the researcher elects qualitative over quantitative methods (although not exclusively), this is often framed in a way that is more adaptable to dealing with multiple realities. These methods illustrate better the interaction between investigator and the focus group participants. In purposive sampling, the researcher is more likely to engage in random (or representative) sampling because it increases the range of data collected. Purposive sampling can be pursued in ways that will maximize the investigator's ability to devise grounded theory that takes adequate account of local conditions, local mutual sharing, and local values, for possible transferability. The researcher prefers inductive, as opposed to deductive, data analysis because that process is more likely to identify the multiple realities to be found in those data. Such data analyses are more likely to make the investigator-respondent interaction explicit, recognizable, and accountable.

Another point of reference is grounded theory, which is used when the researchers prefer to have the guiding substantive theory emerge from the data because no a priori theory could possibly encompass the multiple realities that are likely to be encountered (Lincoln and Guba 1985). For such a study, the interview guide would include questions that would guide the discussion, however, the participants would be expected to lead the discussions and potentially discuss topics that are not in the interview guide (Grinnell and Unrau 2011). In an emergent design, the researcher allows the research design to emerge/unfold rather than to construct it a priori, because it is inconceivable that enough could be known ahead of time about the many multiple realities to devise the design adequately. What emerges as a function of the interaction between investigator and participants is largely unpredictable, and the investigator cannot know the patterns that are likely to exist. The various value systems involved—including the investigator's own—interact in unpredictable ways to influence the outcome.

Thus far, this chapter has presented a foundation upon which the remaining sections can be understood and interpreted. Specifically, a definition of health promotion has been established, health promotion models have been presented, and ways in which qualitative inquiry can be used for health promotion has been discussed. Though the application and translation of research methods and scientific evidence to health promotion efforts have a long history, only recently have scholars begun to document translational measures in health education and promotion. In the next section, we will provide examples from the published, peer-reviewed literature of qualitative evidence used in health promotion efforts.

15.4 Health Promotion Using Qualitative Evidence: Examples from the Field of Public Health

In recent years, there has been an increase in the number of resources that describe ways to apply qualitative approaches to public health and human services research. This is despite the thinking of earlier scholars who noted the few resources that provided explicit detail about how to use qualitative methods for program planning purposes (Farquhar et al. 2006). Given the various resources that exist for ways to apply quantitative methods to program planning, the sparse number of references that describe applications and translations of qualitative methods to health promotion efforts is surprising. Additionally, there has been a growing trend toward evidence-based health promotion (Harris et al. 2012) as well as community-participatory research (Bensley and Brookins-Fisher 2001; Blumenthal et al. 2013). Therefore, one could argue that the ways in which qualitative and quantitative methods are used to inform research and practice should be more closely examined.

A review of the literature on health promotion studies spanning from 1992 to 2013 that applied qualitative research methods uncovered a plethora of studies on specific physical (e.g., cardiovascular disease, human papillomavirus, obesity) and mental (e.g., serious mental illness) health topics, as well as overall health and well-being. After a systematic literature search was conducted for English-only, peer-reviewed articles using the search databases PsycINFO, EBSCOhost, and Google Scholar, 41 articles were found that presented both methodological evidence and examples of studies that utilized qualitative evidence for health promotion purposes. Our review of these articles was systematic as we used specific search terms to locate relevant articles (e.g., *health promotion*, *qualitative research*, *qualitative methods* and *qualitative evidence*) and established a clear distinction between the articles that provided general information and support for this chapter ($n = 15$), and the other 26 that offered empirical cases where qualitative evidence was used to promote health education, research, and practice. The empirical case articles used methods to improve health promotion through three topical areas: (1) health care professionals, (2) clients, and (3) community capacity building.

15.4.1 Using Qualitative Evidence from Health Care Professionals to Improve Health Promotion

One area of qualitative evidence in health promotion has focused on evaluating health care professionals to improve their service delivery practices (Greenway et al. 2013; Hannon et al. 2012). These studies utilized semi-structured interviews and/or focus groups to elucidate ethical and structural barriers to delivering services to clients. For example, a recent UK-based study examined ethical tensions for community health nurses, called health visitors, regarding their need to respond to the public health agenda and how that influenced the needs of clients (Greenway et al. 2013). To uncover these ethical considerations, the authors decided that an exploratory, cross-sectional interpretive method of inquiry was most appropriate. Semi-structured interviews with health visitors were used to provide a rich, in-depth examination of health visitors' perceptions of their role, experiences, current public health interventions, and ethical tensions. After a rigorous, framework-based analysis, findings revealed the priorities of clients and how they sometimes conflicted with the goals of the health visitors' agencies, impeding the ability of employees to meet the needs of clients.

Beyond ethical considerations of health care workers, qualitative methods can also be used to evaluate more tangible health promotion barriers to working with clients. One example of this is a study from the U.S. in which the authors conducted five focus groups with representatives from midsized companies who were based at their company's headquarters and responsible for their company's workplace health promotion (WHP) efforts (Hannon et al. 2012). The authors' rationale for conducting their study using a qualitative approach rather than a survey was that there was limited qualitative research exploring their particular research questions using samples from midsized (with 100–999 workers) agencies. In other words, the topic was "relatively undefined" (Hannon et al. 2012, p. 104). Barriers identified by participants focused on the cost of WHP interventions, problems with planning and coordinating, and lack of support and enthusiasm for WHP interventions in the workplace. For this study, qualitative evidence was used to inform later interventions and quantitative survey studies that addressed the health promotion needs of midsized companies and their employees (Hannon et al. 2012).

Both of these studies utilized qualitative evidence to inform a virtually unexplored area by way of formative research (Salazar et al. 2006). These studies suggested that, though health promotion efforts tend to focus on ways to positively impact the client, deeper qualitative probing with health care professionals can provide a unique context and inform health promotion efforts using a different lens beyond that of the clients.

15.4.2 Using Qualitative Evidence from Clients to Improve Health Promotion

In addition to health care professionals, our review of the health promotion literature also revealed studies reporting the use of qualitative evidence from clients to inform health promotion research and practice efforts (Adams et al. 2013; Ferrari et al. 2009; Handlovsky et al. 2013; Hesketh et al. 2005; Pitts and Tufts 2012; Shiner et al. 2008). Overall, these studies obtained client-level qualitative evidence to determine how the clients define concepts relating to health, as well as client preferences for specific health interventions and policies. Overlapping topical areas existed across these client-focused studies. For example, three studies used qualitative methods to gather parental input for ways to improve children's outcomes. Pitts and Tufts (2012) conducted focus groups with parents in Virginia (U.S.) to explore their understanding of the human papillomavirus and vaccine and their responses to the state mandate that was enacted in 2009. Similarly, Hesketh and colleagues (2005) used data from Australian schools to elicit child and parent views about social and environmental barriers to healthy eating, physical activity, and child obesity prevention programs.

Beyond the motivation to use a qualitative approach because of the sensitivity of the topics of HPV and obesity among youth, the authors also reported the value of using focus groups as a way to enhance community members' knowledge about the topic and heighten individual's communicative self-efficacy (Pitts and Tufts 2012). Methods were similar for these two studies except that Hesketh et al.'s (2005) study also used photographs with the children to engage them and guide their discussions about healthy eating and physical activity. Client-level data was also used in a Canada-based study that focused on gathering input from immigrant families regarding physical health educational materials. Semi-structured interviews were used in this exploratory study to examine immigrants parents' responses to existing public health education materials and strategies (Ferrari et al. 2009). Specifically, the authors highlighted the importance of their use of focus groups, rather than other qualitative methods, as they were particularly interested in the interaction among focus group participants and how participants' ideas were generated out of the ideas of other participants. Study findings suggested that program educational materials needed to be delivered in more culturally relevant ways and with more participation from the community (Ferrari et al. 2009).

The abovementioned studies focused on secondary, client-level data sources: parents of the children who would participate in the health promotion interventions. However, we also found similarities among other client-focused studies we reviewed. For instance, despite their global settings—New Zealand, Canada, and the US—we discovered that the remaining studies that used client-level qualitative evidence were all conducted with vulnerable populations. For example, Adams et al.'s (2013) New Zealand-based study conducted 11 focus groups with 45 gay men in order to understand their definitions of health and strategies to improve it. The authors found that, among the sample, focus groups helped delineate how the acceptance of gay men on a larger societal level was critical to improving health in this community. According to the authors, using qualitative methods assisted them in supplementing "mainstream understandings of how men conceptualize responsibility for health and the implications of these for health policy and planning" (Adams et al. 2013, p. 889).

A Canadian study collected client-level qualitative data in order to develop strategies for health promotion among women who used crack cocaine (Handlovsky et al. 2013). The authors provided a discussion of the theoretical perspectives that informed their study, citing feminist, social justice, and empowerment discourse. Methods were described in the context of these theoretical perspectives and included group interviews with 27 substance-abusing women in a substance abuse clinic. The goal of the interviews was to identify safer drug use strategies for women in that community. Though the authors discussed the limitations of their study, some of which were by virtue of the qualitative design implemented, they also indicated the strengths of qualitative evidence in reaching a vulnerable population that needed more education about safer drug use strategies and safe spaces for drug use. Access to clean and sterile drug paraphernalia was also critical to improving health outcomes in this sample (Handlovsky et al. 2013). Similarly, a U.S.-based study collected qualitative feedback on the effectiveness of an intervention aimed at improving the physical health of persons with serious mental illness (Shiner et al. 2008). The qualitative design helped participants identify components of the intervention that were most effective including forging trusting relationships with health care professionals and receiving individualized program planning in the intervention (Shiner et al. 2008).

Each of the client-level studies reviewed for this chapter presented findings that allowed for a deeper understanding of the lives of clients and their networks. Despite the geographical locations of the studies, the authors found qualitative methods useful in collecting information from vulnerable populations. The use of qualitative evidence by the aforementioned authors, as well as their rationale for choosing qualitative methods over quantitative methods, supports previous methodological conditions under which qualitative inquiry should be used for health promotion purposes (Salazar et al. 2006).

15.4.3 Using Qualitative Evidence from Community Stakeholders for Health Promotion

The final topic area identified in our review clustered around qualitative evidence used as a means to evaluate community involvement in health promotion activities (Joffres et al. 2004; Levy et al. 2004). Generally, the scholarly discourse in this area suggests that this research is primarily conducted with community stakeholders in an effort to assess and enhance community involvement in a variety of health promotion initiatives. For instance, two reports involved acquiring community-level qualitative evidence to inform heart health interventions. A report, from a community-based participatory research effort to eliminate cardiovascular disease disparities among African Americans and Latinos compared to Whites, used qualitative methods as part of a needs assessment and to make preliminary plans for a health promotion intervention (Levy et al. 2004). Specifically, the authors used focus groups and open-ended interviews to gather information that would enhance knowledge about differing cultural characteristics of racial/ethnic minority groups in the community that may impact health promotion, in addition to helping to identify strategies to enhance program planning.

Another study explored the factors that influenced organizational capacity-building efforts for heart health promotion (Joffres et al. 2004). The authors conducted semi-structured and one-to-one interviews with community members and community partners in order to evaluate facilitators and challenges to capacity building for heart health promotion. Given the sparse research in this area, the authors used what they referred to as a "qualitative paradigm" (2004, p. 41) to provide a context for inquiry. Also noteworthy is the authors' decision to pair qualitative methods with participatory action research (PAR) principles to guide their study. With PAR members of the target population are included in the research process. Grounded theory techniques led to the identification of factors that impacted organizational capacity for heart health promotion, including the state of partnerships, the quality of leadership, and the preparedness of organizations.

Using an action research approach, Hugentobler et al. (1992) described the process of implementing a health promotion intervention within a participatory framework. The authors conducted a longitudinal, multi-method study (using four different data sources, collecting both qualitative and quantitative data) to examine the relationship between occupational stress, psychosocial moderating factors, and health outcomes. The study utilized semi-structured interviews and focus group data to highlight the effectiveness of a health intervention that involved the participation of multiple stakeholders, including community members (Hugentobler et al. 1992). The multiple data sources used to achieve this study's research goals (Creswell and Plano Clark 2011) echo the fourth purpose for using qualitative inquiry for health promotion purposes (Salazar et al. 2006). Reducing work stress and improving employee health were additional goals of the study. The intervention sought to reduce work-related stress and improve employee health overall.

Other research has sought to highlight the need and desire of communities to engage in community-based health promotion interventions. For example, a study conducted in a rural community of Tanzania highlighted ways to develop action-oriented health education for children in school and community settings (Mwanga et al. 2007). Like the previous studies that used community-level qualitative data to inform health promotion efforts, the authors of the Tanzania study used concepts of action, participation, and action competence as their guiding conceptual framework. Akin to the study by Hugentobler et al. (1992), the authors also used multiple data sources, although only qualitative data were collected. Findings from this study called for the active involvement of children in the development and delivery of health interventions within a participatory framework (Mwanga et al. 2007).

15.5 Recommendations and Implications

This chapter discussed qualitative evidence in health promotion by first defining health promotion, examining how health promotion has benefited from qualitative research methods, and then reviewing examples from the literature on the various ways that scholars have used qualitative evidence to promote their health initiatives. Despite the important role that qualitative evidence has had in health promotion for the past few decades, health program planning, implementation, and evaluation must always work within the laws and policy guidelines regarding content and research methodology (Salazar et al. 2006). Moving forward, scholars and practitioners who are interested in using qualitative evidence in health promotion efforts should be mindful of three considerations.

First, *health promotion is guided by the multiple levels of influence paradigm*, which can be examined best using multiple data sources. There has been a general acceptance of the need for multilevel interventions, as illustrated in *Healthy people 2020* (USDHHS 2011). The idea that there is no single entity that influences health and health behaviors encourages health educators to take multidisciplinary approaches to the design, implementation, and evaluation of interventions. Possessing the ability to impact people from a multi-level approach is beneficial. Since multiple levels of influence take into account the physical environment and its influence on behaviors, the interaction across dimensions is useful in designing interventions that predict how categories of these behavioral determinants interact. Designing interventions takes into account various determinants, thereby requiring multiple measures and types of data to acquire the appropriate information to be included in interventions. Since quantitative data cannot always capture the level of detail needed to design targeted interventions, qualitative data can be used to gather the relevant context and content needed to design effective interventions that influence these multiple levels of health and health behaviors. Another advantage to using qualitative evidence to probe deeper into the multiple levels of influence is that qualitative evidence can be useful to health promotion program stakeholders. Studies have depicted the power of the human voice in exacting change across institutions and communities. Such context about health challenges can provide insight into how a particular group feels about a program as well as the details around how change can occur at the individual, organization, and political level. Though numerical evidence can help capture prevalence and occurrence rates across multiple levels, qualitative evidence can provide a language for doing health promotion using a multi-level approach at local, regional, and national levels.

The qualitative methods used in some research have also been utilized to evaluate compliance with a health promotion policy, for example, in the HPV study discussed earlier in this chapter (Pitts and Tufts 2012). The factors identified as barriers to compliance with the HPV vaccine requirement in that study included a lack of education regarding the purpose of the vaccine and the rationale behind the mandate for the vaccine. Also, in an effort to gather parent and child perceptions of healthy eating, physical activity, and obesity Hesketh et al. (2005) conducted focus groups with 119 children and 17 parents. Their study identified several themes, including lack of information regarding healthy lifestyle strategies and problems with the logistics of attending obesity prevention programs for parents. It will be important for future scholars and health promotion practitioners to examine all aspects of a health problem from an ecological perspective and acquire knowledge for how to perform rigorous qualitative research in order to inform research and policy on health promotion and disease prevention that benefits various stakeholders.

Second, *the rigor of qualitative methods is more important than the actual methods themselves*. Since one of the goals of health promotion is to encourage the individual to make informed health behavior changes, health advocates should be well aware of the importance of rigor when choosing and implementing qualitative methods. Studying the work of experienced and highly respected qualitative researchers will increase our own ability to conduct sound qualitative research. But the conduct of rigorous qualitative research requires two specific considerations: advanced study and ethical vigilance. In addition to the popularity of mixed methods over the past four decades (Creswell et al. 2011), an evolution in how areas of research can be best studied has also occurred. More and more resources are becoming readily available for how to conduct qualitative research for applied professions, to translate qualitative evidence to practical solutions, and even how to write successful qualitative proposals for funding (Creswell et al. 2011). Likewise, the number of research methods courses that put equal value on quantitative and qualitative research is an indicator that health problems can be best tackled by building on the strengths of both approaches to complement one another and override their weaknesses. So the ways in which we apply rigor to qualitative methods is more valuable than the methods themselves. Without rigor indicators such as trustworthiness, dependability, and credibility (Ulin et al. 2005) applied to every step in the research process, the evidence generated from the findings will always be questionable.

There is also the case of ethical vigilance that needs to be considered in order to conduct rigorous qualitative research, as a number of ethical considerations exist. First, scholars and practitioners are encouraged to educate themselves on the ethical issues associated with qualitative research procedures, and how they might differ from that of quantitative procedures. For example, qualitative methods may have certain ethical issues that are typically associated with gathering personal information through audio-recordings that could identify a participant (Creswell et al. 2011). These issues influence the quality of the data collected as well as the credibility of the overall study.

The final consideration for scholars and practitioners is their important role in *advocating for what qualitative evidence provides to health promotion*. In a world where statistics can be the driving force behind a health topic receiving mandated government support, media attention, and community resources, the voices of our target populations are sometimes muted. In this regard, and for some specific areas of inquiry, qualitative work needs a stronger platform. From a methodological perspective, the purpose of quantitative research is to collect information from a sample of the population from which broader generalizations can be derived about the larger population. So, by nature, quantitative evidence is used to make decisions about federal initiatives and resource allocation. The purpose of qualitative data, unlike quantitative data, is to provide a deeper understanding of a phenomenon of interest. Such rich text data can provide clarity around health behaviors and health decisions that quantitative evidence cannot capture. Though statistics can be helpful in providing the current status of a particular health concern, qualitative data, in the form of participant's words, can be used in the health promotion materials that are developed to reach a certain target group. In future considerations of how qualitative evidence can contribute to health promotion work, it will be important for scholars and practitioners to understand, and advocate for, qualitative evidence and what it can uniquely contribute to the overall health problem, apart from quantitative evidence.

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16 Qualitative Evidence in Pediatrics

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16.1 Introduction

It is well established that qualitative research makes a unique and valuable contribution to health evidence (Dixon-Woods et al. 2004; Harari 2001; Jackson 1982). Qualitative research can illuminate the attitudes, opinions, feelings, and behavior of individuals or groups of individuals around common phenomena (Co and Perrin 2005). Qualitative approaches are often used when attempting to understand poorly understood phenomena with limited previous investigation. Indeed, the intricacy of current health care environments, the diverse range of acuity and health conditions people face and the numerous players that are involved in the health care system requires research approaches that contextualize this complexity. Qualitative research illuminates these complexities and is often the most ideal approach to understand complex phenomena. For these reasons, when discussing knowledge of the state of qualitative research in pediatrics, a domain where the described complexities are a reality, it is important to identify *what* qualitative research has been completed, *how* qualitative evidence has been used and to identify opportunities for future qualitative work in this domain.

Qualitative evidence can and does make a substantial contribution to the field of pediatric health care. The settings that deliver health care to children are unique and vastly multidisciplinary, encompassing a wide-range of health care professions. There are well-documented distinctive challenges of providing health care to children including factors such as: (1) children (in comparison to adult patients) require additional time, effort and skill from staff caring for them due to their developmental needs; (2) children demand higher emotional investment from health care professionals; (3) the dynamic nature of children's health care needs; (4) the expectation of family-centered care and; (5) the unique ethical situations encountered in pediatric care. In the context of pediatric practice environments, parents, siblings and other family members play a central role in patient care—a unique element to this domain. The family-centered care principles evident in many pediatric practice environments are testimony to this familial involvement. Understanding the relationships and experiences of pediatric care recipients and

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their families is an integral component of health evidence and impacts how clinical decisions and care are provided. Qualitative inquiry is valued in this domain to gain understanding and attribute meaning to experiences of health and illness, family dynamics, care experiences, care delivery systems and patient, health care provider and family perspectives, in a way not possible through quantitative approaches (Beaune et al. 2004; Björk et al. 2006).

The purpose of this chapter is to provide a systematic overview of the use of qualitative research in the field of pediatrics. To do so, we conducted a scoping review of qualitative research in pediatrics, guided by a specific definition of pediatrics, to identify key qualitative approaches, applications, and trends in the use of qualitative methods. We used the following definition of pediatrics to guide our review:

> Pediatrics is the specialty of medical science concerned with the physical, mental and social health of children from birth to adulthood. Pediatrics encompasses a broad spectrum of health services ranging from previous health care to the diagnosis and treatment of acute and chronic diseases. (American Academy of Pediatrics 2012).

For the purposes of this scoping review we have conceptualized *evidence* as being synonymous with research by virtue of our methodological approach of reviewing only published qualitative research with this scoping review. We acknowledge that evidence has many forms and a multitude of understandings. The literature is rife with calls for inclusivity in terms of what evidence is and the unfortunate result is conceptual confusion with the term (Scott-Findlay and Pollock 2004). We want to stress, that while we have conceptualized evidence in this fashion for this scoping review, we acknowledge the importance of other influences on the clinical decision-making process (e.g., personal experience, patient preference).

Through this review, we provide an overview to identify qualitative research trends in pediatrics, discuss how qualitative evidence can be used to inform practice and decision making, and offer general recommendations for researchers wanting to use these approaches in future work. The health care professionals included in our approach included physicians, nurses, rehabilitation specialists, social workers, dieticians, respiratory therapists, and pharmacists. Although other disciplines are involved in pediatric care, these disciplines were selected due their prominent role in the care of children.

16.2 Methods

16.2.1 Search Strategy

We conducted a broad search of the literature in August 2012 to explore the state of qualitative research in pediatrics. A health research librarian (TC) searched the electronic databases of Medline and CINAHL with no date limiters or language restrictions. A qualitative filter with relevant MeSH headings, such as “pediatrics” and “qualitative research,” was used. We employed a variety of search terms relating to qualitative research methods, qualitative data collection approaches and child health (e.g., “nursing methodology research,” “focus groups,” “ethnography,” “field note,” and “participant observation”). Our complete search strategy is available in Appendix A. The principle of comprehensiveness guided this project, however we acknowledge that specific subjects areas, such as pediatrics, bring their own additional challenges to identifying the literature, such as the breadth and indexing of the topic area (Sladek et al. 2006). We aimed to mitigate these challenges through development of a comprehensive search strategy, searching multiple databases and working closely with a research librarian.

16.2.2 Inclusion and Exclusion Criteria

In September 2012, a graduate research assistant (LP) commenced primary screening of the titles and abstracts according to preestablished inclusion and exclusion criteria. Qualitative research articles of any design focusing on pediatrics (from the perspective of children or adolescents, family members, and health care providers) were included and passed onto secondary level screening. Studies including a quantitative component, non-English articles, and gray literature were excluded from our review. We revised our inclusion criteria in an iterative manner during the initial screening process to more precisely reflect the scope of our review and to maintain consistency with our definition of "pediatrics" which guided our literature search. At the secondary screening stage, research conducted on the "well" child, ethics in pediatric research, decision-making processes, transition to adult care settings, or evaluation research of experimental interventions were excluded.

16.2.3 Data Extraction

We extracted data in December 2012 based on a collaboratively developed, standardized data extraction form. In addition to the citation information (i.e., authors, year of publication, title, journal), we extracted data on the first author's discipline, country, research design, method, and methods of data collection. We collected information on the intended perspective of the research; that is, we examined the purpose statement in the research to garner which perspective was the focus of the research (if relevant). For instance, was it the child, parent or health care provider or iterations of these groups? Furthermore, we extracted information on the sample and source of the data. We also captured whether or not the investigator discussed outcomes related to research, practice, and policy. Finally, we also extracted data on the purpose of each study to identify the overall themes represented in these studies. As the purpose of our scoping review was to provide an overview of the state of qualitative research in pediatrics, we did not conduct methodological quality assessments of the included articles.

16.2.4 Data Analysis

To explore themes and trends pertaining to the use of qualitative research in pediatrics, we coded and categorized data from the 163 included articles for descriptive analysis in SPSS. We conducted a cross-comparison of five variables in four comparison groups: methods and discipline, methods and year, perspective and year, and sample and year. Cross-comparison analysis of research designs was not conducted due to variability in how research design was conceptualized and explained in the included studies.

16.3 Findings

Our search yielded 4171 articles. After 565 duplicates and 3606 non-relevant articles were excluded, the remaining 434 articles were reviewed by one author (LP) and checked by another author (MA). In total, 163 articles met our inclusion criteria. Please see our quorum flow diagram in Fig. 16.1.

16.3.1 Discipline and Country of the First Author and Prominent Publication Venues

Of the total 163 included articles, nursing ($n=114$) was the discipline most commonly using qualitative methods, followed by medicine ($n=18$), social work, ($n=14$), not clear ($n=12$), rehabilitation specialists ($n=4$), and nutritional science ($n=1$). The "not clear" category encompassed the articles where the disciplinary background of the first author was not clearly identified in the article and was not verifiable during an online search. The most frequently identified countries of the first author included the United States ($n=57$), Canada ($n=22$), the United Kingdom ($n=22$) and Australia ($n=13$). The top three venues in our sample for publishing qualitative research in pediatrics were the *Journal of Pediatric Oncology Nursing* ($n=16$), the *Journal of Pediatric Nursing* ($n=12$), and *Oncology Nursing Forum* ($n=8$).

16.3.2 Method Used

The methods among the included studies ($n=163$) varied and were categorized into six groups. Overall, the dominant qualitative tradition employed

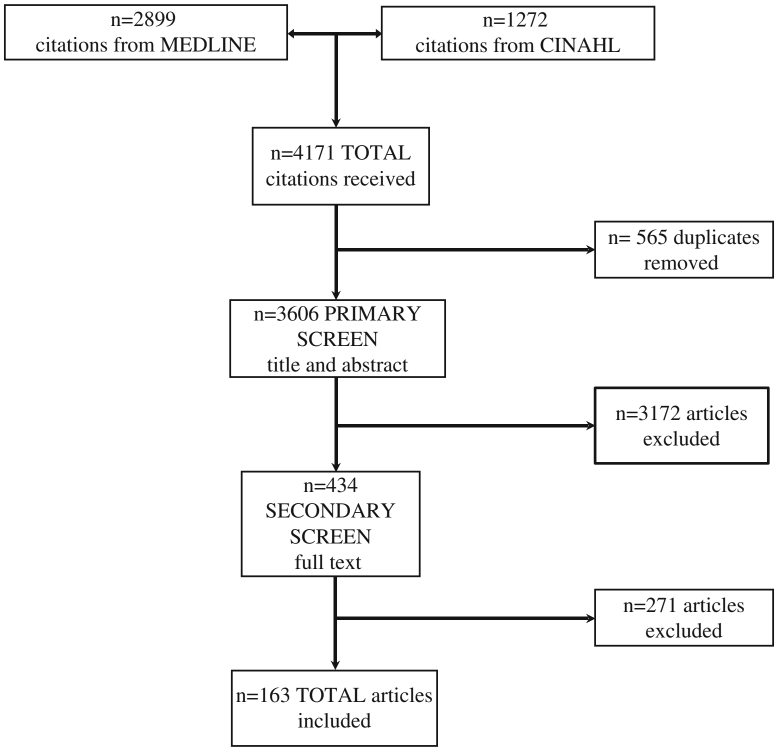


Fig. 16.1 Quorum flow diagram. The Quality of Reporting of Meta-analyses (QUOROM) flow diagram. Adapted from "Improving the quality of reports of meta-analyses of randomised controlled trials: the QUOROM statement," by D. Moher, D.J. Cook, S. Eastwood, I. Olkin, D. Rennie, D.F. Stroup, for the QUOROM Group, 1999, The Lancet, 354 p. 1898

was phenomenology (n=46), general or generic qualitative research (n=45), and grounded theory (n=32). In 29 of the articles, the qualitative method was unclear or not stated; rather the data collection sources were described. The use of ethnographic methods or approaches were of the second lowest frequency (n=10) above case study (n=1). When authors drew on techniques, principles or theories of a particular method, they were coded according to the referenced method. For instance, Auslander et al. (2010) study "used a modified grounded theory approach" and thus, was coded as grounded theory (p. 613).

16.3.3 Cross-Comparison: Discipline and Methods

We used a stacked bar graph to cross-compare research methods and discipline (see Fig. 16.2). Of the total (n=46) phenomenological methods, disciplinary backgrounds included nursing (n=41), medicine (n=2), rehabilitation (n=2), and social work (n=1). Within the "qualitative" grouping (n=45), disciplines included nursing (n=22), social work (n=8), medicine (n=7), not clear (n=6), and rehabilitation (n=2). Disciplinary backgrounds from the grounded theory (n=32) articles included

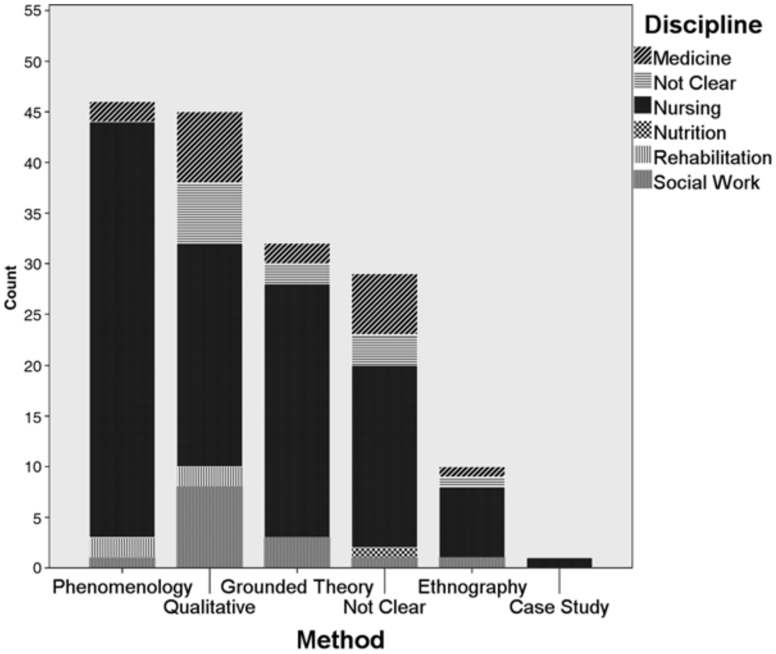


Fig. 16.2 Conventional qualitative methods by discipline. Method (discipline). Case study (nursing, $n=1$) (Total, $n=1$). Ethnography (medicine, $n=1$) (not clear, $n=1$) (nursing, $n=7$) (social work, $n=1$) (Total, $n=10$). Grounded theory (medicine, $n=2$) (not clear, $n=2$) (nursing, $n=25$) (social work, $n=3$) (Total, $n=32$). Not clear (medicine, $n=6$) (not clear, $n=3$) (nursing, $n=18$) (nutrition, $n=1$) (social work, $n=1$) (Total, $n=29$). Phenomenology (medicine $n=2$), (nursing, $n=41$) (rehabilitation, $n=2$) and ($n=1$) (social work, $n=1$) (Total, $n=46$). Qualitative methods (medicine, $n=7$) (not clear, $n=6$) (nursing, $n=22$) (rehabilitation, $n=2$) (social work, $n=8$) (Total, $n=45$)

nursing ($n=25$), social work ($n=3$), medicine ($n=2$), and not clear ($n=2$). In the 29 “not clear” methods, disciplines included nursing ($n=18$), medicine ($n=6$), unclear disciplines ($n=3$), nutrition ($n=1$) and social work ($n=1$). In the ten ethnography articles, disciplines included nurses ($n=7$), medicine ($n=1$), social work ($n=1$), and unclear ($n=1$). Finally, the discipline from the one article employing case study methods was nursing.

16.3.4 Year of Publication Categories

As reflected in Fig. 16.3, the number of included articles ($n=163$) employing qualitative methods has steadily increased across time in the field of pediatrics. There was only one article prior to 1993 that met our inclusion criteria, then the following number of articles were published in the time intervals: 1993–1996 ($n=12$ articles); 1997–2000 ($n=15$); 2001–2004 ($n=35$ articles); 2005–2008 ($n=42$); 2009–2012 ($n=58$).

16.3.5 Cross-Comparison: Methods and Year

Trends in the use of different qualitative approaches were observed over time, with particular approaches (e.g., phenomenology and qualitative) gaining popularity in more recent years. As Fig. 16.3 illustrates, of the 58 articles in the most recent time interval (2009–2012 category), methods included phenomenology ($n=18$), qualitative ($n=17$), grounded theory ($n=11$), not clear ($n=10$), and ethnography ($n=2$). Within the

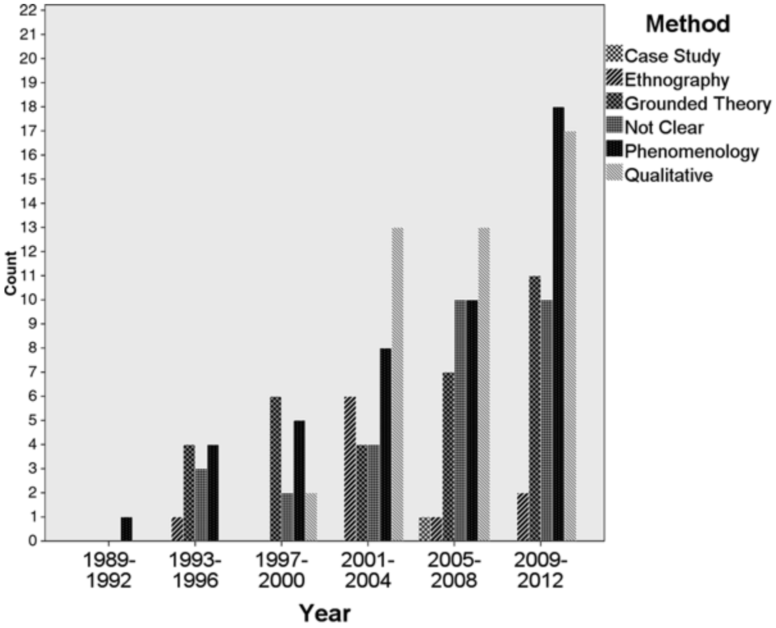


Fig. 16.3 Methods across time. Method (year). Case study (2005–2008, $n=1$) (Total, $n=1$). Ethnography (1993–1996, $n=1$) (2001–2004, $n=6$) (2005–2008, $n=1$) (2009–2012, $n=2$) (Total, $n=10$). Grounded theory (1993–1996, $n=4$) (1997–2000, $n=6$) (2001–2004, $n=4$) (2005–2008, $n=7$) (2009–2012, $n=11$) (Total, $n=32$). Not clear (1993–1996, $n=3$) (1997–2000, $n=2$) (2001–2004, $n=4$) (2005–2008, $n=10$) (2009–2012, $n=10$) (Total, $n=29$). Phenomenology methods (1989–1992, $n=1$) (1993–1996, $n=4$) (1997–2000, $n=5$) (2001–2004, $n=8$) (2005–2008, $n=10$) (2009–2012, $n=18$) (Total, $n=46$). Qualitative (1997–2000, $n=2$) (2001–2004, $n=13$) (2005–2008, $n=13$) (2009–2012, $n=17$) (Total, $n=45$)

42 articles in the 2005–2008 interval, methods included general qualitative ($n=13$), phenomenology ($n=10$), not clear ($n=10$), grounded theory ($n=7$), ethnography ($n=1$), and case study ($n=1$). The 35 methods within the 2001–2004 category included qualitative ($n=13$), phenomenology ($n=8$), ethnography ($n=6$), grounded theory ($n=4$), and not clear ($n=4$). The 15 articles in the 1997–2000 category included grounded theory ($n=6$), phenomenology ($n=5$), not clear ($n=2$) and qualitative ($n=2$) methods. The 1993–1996 grouping encompassed 12 articles employing grounded theory ($n=4$), phenomenology ($n=4$), not clear ($n=3$), and ethnography ($n=1$). The earliest grouping (1993–1996) only contained one qualitative article published in 1990.

16.3.6 Sample Categories

Participant samples represented in our review were classified into eight categories (please see Fig. 16.4). Overall, child participants ($n=51$) represented the most common sample in our data set. Parent participants ($n=49$) represented the second most frequent category. Families, conceptualized as including two or more family member perspectives (i.e., mother and child), were sampled in 24 included studies. Sixteen articles gathered their data from exclusively health professionals and ten articles gathered their data from exclusively from mothers. Nine articles gathered their data from health care professionals in addition to at least one other family member

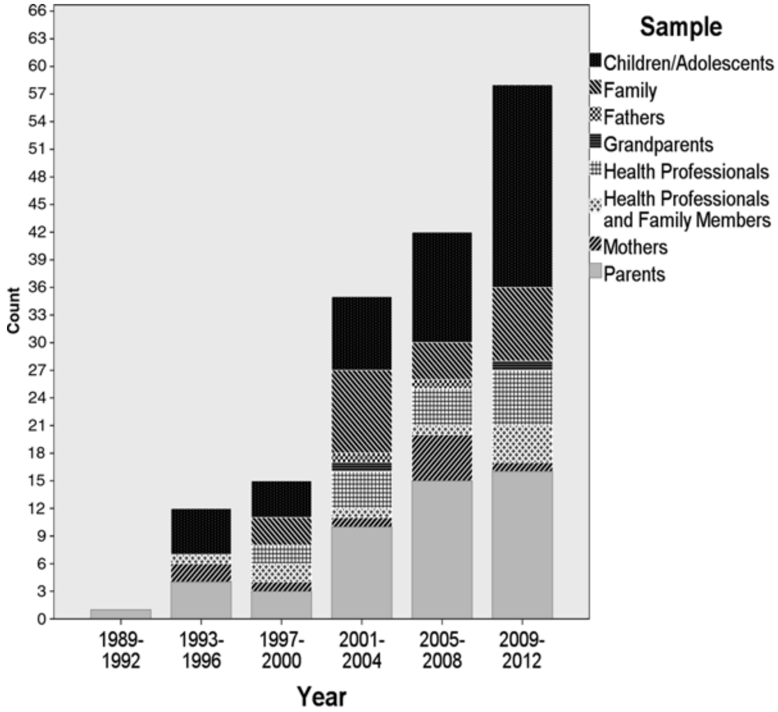


Fig. 16.4 Sample foci across time. Sample foci (years). Children/adolescents (1993–1996, $n=5$) (1997–2000, $n=4$) (2001–2004, $n=8$) (2005–2008, $n=12$) (2009–2012, $n=12$) (Total, $n=51$). Family (1997–2000, $n=3$) (2001–2004, $n=9$) (2005–2008, $n=4$) (2009–2012, $n=8$) (Total, $n=24$). Fathers (2001–2004, $n=1$) (2005–2008, $n=1$) (Total, $n=2$). Grandparents (2001–2004, $n=1$) (2009–2012, $n=1$) (Total, $n=2$). Health professionals (1997–2000, $n=2$) (2001–2004, $n=4$) (2005–2008, $n=4$) (2009–2012, $n=6$) (Total, $n=16$). Health professionals and family members (1993–1996, $n=1$) (1997–2000, $n=2$) (2001–2004, $n=1$) (2005–2008, $n=1$) (2009–2012, $n=4$) (Total, $n=9$). Mothers (1993–1996, $n=2$) (1997–2000, $n=1$) (2001–2004, $n=1$) (2005–2008,$n=5$) (2009–2012, $n=1$) (Total, $n=10$). Parents (1989–1992, $n=1$) (1993–1996, $n=4$) (1997–2000, $n=3$) (2001–2004, $n=10$) (2005–2008, $n=15$) (2009–2012, $n=16$) (Total, $n=49$)

(i.e., child, parents). Grandparents ($n=2$) and fathers ($n=2$) represented the least sampled population in our data set.

16.3.7 Cross-Comparison: Sample and Year

Sample participants and year of publication were cross-compared (please see Fig. 16.4). Generally speaking, across time, there was increasing use of child participants and parents as participants (with the exception of the 1997–2000 time period). Of note, there was an increased reliance on mothers as research participants in the 2005–2008 time period.

16.3.8 Perspective Categories

In our review, perspective refers to the *focus* of the data collection and differs from sample, which refers to the *source* of data collection. Eight different perspective categories were identified including children ($n=84$), parents ($n=32$), family (18), health professionals ($n=15$), mothers ($n=8$), fathers ($n=3$), grandparents ($n=2$), and a multiple perspective category: health professionals and family members ($n=1$). Furthermore, as Fig. 16.5 illustrates, over time, there is an increasing focus on obtaining the children's perspective. Of note, as described above, 51 articles had children as their sample, yet 84 studies had *children* as the focus (perspective). This discrepancy is important and

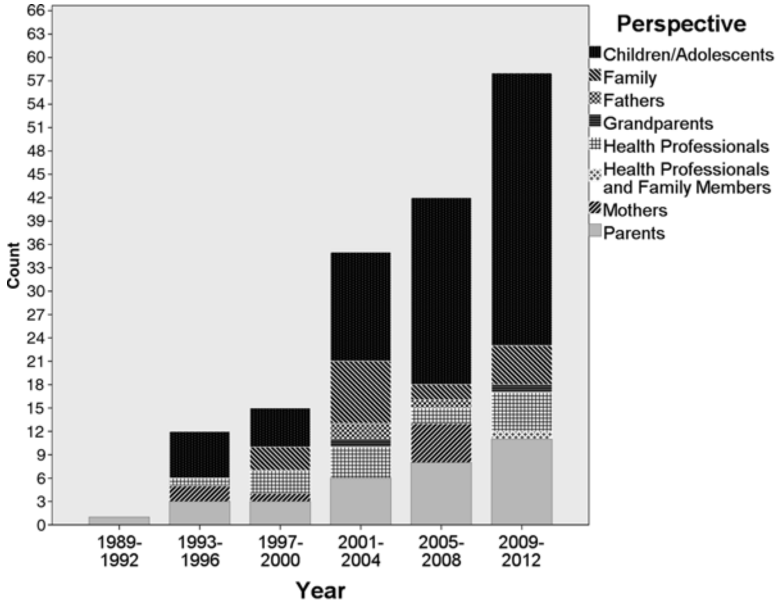
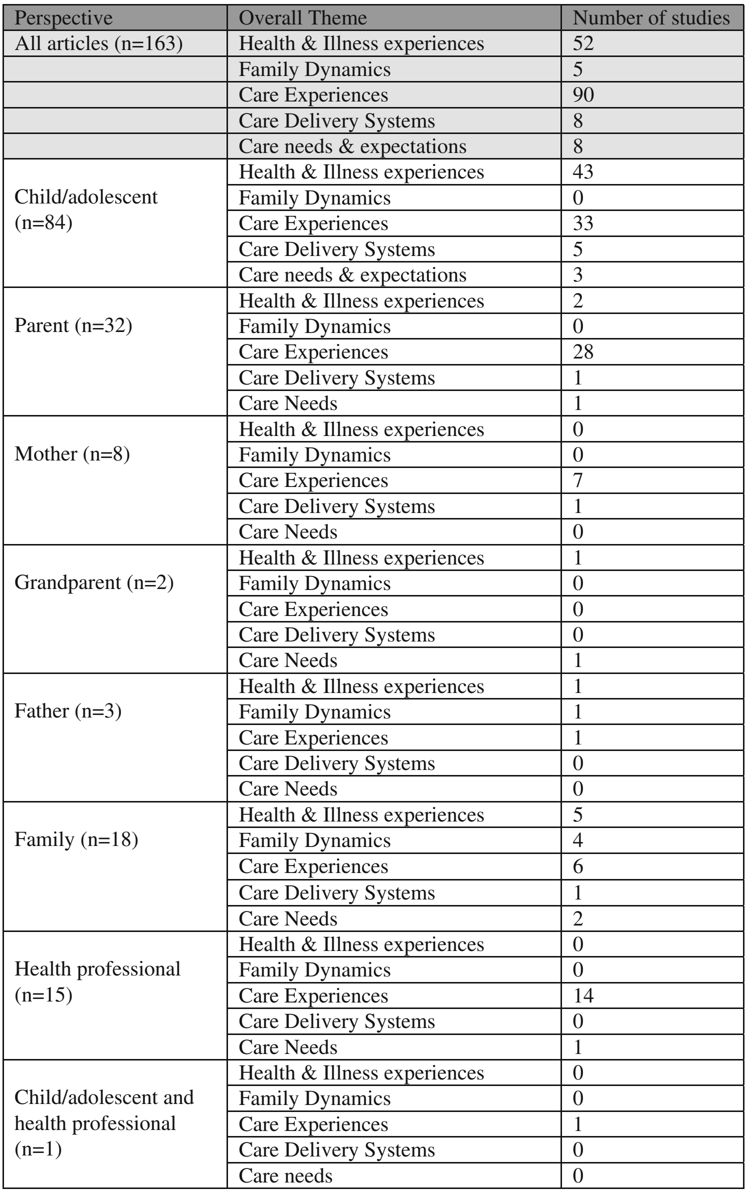


Fig. 16.5 Perspective foci across time. Perspective foci (years). Children/adolescents (1993–1996, $n=6$) (1997–2000, $n=5$) (2001–2004, $n=14$) (2005–2008, $n=24$) (2009–2012, $n=35$) (Total, $n=84$). Family (1997–2000, $n=3$) (2001–2004, $n=8$) (2005–2008, $n=2$) (2009–2012, $n=5$) (Total, $n=18$). Fathers (2001–2004, $n=2$) (2005–2008, $n=1$) (Total, $n=3$). Grandparents (2001–2004, $n=1$) (2009–2012, $n=1$) (Total, $n=2$). Health professionals (1993–1996, $n=1$) (1997–2000, $n=3$) (2001–2004, $n=4$) (2005–2008, $n=2$) (2009–2012, $n=5$) (Total, $n=15$). Health professionals and children/adolescents (2009–2012, $n=1$) (Total, $n=1$). Mothers (1993–1996, $n=2$) (1997–2000, $n=1$) (2005–2008, $n=5$) (Total, $n=8$). Parents ($n=1$) from 1989 to 1992, $n=1$) ($n=3$) from 1993 to 1996, $n=3$) (1997–2000,$n=3$) (2001–2004,$n=6$) (2005–2008, $n=8$) (2009–2012, $n=11$) (Total, $n=32$)

demonstrates how several studies were attempting to garner children's perspectives by collecting data from a different sample (non-children)—an approach often referred to as using "shadowed data" (Morse 2001). The *family* category was inclusive of articles that captured at least two family members' perspectives. Many articles captured the family in the traditional sense of immediate family members, such as parents and children (Franciosi et al. 2012; Gagnon et al. 2008; Hansson et al. 2012; Hughes and Callery 2004) as well as parents, ill children, and well siblings (Björk et al. 2005; Bray et al. 2012; Woodgate and Degner 2003a; Woodgate and Degner 2003b; Woodgate et al. 2003; Yin and Twinn 2004). However, other studies encompassed a broader mix of family members, including aunts (Bousso and Angelo 2003; Beyer and Simmons 2004), grandparents (Bousso and Angelo 2003; Contro et al. 2010; Scott-Findlay and Chalmers 2001), cousins and brother-in-laws (Contro et al. 2010).

The *parent* category was used to encompass not only parents (e.g., Carnevale 1990; Carnevale et al. 2006; DeLuca et al. 2011; Diaz-Caneja et al. 2005; Fereday et al. 2009; Green et al. 2009; Hall 2005; Harbaugh et al. 2004; Hendricks-Ferguson 2008; Kars et al. 2011; Lam et al. 2006; Lang et al. 2005; Latour et al. 2011; Lim et al. 2012; Maxton 2008; Reis et al. 2010; Rempel et al. 2009; Rini and Loriz 2007; Smith and Daughtrey 2000; Watt et al. 2012; Wills 1999; Weidner et al. 2011), but other primary caregivers and legal guardians as well. For instance, grandparents (e.g., Hinds et al. 1996; Lee and Weiss 2009; Mu and Tomlinson 1997; Mulvaney et al. 2006; Palmer 2001; Wu et al. 2010), adoptive parents (e.g., Hammami et al. 2004), step-parents (e.g., Neil-Urban and Jones 2002), and aunts (e.g., Contro et al. 2010; Beyer and Simmons 2004; Horner 1998) were included in the sample if they were considered the primary caregiver.



Perspective	Overall Theme	Number of studies
All articles (n=163)	Health & Illness experiences	52
	Family Dynamics	5
	Care Experiences	90
	Care Delivery Systems	8
	Care needs & expectations	8
Child/adolescent (n=84)	Health & Illness experiences	43
	Family Dynamics	0
	Care Experiences	33
	Care Delivery Systems	5
	Care needs & expectations	3
Parent (n=32)	Health & Illness experiences	2
	Family Dynamics	0
	Care Experiences	28
	Care Delivery Systems	1
	Care Needs	1
Mother (n=8)	Health & Illness experiences	0
	Family Dynamics	0
	Care Experiences	7
	Care Delivery Systems	1
	Care Needs	0
Grandparent (n=2)	Health & Illness experiences	1
	Family Dynamics	0
	Care Experiences	0
	Care Delivery Systems	0
	Care Needs	1
Father (n=3)	Health & Illness experiences	1
	Family Dynamics	1
	Care Experiences	1
	Care Delivery Systems	0
	Care Needs	0
Family (n=18)	Health & Illness experiences	5
	Family Dynamics	4
	Care Experiences	6
	Care Delivery Systems	1
	Care Needs	2
Health professional (n=15)	Health & Illness experiences	0
	Family Dynamics	0
	Care Experiences	14
	Care Delivery Systems	0
	Care Needs	1
Child/adolescent and health professional (n=1)	Health & Illness experiences	0
	Family Dynamics	0
	Care Experiences	1
	Care Delivery Systems	0
	Care needs	0

Fig. 16.6 Overall themes in articles

16.3.9 General Themes Represented in the Included Studies

We explored the purpose and findings of all studies and five themes were identified to synthesize the overall focus of this body of literature: (1) care experiences; (2) health and illness experiences; (3) care delivery systems; (4) care needs; and (5) family dynamics (see Fig. 16.6). *Care experiences* ($n=90$) was the most commonly identified overall theme. This theme includes studies that focused on the experiences of receiving or giving care. This theme was most prominent when obtaining parental perspectives ($n=32$). The majority of these studies (28/32) focused on the care experiences of the parent. Issues such as caring at home or in hospital for a sick child, participation in care, and caring experiences of parents for children with specific illness such as diabetes and cancer also fit within this theme.

An example of a methodologically rigorous study that reflected the common focus of this theme is the phenomenological study by Kars et al. (2011). Through in-depth interviews, the authors explored the experiences of 42 parents of a child with cancer through the end-of-life course. Four predominant themes were identified: (1) the inevitability of death; (2) making the child's life enjoyable; (3) managing the change for the worse; and (4) being with the dying child. In contrast, Hinds and colleagues (1996) employed grounded theory to understand how parents respond to their child's first cancer recurrence. The authors identified four related components that contribute to parents' ability to cope with their child's cancer recurrence, including: (1) regulating shock; (2) situation monitoring; (3) alternating realizations; and (4) eyeing care-limiting decisions. Such findings may be useful for health care professionals to understand and support families throughout periods of health and illness and transition.

The next most commonly identified theme was *health and illness experiences* ($n=52$ studies). Studies with this theme discussed the child/adolescent lived experiences of illness (i.e., cancer, HIV, and asthma) and illness symptoms or procedures were categorized under this theme. This theme was most commonly used when exploring the perspective of the child/adolescent ($n=43$), however family, parent, father, and grandparent perspectives were captured in this literature.

Consistent with the most commonly used methodology used in this theme, Wise (2002) used a phenomenological approach to uncover children's experiences of liver transplantation. Themes related to searching for connections, ordinary experiences of hospitalization, unpleasant experiences and parental responses were identified, shedding light on the challenges faced by children along the transplantation trajectory. Another example of a rigorous study included in this theme was conducted by Woodgate et al. (2003). The authors conducted 230 interviews with 39 children with cancer, their parents, and siblings to examine the experiences of cancer symptoms in a longitudinal interpretive study illustrating how children experience their symptoms as "feeling states," rather than exclusively on a physiological level. Implications for how health care professionals approach symptom management in childhood cancer were identified.

Studies exploring experiences of health programs and services were categorized under the theme *care delivery systems* ($n=8$) and reported on the perspective of the patient, parent, family, or father. These studies explored issues such as the experiences of a hospital-based program, services provided while in hospital, experiences while in specific hospital units and the delivery of care. To explore why parents seek emergency department (ED) treatment for their child's non-urgent health condition, Berry and colleagues (2008) discovered, through semi-structured interviews with 37 caregivers, that care-delivery system challenges influenced caregiver's decisions of where to seek treatment. Problems with primary care providers (PCP) (e.g., long wait times, negative attitudes and communication difficulties), referrals by the PCP, and perceived advantages to ED care were identified as the most influential factors. In contrast, DeLuca and colleagues (2011) studied parental perceptions of diagnostic testing for new disorders, for which little information is available, using a longitudinal design. Parental uncertainty regarding their child's health and the meaning of the test results was identified; information seeking behaviors were noted, particularly following the period after receiving the initial result; and parental misconceptions regarding the disorder persisted despite these information exposures. Based on these results, the authors concluded that clinical and communication service improvement for parents may be of merit.

Studies that focused on the needs (information, support, services) and expectations of multiple groups within the realm of pediatrics were categorized as *care needs* ($n=8$). This theme was explored from the perspective of the child/adolescent ($n=3$), parent ($n=1$), grandparent ($n=1$), family ($n=2$) and health professional ($n=1$). Issues such as the needs of parents and children after injury, support and service needs of sick children, support needs of health professionals and family needs were categorized under this theme.

For instance, Gagnon and colleagues (2008) used phenomenology to explore adolescent and parent perspectives on service need requirements following mild traumatic brain injury. Study findings illuminate that service needs related to recovery, information, and support exist and differ by level of care received. The opportunity to enhance professional service delivery for these populations is highlighted by the authors. Service requirements were also explored by Smith and Daughtrey (2000); however, the authors were interested in identifying gaps in nursing service delivery for acutely ill children and families following discharge. Parents expressed a need for information and reassurance following discharge and commonly experienced feelings of isolation. The authors indicate that improvements in communication and integration between hospital and primary care services may be warranted.

Finally, studies categorized under the theme *family dynamics* focused on the perspective of the family ($n=4$) or father ($n=1$). These studies explored issues such as the effects of cancer on the child, parents, and siblings. For example, Clarke-Steffen (1997) generated a grounded theory of how families transition to a child's cancer diagnosis, including familial strategies to aid adaptation. The concepts of limbo, new normal, and reconstructing reality that were encapsulated in the model may be useful for health care providers as they support families through periods of transition. Yin and Twinn (2004) also explored the effects of cancer on the family unit but used ethnographic methods. The authors found that while parents were knowledgeable about their child's condition and associated treatments, children's understandings and knowledge were inconsistent. A second theme, entitled being truthful about the disease, captured how children often knew more about their cancer than their parents anticipated, highlighting the importance of communication and disclosure between family members.

Overall, in the pediatric qualitative literature to date, there is great emphasis on using qualitative methods to explore multiple perspectives of experiences of illness and care. Our findings suggest while experiences of illness and care have been thoroughly explored, qualitative approaches to exploring family dynamics in pediatric health and illness have received less attention. Further, there is an underutilization of these methodological approaches to explore more health services research concepts, such as evaluation of pediatric care delivery systems.

16.4 Discussion

In the past 5 years, there has been an emergent theme in pediatric research literature of the lack of investment in rigorous quantitative pediatric research. It is predictable that this argument is framed by emphasizing that children are the future of society and thus optimizing their health outcomes holds important returns on investment for public health (Klassen et al. 2009). However despite the importance of children in society, there is a well-documented lack of clinical trials in pediatrics (Klassen et al. 2008; Cohen et al. 2007, 2010; Hartling et al. 2012). In fact, the quantity, quality, and relevance of quantitative research data involving children are substantially lower than for adults (Hartling et al. 2012). The reasons for this lack of research are largely methodological and practical and encompass challenges such as ethical issues (Dove et al. 2013), smaller sample sizes, more often single-centered studies, and large variability in age subgroups in children across studies thereby impairing study comparability (Martinez-Castaldi et al. 2008; Cohen et al. 2007, 2010). These challenges that plague quantitative research in pediatrics hold important opportunities for qualitative research in this domain. In fact, a great deal of qualitative methods can mitigate and overcome many of these challenges. Given the recent push for consumer involvement in health care and health care decisions, qualitative methods continue to offer a crucial methodological platform for children and their families to participate, have their perspectives heard (Beck 2009; Thorne 2008), and contribute to knowledge creation. As our scoping review demonstrates, there is increasing recognition of the value and opportunity for qualitative research to shape decisions and link evidence with practice.

In the field of pediatrics and medicine in general, there have been several seminal papers published on the importance of qualitative research highlighting its unique contributions (e.g., Mays and Pope 1995a, b; Mistry 2012; Pope and Mays 1995; Poses and Isen 1998; Rowan and Huston 1997; Saxena and Wiedermann 2009). These works highlight that qualitative research is becoming more prominent in health care and there have been increasing numbers of published qualitative studies in prominent medical journals (Poses and Isen 1998). Noteworthy is that in 1990, Beck described increasing interest and receptivity in pediatric nursing for qualitative research while emphasizing that nursing was currently undergoing a paradigm shift as a result of this widespread enthusiasm for qualitative inquiry (Beck 1990). On the other hand, in 1997, Rowan and colleagues underscored that qualitative research was "relatively new in the medical literature" (p. 1442). We found similar trends in this review with the nursing discipline leading the majority of qualitative pediatric research. Additionally, Rowan and colleagues suggested that there was much reporting variation in the current qualitative research in medicine, particularly in terms of the amount of detail provided in describing the methods and findings. Again, our synthesized findings echoed this reporting variation, noting that 29/163 articles did not report adequate details about the methods used. Going forward, we urge qualitative researchers to pay particular attention to ensure that there is adequate reporting of the methods that they use. In an era of evidence-based practice, it is critical that published research can be critically appraised and, central to this mission, is complete and clear reporting in research articles. Wilkins and Woodgate (2005), in their review of qualitative research on childhood cancer experiences from the perspective of siblings, noted similar findings. For example, they highlighted a lack of detail about research processes, particularly poorly described study samples, data collection, and analysis strategies.

In our review we noted that, across time, there were increasing numbers of studies employing a "general qualitative" approach (that is, not employing specific qualitative traditions). The origins of qualitative health research are rooted in a number of distinct but related disciplinary traditions (Thorne 1991, 2001) including phenomenology (adapted by psychology from philosophy), ethnography (from anthropology), and grounded theory (from sociology). These three social sciences, in particular, have long and rich histories in academia and since the 1980s, the health sciences have adopted and then adapted these methods and applied them to the research problems looming in the health sciences (Thorne 2001). The use of research traditions from the social sciences in the health sciences is not without challenges—the most significant is perhaps the difference in purpose between the social sciences (which is typically theoretical inquiry) and the health sciences (which generally has an applied or problem solving tradition). In our scoping review, the results mirror this point. That is, when qualitative methods started to be used in the field of pediatrics, there was a greater reliance on more tradition or purist forms of qualitative approaches from the social sciences. As time progressed however, there was an emergence and then increasing use of naturalistic approaches not explicitly grounded in the social sciences.

The increasing prevalence of qualitative research in pediatrics across time suggests a growing receptivity to the power of naturalistic inquiry to give voice to patient and family experiences, to evaluate treatment responses and to explain processes in relation to disease trajectories and health care systems. The work of Waters (2004) also echoes this increasing value on qualitative approaches in pediatrics. Increasing amounts of qualitative inquiry in health research in general (Macdonald 2009) and in pediatrics is a strong indicator that these approaches make an important contribution to the pediatric knowledge base (Wiart 2012). Furthermore, the amount of qualitative work in pediatrics points to the impact of context on the knowledge (that can be captured through qualitative approaches) that is required. So while there was increasing receptivity to qualitative work in pediatrics, recent work highlights that overall qualitative research makes up a very small percentage of general medical literature. Specifically, Gagliardi and Dobrow (2011) identified and compared the number of qualitative and non-qualitative research studies published in high impact health care journals from 1999 to 2008. During this time period, up to 0.6 % of the empirical research articles in general medical journals covered qualitative research and up to 6.4 % of the empirical research articles in the health services and policy research journals were qualitative research. This is a critical point for reflection as, while our findings and the resulting figures appear very encouraging in terms of the increasing number of qualitative studies published in pediatrics over time, there has been on average a 4.73 % increase in scientific publications, each year (Larsen and von Ins 2010).

As our scoping review demonstrated, qualitative research is being increasingly used with children and families in order to develop a knowledge base in pediatrics. However, despite this increased use of qualitative methods, there are multiple challenges in conducting this work such as ethical issues, and conceptual challenges. The results from our review highlight the main conceptual challenge that is the congruence between the sample and the perspective sought in the research (shadowed data). In other research areas, particularly those involving adults that are cognitive functional, this is not a concern, however in pediatrics often other individuals, typically mothers, fathers, and families are targeted as participants to garner the child's perspective as typically obtaining the child's perspective directly affords ethical and often developmental challenges. In qualitative research there is a pervasive tendency to select participants who can articulate their experiences in reflective and meaningful ways (Paterson and Scott-Findlay 2002); often children are considered to not fit these criteria of being a "good research respondent" (Darbyshire et al. 2005) due to developmentally limited abstract thinking. In some cases, this phenomenon or paradox is called "the missing child" (Darbyshire et al. 2005); as the predominant approach to exploring children's experiences is grounded in "research on" rather than "research with" children (Darbyshire 2000; Darbyshire et al. 2005; Oakley 1994). The essence of this paradox is that other individuals are invited to speak as proxies on children's experiences, rather than having the children themselves as research participants. Our findings lend weight to this phenomenon, however, across time there was increasing use of children as study sample participants. This is potentially related to developing expertise with the methods and increasing confidence doing qualitative research with vulnerable populations, including such issues as consent and ethics.

Contextually, it is important to note that amidst the increased use of qualitative approaches in pediatrics was the emergence of the evidence-based practice movement in the 1990s (Sackett 1997; Gray 1997). At the core of the EBP movement are clinicians applying the best available research evidence in their practice. Congruent to the EBP movement is the emergence of multiple evidence hierarchies that heavily value the randomized controlled trial as the most legitimate form of research. Furthermore the concomitant emergence of the Cochrane collaboration which privileges RCTs and other highly quantitative research methods was simultaneously occurring with increasing frequency in qualitative research in pediatrics. The increasing prevalence of qualitative research in pediatrics during this time when rigorous quantitative methods were being privileged suggests the power of naturalistic inquiry to give voice to patient and family experiences, to evaluate treatment responses, and to explain processes in relation to disease trajectories and health care systems. Increasing amounts of qualitative research in pediatrics is a strong indicator that these approaches make an important contribution to the pediatric knowledge base. Furthermore, the amount of qualitative work in pediatrics points to the impact of context on the knowledge that can be captured through qualitative approaches, and that is needed in pediatrics.

Our findings further demonstrate that qualitative research in pediatrics demands sophisticated skillsets in research to attend to the additional complexities (Heary and Hennessy 2002) including the developmental variability across childhood (if children are used as participants), the ethical concerns (Dove et al. 2013), and conceptual issues such as operationalization of key terms such as the "family." Qualitative research has a strong history in pediatrics, particularly because the methodological approach was highly recommended by researchers to capture children's own illness experiences (Woodgate 2000; Hockenberry-Eaton and Minick 1994), and it enables children to be studied in real-life situations (Bearison 1991). Furthermore, qualitative approaches enable a richer understanding of children's cognitive, emotional and behavioral abilities and do not rely on standardized scales or checklists, thereby restricting a rich, detailed understanding from the child's perspective. As Woodgate (2000) suggests, this is the rationale for qualitative methods being consistently advocated in pediatric oncology. This trend seamlessly fits with our findings as well given that the *Journal of Pediatric Oncology Nursing* and *Oncology Nursing Forum* were among the most prominent publication venues.

16.5 Conclusion

In our review, we provided a synthesis of the published qualitative research in pediatrics. Our review identified 163 qualitative articles in the field and synthesized key trends in the field including: (1) increasing use of qualitative methods in pediatrics over time; (2) greater use of qualitative methods by the nursing discipline compared to other health care disciplines; (3) across time there was decreased use of traditional qualitative approaches and more emphasis on "general qualitative" methods not specifically tied to a particular tradition; (4) a significant portion of the studies had not enough detail about the research methods employed; and (5) increasing use of children as research participants over time. Overlaying the enhanced productivity in pediatric qualitative research with the trends in health care at the time, such as the emergence of the evidence-based practice movement and the Cochrane Collaboration (both of which privilege quantitative research), our story becomes more multifaceted and notable. As a result, we applaud this progress to date in pediatrics, and highlight that going forward, future qualitative research must have more detailed methods reporting and we encourage even more qualitative inquiry in pediatrics, so that larger percentages of the published empirical research in this subspecialty is qualitative. Finally, our review demonstrates that qualitative evidence makes important contributions in poorly understood or complex areas in pediatrics and pushes thinking outside of conventional boundaries.

Acknowledgment We would like to acknowledge the contribution of Ms. Rachel Flynn for her assistance in formatting and editing this book chapter.

16.6 Appendix A

Searches run 8 August 2012.

Search in Ovid MEDLINE In-Process and Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) 1946 to Present.

2899 citations retrieved.

1. exp pediatrics/
2. exp qualitative research/
3. exp Nursing Methodology Research/
4. anthropology, cultural/
5. exp focus groups/
6. qualitative.mp.
7. (ethnol$ or ethnog$ or ethnonurs$ or emic or etic).mp.
8. (leininger$ or noblit).mp. or hare.ti,ab.
9. (field note$ or field record$ or fieldnote$ or field stud$).mp.
10. (participant$ adj3 observ$).mp.
11. (nonparticipant$ adj3 observ$).mp.
12. (non participant$ adj3 observ$).mp.
13. (hermeneutic$ or phenomenolog$ or lived experience$).mp.
14. (heidegger$ or husserl$ or merleau-pont$).mp.

15. (colaizzi$ or giorgi$).mp.
16. (ricoeur or spiegelberg$).mp.
17. (van kaam$ or van manen).mp.
18. (Grounded adj5 theor$).mp.
19. (constant compar$ or theoretical sampl$ or triangulat$).ti,ab.
20. (glaser and strauss).mp.
21. (content analys$ or thematic analys$ or narrative analys$).mp.
22. (unstructured categor$ or structured categor$).mp.
23. (unstructured interview$ or semi-structured interview$ or semistructured interview$).mp.
24. (maximum variation or snowball).mp.
25. (audiorecord$ or taperecord$ or videorecord$ or videotap$).mp.
26. ((audio or tape or video$) adj5 record$).mp.
27. ((audio$ or video$ or tape$) adj5 interview$).mp.
28. (metasynthes$ or meta-synthes$ or metasummar$ or meta-summar$ or metastud$ or meta-stud$).ti,ab.
29. (meta-ethnog$ or metaethnog$ or metanarrat$ or metanarrat$ or meta-interpret$ or metainterpret$).mp.
30. (qualitative adj5 meta-analy$).mp.
31. (qualitative adj5 metaanaly$).mp.
32. purposive sampl$.mp.
33. action research.mp.
34. focus group$.mp.
35. (exp interview/ or exp interview as topic/) and px.fs.
36. (theme*.ti,ab. or experience*.ti. or audio*.ti,ab. or video*.ti,ab. or recording.ti,ab. or exp Tape Recording/ or exp Video Recording/) and px.fs.
37. (experience*.ti. or theme*.ti,ab.) and ((audio* or video* or recording).ti,ab. or exp Tape Recording/ or exp Video Recording/).
38. interview*.ti,ab. and (views or perception* or belief* or attitude* or barrier* or facilitat* or perspective*).mp.
39. or/2–39
40. 1 and 39
41. P?ediatric*.tw.
42. (ethnol$ or ethnog$ or ethnonurs$ or emic or etic).mp.
43. exp qualitative research/
44. exp nursing methodology research/
45. qualitative.mp.
46. (ethnol$ or ethnog$ or ethnonurs$ or emic or etic).mp.
47. (hermeneutic$ or phenomenolog$ or lived experience$).mp.
48. (Grounded adj5 theor$).mp.
49. (content analys$ or thematic analys$ or narrative analys$).mp.
50. (metasynthes$ or meta-synthes$ or metasummar$ or meta-summar$ or metastud$ or meta-stud$).ti,ab.
51. (meta-ethnog$ or metaethnog$ or metanarrat$ or metanarrat$ or meta-interpret$ or metainterpret$).mp.
52. (qualitative adj5 meta-analy$).mp.
53. (qualitative adj5 metaanaly$).mp.
54. action research.ti,ab.
55. or/42–54
56. 41 and 55
57. 40 or 56

16.6.1 Search in EBSCOhostCINAHL

1272 citations retrieved.

S1 (MH “Pediatrics+”).

S2 (qualitative OR ethnol* OR ethnog* OR ethnonurs* OR emic OR etic OR leininger OR noblit OR field note* OR field record* OR fieldnote* OR field stud* participant observ* OR participant observation* OR hermaneutic* OR phenomenolog* OR lived experience* OR heidegger* OR husserl* OR merleau-pont* OR colaizzi OR giorgi OR ricoeur OR spiegelberg OR van kaam OR van manen OR grounded theory OR constant compar* OR theoretical sampl* OR glaser AND strauss OR content analy* OR thematic analy* OR narrative* OR unstructured categor* OR structured categor* OR unstructured interview* OR semi-structured interview* OR maximum variation* OR snowball OR audio* OR tape* OR video* OR metasynthes* OR meta-synthes* OR metasummar* OR metasummar* OR metastud* OR meta-stud* OR metaethnograph* OR metaethnog* OR meta-narrative* OR metanarrat* OR meta-interpretation* OR metainterpret* OR qualitative meta-analy* OR qualitative metaanaly* OR qualitative metanaly*

OR purposive sampl* OR action research OR focus group*).

S3 S1 and S2.

S4 pediatric* or paediatric* Clinical Queries: Qualitative—High Specificity; Human.

S5 S3 or S4 research article.

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Qualitative Evidence in Working with Cognitively Impaired Older Adults

17

Jennifer Hagerty Lingler and Lu Hu

17.1 Introduction

The global prevalence of dementia syndromes has been estimated at over 35 million individuals and is expected to double every 20 years of this century (Alzheimer's Disease International 2009). Alzheimer's Disease (AD) is the most common form of dementia, with over three fourths of all dementia cases that come to autopsy showing the pathological hallmarks of AD (Schneider et al. 2009). Examples of other types of dementia include vascular dementia, dementia with Lewy bodies, and frontotemporal dementia. While the underlying pathologies of these disorders vary, all represent incurable conditions that are more common in late life than in midlife or early adulthood, and each are associated with a multiyear process of neurodegeneration. This process of neurodegeneration typically involves a gradual decline in cognition and is often associated with behavioral changes. The costs of dementia disorders are staggering with the annual worldwide cost of dementia being estimated at 604 billion US dollars and growing (Wimo and Prince 2010).

In response to the growing public health threat posed by dementia, research on late life cognitive disorders has flourished in recent decades with a majority of efforts directed at better detecting and treating Alzheimer's disease and related disorders (ADRD). Paralleling the proliferation of basic science research and clinical trials targeting ADRD, there has been a marked increase in qualitative research on late life cognitive impairment. A search of the electronic databases PubMed, Cumulative Index of Nursing and Allied Health (CINAHL), and PyschINFO® revealed fewer than ten qualitative articles on this topic prior to 2000. An updated search of these three databases pairing the search term "qualitative research" with "cognitive impairment," "dementia," and "Alzheimer's disease" yielded 156 unique articles from that time through 2012. While early qualitative research on late life cognitive disorders was conducted almost exclusively in Western countries, current qualitative evidence on such disorders draws from studies conducted on five continents.

Departing from the medical model that underpins basic science and most clinical trials in ADRD, qualitative research on late life cognitive disorders is rarely concerned with one specific pathological process or cause of dementia. With relatively few exceptions, qualitative studies report on the intra and interpersonal experiences associated with ADRD, or milder forms of cognitive impairment, on the whole. The purpose of

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this chapter is to review the state of the science of qualitative research on late life cognitive impairment. To achieve that goal, we synthesize evidence from the four areas of research on late life cognitive impairment that were most prominent in the above-described database search. These include: existential implications of late life cognitive impairment; the diagnostic process and its impact on affected individuals; functional impact of late life cognitive impairment; and the intersection of late life cognitive impairment and comorbid medical conditions. Careful screening of the 156 qualitative studies involving cognitively impairment populations resulted in 53 articles addressing one or more of those four topical areas.

17.2 Cognitive Impairment and Existential Issues

Qualitative approaches have been the primary methods through which researchers from the health and social sciences have sought to characterize the impact of late life cognitive impairment on notions of selfhood, identity, and personhood. With sample sizes ranging from one to 115, interview-based and observational investigations into these interrelated existential aspects of cognitive deterioration have used qualitative analytic methods to illuminate what are arguably the most challenging questions facing dementia care practitioners: As one's brain changes at the cellular level, are there corresponding changes to the essence of one's being? As our memories fade, does our humanity fade, too? Or, are we, as humans, present in a way that can defy physiology?

17.2.1 Experiencing and Anticipating Loss

Scrutiny of this group of studies reveals loss to be a common theme. Specifically, findings from qualitative studies of both persons with cognitive impairment and their family caregivers often center on the experience of, or the expectation of eventual, loss in relation to selfhood, identity, or personhood. One of the strongest of such loss accounts is found in Svanström and Dahlberg's (2004) report characterizing five individuals with established dementia and their spouses. Focusing on the interpersonal impact of dementia, Svanström provided evidence that the disorder can lead couples to a state of "strangerhood," and can lead individuals to a state of feeling lost, alone, and without an identity. Other reports of existential loss among persons with dementia are found in Bakker's case study of a relatively young person with advanced stage AD (2010), Jonas-Simpson and Mitchell's (2005) qualitative description of 17 persons with advanced dementia, and Edvardsson and Nordvall (2008) phenomenological study of six institutionalized persons with dementia.

In addition to the above described studies of persons with moderate to severely advanced dementia, Parsons-Suhl and colleagues (2008) offered corresponding evidence that existential loss can occur much earlier in the trajectory of cognitive decline. This group conducted a phenomenological study of 12 persons with mild cognitive impairment and found that "being in the nothingness" was one three key features of these individuals' experiences (Parsons-Suhl et al. 2008).

Although the Parsons-Suhl team emphasized the notion of nothingness, the theme, "being in the nothingness," which draws its label from a participant quote, is also compelling because the term "being" implies that one is actively experiencing the human existence. Stated another way, referring to one's self as "being" connotes the presence of agency. Congruent with this notion, when prompted with the question, "Who am I?" participants in a study of living with early stage AD described a wide range of personal identities (e.g., "loving husband," "good person"). The diverse array of identities reported by these individuals led the researcher to conclude that dementia does not subsume views of one's self in early AD (MacRae 2010).

While it may be expected that expressions of selfhood would emerge in studies of those experiencing mild cognitive impairment and early stage AD, other research provides evidence for the persistence of selfhood, and expressions thereof, far later in the course of cognitive impairment (Fazio and Mitchell 2009; Russell and Timmons 2009; Tappen et al. 1999). Consistent with the above described study by MacRae, findings of profoundly heterogeneous views of self were reported by Russell and Timmons who used narrative research methods to elicit life stories and perceptions of self in a sample of nursing residents with dementia (Russell and Timmons 2009). Similarly, using the methodology of conversational analysis, Tappen's group reported on the use of the first person indexical in speech among 23 individuals with moderate to severe Alzheimer's disease concluding that frequent references to one's self in speech offer evidence for the persistence of selfhood well into the disease process. This suggests that it may be important to distinguish between *losing* one's selfhood and feeling that one's selfhood is *threatened*. The latter may be interpreted to represent a state of existential suffering and has implications for dementia care, including the implementation of interventions designed to promote a sense of meaning in life and connection to others.

17.2.2 Managing Loss

In support of the notion that existential loss may be attenuated, the qualitative literature on this topic includes several studies which frame such loss as a phenomenon that can indeed be managed. In these studies, efforts to minimize or otherwise cope with the experience or fear of loss emerge prominently, at times overshadowing negative characterizations of living with dementia. One example is found in Steeman and colleagues (2007) grounded theory analysis of interview with 20 individuals with mild dementia and their caregivers (Steeman et al. 2007). This group found that being valued, rather than lost, was central to this sample's experience. These authors caution that positive narratives may be interpreted by some to reflect a lack of insight among participants with cognitive impairment. Rejecting this notion, Steeman and colleagues posited that positive narratives from persons with cognitive impairment may serve to counterbalance the devaluation that these individuals experience during interactions with others.

Another key example of a positive portrayal of cognitive impairment is found in Clare's (2003) study of coping in 12 persons with dementia. Findings from this study emphasized that persons with dementia voice a need to maintain one's perception of selfhood. Clare concurrently analyzed qualitative data from participants' care partners, which reinforced the finding that sense of selfhood can be maintained in the face of dementia. Similarly, a phenomenological study of coping with dementia involving 12 persons with early stage disease reported managing one's identity to be major goal among those individuals (Preston et al. 2007).

For participants in Edvardsson and colleagues' study, the importance of continuing the notion of self was linked to one's sense of "normality" (Edvardsson et al. 2009). The concept of normality also surfaced in MacRae's (2010) phenomenological study of eight persons with dementia. In this study, normalization, along with humor, present-time orientation and life review, are used to create what the authors labeled a meaningful life. It should be noted that in several additional studies, spirituality emerged as a key means of coping with the existential threats associated with late life cognitive impairment (Banerhee et al. 2010; Beuscher and Grando 2009; MacKinlay and Trevitt 2010; Snyder 2003).

17.2.3 Overcoming Loss

In an investigation of 70 persons with dementia and 73 family caregivers conducted in Australia, Moyle takes the notion of preserving selfhood a step further by describing individuals who, not only cope with, but overcome the loneliness associated with cognitive deterioration (Moyle et al. 2011). Paralleling Svanström's emphasis on the interpersonal, Moyle's exemplars of overcoming loss focus specifically on the value of engaging in relationships with familiar individuals. Cross validation for this possibility is found in Öhman and Nygård's (2005), who reported that engagement with others, even through the workplace, may strengthen one's sense of identity and give meaning to life for a person with dementia.

17.2.4 Summary and Implications for Practice

Taken together, these studies offer consistent evidence that the experience or fear of isolation is one of the most prominent features of late life cognitive decline, and provide preliminary evidence to suggest that positive interpersonal experiences can ameliorate such existential threats. This finding has implications for holistic approaches to dementia care. Chief among such implications is that clinical interventions targeting persons with cognitive impairment may include existential well-being as a measure of effectiveness. While a number of research studies, particularly those evaluating art and music therapies, have used such outcomes (e.g., Hagens et al. 2003), there is lag in the adoption of these assessments to clinical practice.

The above described body of research provides clear evidence that selfhood, identity, and personhood are key facets of the experience of late life cognitive decline and perceived deterioration in these dimensions of well-being may contribute to suffering. Addressing existential well-being in clinical practice could take many forms. At minimum, dementia care providers could routinely assess the existential impact of cognitive disorders among affected persons to identify those in greatest need for interventions to minimize this form of suffering. The research reviewed above suggests that interventions, which emphasize meaningful engagement between persons with cognitive impairment and their family members may hold particular promise. At the policy level, taking existential suffering seriously could also mean developing standards for using measures of existential well being as a marker of dementia care quality in long-term care settings.

17.3 Diagnosis

The clinical event of diagnostic disclosure has been the focus of over a dozen qualitative investigations from a diverse range of geographical locations with differing health care systems. In addition to studies that directly focus on diagnostic disclosure, the longer-term impact of being diagnosed with a cognitive disorder surfaces in several additional studies which were designed to address other questions (e.g., Adler 2010; Bakker et al. 2010; Steeman et al. 2007).

17.3.1 Awareness of Cognitive Changes

Of particular relevance to investigations into the impact of a clinical diagnosis of a cognitive disorder, is the question of how much persons with cognitive impairment understand or find relevant about what healthcare providers communicate during disclosure sessions. With some studies finding persons with cognitive impairment to lack insight into their symptoms, and others showing affected individuals to demonstrate marked awareness of their cognitive changes, this body of research suggests that there are widely varying degrees to which persons experiencing cognitive decline appreciate what is happening.

In a study of 15 persons with dementia, MacQuarrie found that awareness and lack thereof are not always mutually exclusive states (MacQuarrie 2005). This analysis underscores how complex the concept of insight is by offering evidence that persons experiencing cognitive decline may at once acknowledge and resist aspects of the disorder, including the diagnostic label. MacQuarrie interpreted this simultaneous acknowledgment and resistance to function as a means of maintaining agency in the face of cognitive loss. In light of the above-described literature on existential loss, framing resistance as an act of self-preservation may be a fitting interpretation.

Under another conceptual scheme, Aminzadeh and colleagues report that variation in awareness of cognitive decline can occur in stages (Aminzadeh et al. 2007). These researchers conducted an analysis integrating individual interview and focus group data from 30 dementia care dyads (patient + caregiver) finding that the diagnostic process is preceded either by noticing and covering up, or by noticing and revealing to others, one's symptoms. This longitudinal study found the diagnostic process to be followed by the sense of either confirmation or shock, with denial, crisis, or maximizing occurring next, leading to a final stage characterized by either disorganization or adaptation.

Complementing this work, Leung and colleagues' analysis of seven persons with dementia focused specifically on the process leading up to diagnostic assessment (Leung et al. 2011). Each of the participants in the Leung study exhibited awareness of their cognitive changes. Expanding beyond what MacQuarrie referred to as acknowledgment and Aminzada described as noticing symptoms, Leung and colleagues characterized the pre-diagnostic experience to encompass the sequential processes of: becoming aware of memory problems, assigning meaning to symptoms, initiating help-seeking, acknowledging the severity of cognitive changes and finally obtaining a diagnosis.

17.3.2 Perceptions of Clinical Evaluations

In-depth explorations of how persons with cognitive impairment perceive the diagnostic assessment process have generally found those affected to be resigned to (Byszewski et al. 2007), content with or satisfied (Cahill et al. 2008) following their evaluations, with reports of marked distress over the evaluation being infrequent (Langdon et al. 2007; Derksen et al. 2006). It should be noted that at least three studies, one conducted in Ireland, one in the Netherlands, and one in Canada emphasized that individuals, though generally satisfied, expressed an explicit desire for additional information to be provided following a dementia diagnosis (Bakker et al. 2010; Byszewski et al. 2007; Cahill et al. 2008). Family caregivers in a study by Byszewski and colleagues (2007) pointed specifically to the need to provide detail about the disease and its progression, but to do so in a gradual manner, ensuring that patients and families are prepared for, rather than surprised by, the information.

17.3.3 Emotional Reactions to Cognitive Disorders

With respect to the emotional aspect of pursuing and receiving a diagnosis Aminzada and colleagues reported each stage of symptom recognition to correspond with an emotional reaction such as grief, emotional crisis or, in the face of adaptation, positive emotion (Aminzadeh et al. 2007). Participants in Qazi and colleagues' (2010) investigation described anxiety and apprehension prior to receiving the diagnosis, with some experiencing great anguish upon receiving the diagnosis, and most persons eventually "coming to terms" with the diagnosis (Qazi et al. 2010). Several other investigators have reported individuals with dementia in particular to exhibit a sense of emotional contentedness as a long-term response to cognitive symptoms and/or diagnoses. The extent to which providing ongoing information and support may foster such adaptation has not been examined.

17.3.4 The Special Case of Mild Cognitive Impairment

Responses to a diagnosis of MCI may be considered separate from those related to dementia. While a dementia diagnosis indicates that a degenerative, incurable process is underway, the clinical course of MCI is far more variable. Thus, diagnostic disclosures of this syndrome, viewed by many to represent a potential precursor to dementia, must acknowledge the uncertainty that this diagnostic label implies. Frank and colleagues conducted focus groups with both persons with MCI and their family-care partners with "uncertainty of diagnosis" emerging as a key theme in their analysis (Frank et al. 2006). Similarly, Lingler and colleagues reported that persons with MCI are at risk for both over and underestimating the significance of an MCI diagnosis within the first few months following diagnostic disclosure (Lingler et al. 2006). For the former, MCI was synonymous with Alzheimer's disease and reported to engender significant fear among affected individuals. This finding was similar to that reported by Frank and coauthors who described anger, paranoia, and depression within their sample. By contrast, participants in the Lingler study who underestimated the potential significance of MCI reported feeling pleased with their diagnosis, appearing to have focused on the message that they do not currently meet criteria for a dementia diagnosis.

17.3.5 Summary and Implications for Practice

Together these studies provide consistent evidence for person-centered approaches to the disclosure of clinical diagnoses of cognitive disorders. Given the wide range of insights and perceptions that individuals bring to the clinical setting, discussions of a dementia diagnosis may need to begin with an invitation for the patient to share his or her understanding of what has been happening. Clinicians should be mindful that patients may have their own terminology for referring to cognitive symptoms, and quite possibly, adopting the patient's preferred language may facilitate communication. The above studies also suggest a need to carefully attend to the process and timeline of providing information and support to persons with cognitive impairment and their family members. Specifically, the qualitative evidence provided from this body of research indicates that those diagnosed with dementia and MCI may have ongoing and evolving needs following the diagnostic disclosure visit. This suggests the need for clinicians to shift from viewing diagnostic disclosure as a discrete event and to conceptualizing diagnostic disclosure as a process.

17.4 Functional Status

Researchers, particularly those from the health sciences, have also used qualitative methods to deepen the field's understanding of how late life cognitive impairment affects one's abilities and experiences related to performing daily activities. These investigations cover multiple facets of daily life ranging from basic self-care to more complex activities like driving. As with investigations into the existential dimension of cognitive decline, this body of work focuses largely on phenomena of loss and is punctuated by exemplars of affected individuals striving to maximize functional status in the face of decline. There are three primary ways in which the theme of loss manifests within this group of studies. These include loss of ability, loss of interest, and loss of independence as a result of declining functionality. Across studies it is evident that for some abilities, like driving, one's interest in the activity may persist longer than one's ability to safely perform it. Conversely, studies focused on other activities, like maintenance of personal hygiene show that one's ability to perform an activity may outlast one's interest in doing so.

In regard to variation in the types of activities in which individuals with cognitive impairment remain interested, the role of culture must be considered. A grounded theory analysis of interviews of 11 Black Caribbean, nine South Asian, and ten White British persons with dementia showed that impaired cognition posed a "threat to the valued elements of life," with findings emphasizing that what one values may be culturally informed (Lawrence et al. 2011). While not a specific focus of the study by Lawrence and colleagues, driving is a key example of an activity to which different cultures assign differing levels of value. As demonstrated below, investigations focused on driving have been conducted almost exclusively in North America, perhaps suggesting that driving may not be such an important aspect of the culture in other geographic regions. In fact, most studies conducted outside of North America discuss functional status more generally, with few devoting an entire article to one particular activity.

17.4.1 Emotional Impact of Functional Decline

Investigations of the emotional impact of functional decline have focused largely on activities that are closely tied to one's sense of independence. Across studies, maintaining independence has consistently been reported as a major goal of persons experiencing the functional impact of cognitive impairment. The importance of remaining independent is exemplified by this quote from a participant in an interpretative phenomenological analysis: "That I can do my own housework […] pay my own bills. That's just what I hope for until I die" (Wolverson et al. 2010, p. 455).

De Vriendt and colleagues used constant comparison to analyze interviews with 37 persons with mild cognitive impairment and early stage dementia to ascertain their views on activities of daily living (ADL; De Vriendt et al. 2012). Their analysis revealed that decline in ADLs is a process that begins with subtle changes in advanced daily activities, like using specific appliances or electronic devices, or playing high-skill games of leisure. Their analysis offers evidence that, in the early stages of cognitive impairment, its subtle impact on functional status can be managed by adaptive strategies, which allow for a temporary preservation of independence despite a reduction in one's skills. For participants in Cahill and colleagues' mixed methods study on quality of life, maintaining independence in one's ability to perform household chores was associated with positive emotions, including a sense of usefulness (Cahill et al. 2004). The aptly titled theme "making it on my own" emerged in a grounded theory investigation of persons with Alzheimer's disease who live alone (Harris 2006). For this group of individuals, maintaining independence is associated with varying levels of uncertainty and is typically held in tension with the threat of its loss as exemplified by the theme, "living on the edge." In addition to uncertainty, the phrase "living on the edge" connotes the presence of anxiety.

Anxiety is an emotion that surfaces in much of the qualitative literature on functional decline among persons with cognitive impairment (e.g., Brittain et al. 2010; Qazi et al. 2010). For example, Qazi and colleagues' (2010) analysis of focus groups with 23 persons with dementia and their caregivers provided evidence that anxiety was linked to the loss of a wide array of functional abilities, from answering the phone to driving. This group described the relation of anxiety to activities as complex and bidirectional suggesting that not only can functional decline lead to anxiety, but that heightened anxiety can exacerbate functional impairment. Through interviews with caregivers and long-term care staff, these researchers further concluded that engagement in meaningful activities can ameliorate anxiety among persons with dementia.

While references to meaningful activity are present in several studies, other researchers describe what may represent the opposite end of a spectrum of meaning, labeling life with dementia as futile when affected individuals are "unable to do anything constructive." (Svanström and Dahlberg 2004, p. 678). Participants in Svanström and Dahlberg's (2004) study described daily activities like shopping to be humiliating for spouses of persons with dementia who may inappropriately touch other people's merchandise. At the midrange of a continuum from meaningful to futile, were participants in Johansson and colleagues' ethnographic study of 15 persons with dementia that focused on activities associated with food acquisition, preparation, and consumption (Johansson et al. 2011). Within this sample, balancing old habits (like including dessert) with new strategies and establishing routines (like eating pre-prepared meals) led individuals who consistently expressed a desire for independence, to feel satisfied with their present abilities and receipt of assistance from others.

Studies that included family caregivers offer evidence that the emotional impact of functional decline is not limited to persons with dementia, but also extends to family members. For example, the caregiver participant in Bakker and colleagues' case study described feeling abandoned upon being thrust into the responsibilities of managing the household and the finances without her partner.

From a conceptual perspective, Ward-Griffin and colleagues offered an alternative view by describing the phenomenon of mutual problem solving among caregivers and care recipients who are managing functional and other aspects of decline associated with dementia (Ward-Griffin et al. 2007). Focusing on mother-daughter care dyads, these researchers describe a subgroup of care dyads who maintain cohesive, enjoyable relationships by adapting to the changes brought about by dementia using a “power with” rather than “power over” mindset. This may be a promising approach for offsetting the loss of independence perceived by persons with cognitive impairment and the sense of isolation perceived by caregivers like the subject of Bakker and colleagues’ case study.

In regard to driving, Byszewski and colleagues interviewed 15 Canadian persons with dementia and their family caregivers, finding that most were in agreement with recommendations for driving cessation (Byszewski et al. 2010). Among this group’s interviewees, negative emotional reactions like shock and anger occurred primarily among those who disagreed with the recommendation to stop driving. Findings from a US-based analysis of focus groups involving persons with dementia and their caregivers revealed that, similar to other activities, dementia care dyads enact compensation strategies with the goal of maximizing independence in the face of functional decline (Adler 2010). For driving, these strategies included driving at off-peak hours, during daylight, and in familiar hours, as well as using driving aids like global positioning satellites (GPS). It is important to note that while qualitative methods have been used to describe patient and caregiver reports of such strategies, this body of literature does not provide evidence of impact on driving safety. Given the potential for negative emotional responses to loss of driving privileges, qualitative methods have been incorporated into mixed methods investigations of interventions to ease the transition to driving cessation. Using such an approach, Dobbs and colleagues found specialized driving cessation support groups to ameliorate the negative consequences of loss of driving privileges for individuals with dementia and their caregivers (Dobbs et al. 2009).

17.4.2 Counter Narratives

Although most research highlights the experience of decreased participation in skill-based activities, a handful of qualitative studies document the ability of persons, particularly those with mild dementia, to acquire new skills. A notable example is found in Stevens (2012) study teaching stand-up comedy and improvisation to persons with mild dementia. Stevens interpreted his findings on the feasibility of teaching such skills to persons with dementia to mean that “mild dementia does not have to be an impediment to developing skills” (p. 69).

17.4.3 Summary and Implications for Practice

The desire for independence among persons with cognitive impairment spans multiple domains of functioning and, as Lawrence and colleagues point out, may reflect those activities that are most meaningful to an individual and are likely influenced by culture. On the whole, this literature suggests that in practice it may be preferable to identify which aspects of daily functioning are most valued by individuals early in the course of cognitive decline and work with persons with cognitive impairment and their families to mitigate the impact of eventual skill loss. The driving literature in particular points to a lack of planning as problematic for individuals facing the loss of independence in a valued functional domain (Adler 2010). The above studies, more broadly, suggest that advance planning for functional decline should encompass not only logistical planning for the performance of tasks when an individual can no longer execute them, but should also include anticipatory guidance for the emotional impact that functional decline is likely to have on affected individuals and their family members. The need for individualized planning for functional decline cannot be overestimated. While driving cessation, for example, may be devastating to some, there is evidence that many individuals with dementia do give up driving voluntarily (Harris 2006). This suggests the need to evaluate and intervene with individuals and their family caregivers on a case-by-case basis. Further research is needed to examine the potential for new skill acquisition to offset the perception of loss among such individuals.

17.5 Cognitive Impairment and Comorbid Medical Conditions

As disorders of late life, AD and related disorders often occur concurrently with other chronic disorders. Research suggests that the most persons with ADRD have at least two comorbid medical conditions (Rosenwax et al. 2009) and take an average of seven to eleven prescription medications (Holmes et al. 2008; Erlen et al. 2013). While quantitative investigations have generally sought to examine how dementia syndromes interact with medical comorbidity to impact health outcomes, qualitative studies have focused on the experiential aspects of living and dying with coexisting cognitive and physical health problems.

17.5.1 Early Stage Cognitive Impairment and Physical Health

Studies suggested that in the early stages of cognitive impairment, concurrent physical health problems may influence how affected individuals both interpret, and react to, emerging cognitive symptoms. Findings from Lingler and colleagues (2006) grounded theory investigation suggested that perceptions of cognitive impairment can be affected by concurrent health problems in at least two ways. First, some individuals with mild cognitive impairment may view medical problems to be the cause of changes in functional status, with such attribution serving, in some cases, to lessen the perception of cognitive impairment as a potential cause of functional decline. For example, participants in the Lingler study were reluctant to endorse functional impairment as related to their cognitive symptoms, but readily attributed changes in functional status to such issues as musculoskeletal problems, chronic fatigue syndrome, eye disease, bereavement, and general physical slowing. Second, that same investigation revealed that individuals who are experiencing a number of medical problems may view cognitive impairment as just one more indicator of aging, rather than as a uniquely distressing syndrome. For these individuals, the experience of having a host of co-occurring medical problems provided a context and point of reference for coping with a late life cognitive disorder. Whether such previous experience with chronic illnesses of aging promotes positive adaptation to ADRD has not been examined.

17.5.2 Cognitive Impairment and Common Physical Health Problems

Several qualitative studies have focused on understanding such phenomena as incontinence, pain, insomnia, and physical frailty in the context of cognitive impairment. Of note these studies span conditions that are, and are not, related to dementia. In contrast to many of the other qualitative investigations in this population, most of these studies have relied on caregiver data, rather than data provided by persons with cognitive impairment. For example, Drennan and colleagues interviewed 32 family caregivers to understand their views about urinary incontinence in the context of dementia (Drennan et al. 2011). For these caregivers, incontinence is perceived as a common, frustrating problem about which little to nothing may be done. This sample reported having difficulty getting helpful information from professionals as well as difficulty accessing tangible resources like pads and other supplies. Similar frustration has been noted in studies of other conditions comorbid with dementia. For example, integrating focus group data from both persons with dementia and family caregivers, Gibson et al. (2013) used thematic analysis to advance and enrich the field's understanding of sleep problems within dementia care dyads. Congruent with the therapeutic nihilism

(Kitwood 1997) observed in the incontinence research, this group noted that sleep problems were often normalized among participants, several of whom were resigned to adjusting to the situation, viewing sleep disturbances as an intractable aspect of either aging and/or dementia.

In contrast to these findings, review of the literature indicates that pain represents a physical health problem about which care providers generally feel that more can be done in the context of dementia. Qualitative studies of both professional and family caregivers, conducted on multiple continents, provide consistent evidence that these individuals perceive pain management in this population to be inadequate or otherwise unsatisfactory (Chang et al. 2009; Gilmore-Bykovskyi and Bowers 2013; Karlsson et al. 2012; Lawrence et al. 2011a, b). A grounded dimensional analysis of in-depth interviews with 15 long-term care nurses concluded that residents with dementia were at greatest risk for experiencing underassessment, under treatment, and delayed treatment for pain (Gilmore-Bykovskyi and Bowers 2013). Going beyond the conventional explanation that pain assessment is challenging because patients are nonverbal, Kaarlson and coauthors offered an alternative explanation. This group's analysis of interview data from registered nurses (RNs) in long-term care revealed that professional nurses' limited contact time with residents, which they term a lack of presence, is a major source of problems with pain assessment, documentation, and management (Karlsson et al. 2012).

Focusing specifically on visual impairment, a study by Lawrence and colleagues (2009) interviewed persons with cognitive impairment, family caregivers, and professional care providers (Lawrence et al. 2009). Findings revealed the relationship between visual and cognitive impairments to be perceived as additive by participants. For example, visual impairment compounded dementia for some individuals by contributing to confusion and misperceptions. In other instances, the two forms of impairment interacted to doubly challenge individuals' ability to perform activities. Driving was cited as a key example of this phenomenon as visual impairment may compromise environmental sensing while cognitive impairment may impede judgment, the combined effect of which is unsafe driving. The triangulation of data from multiple sources in this study led to a key finding that health care providers specializing in low vision services perceived themselves as inadequately prepared to address dementia patients, where dementia care practitioners were not generally placing a high priority of vision problems. The extent to which such care fragmentation impacts other conditions comorbid with dementia is not well documented.

17.5.3 Cognitive Impairment and End of Life

Finally, a handful of qualitative investigations have focused on end of life issues specific to persons with cognitive impairment. Lawrence and colleagues (2011a, b) offered evidence that, despite the abovementioned issues with pain management, family members generally had positive experiences of nursing staff members' interactions with their dying relatives. Positive experiences seemed to be linked to the ability to go beyond the task-oriented aspects of end of life care to take into account the unique needs of people with dementia. In Livingston and colleagues' study, family members stressed the difficulties related to end of life decision making for persons with dementia, reporting that such decisions were straining even when advance directives were available (Livingston et al. 2010). While this literature is limited, findings do highlight the need for care providers to extend the notion of person-centered care to incorporate the family into efforts to optimize end of life care for persons with cognitive impairment.

17.6 Summary

Qualitative research involving persons with late life cognitive impairment and their care providers offers considerable insight into the experiences, challenges and opportunities for improving the lives of individuals at all points along the spectrum of Alzheimer's disease and related disorders. In each of the areas addressed in this review—existential implications, the diagnostic process, functional impact, and medical comorbidities—qualitative research provides an enriched understanding of the complexities that health and social services must consider in working with older adults and family members of those who are cognitively impaired. Striking dichotomies were noted in each of the areas reviewed. In regard to existential well-being, fear of an eventual loss of self dominated accounts provided by persons in the early stages of cognitive impairment, yet studies of persons in the advanced stages of illness provided consistent evidence for the persistence of selfhood in dementia. Studies focused on the diagnostic process revealed that individuals bring to, and take away from, clinical encounters the full gamut of insight and emotions related to their cognitive symptoms and what those symptoms may mean for the future. In regard to the functional impact of cognitive disorders, this review provided clear evidence that affected individuals and families hold varying perceptions of how every day activities are impacted by cognitive impairment. Accounts from these individuals revealed a continuum of perceptions with meaningful engagement and interdependence with others at one end of the spectrum, and futile existence and complete dependency at the other. Perceptions of medical comorbidities were equally complex with other chronic disorders serving to dilute the perceived impact of cognitive impairment in its early stages and to compound the perceived effects of cognitive impairment in later stages.

Taken together, this body of research provides strong evidence that one-size-fits-all approaches to dementia care will likely prove ineffective as individuals' experiences with such disorders are highly variable. Rather, tailoring care and services to affected persons and their families, from the time of diagnosis through end of life, will likely yield the most optimal outcomes. Promising areas for future research include identifying clinically useful measures of existential well-being and family-centered care and testing ways of maximizing such phenomena in the context of dementia.

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18 Qualitative Evidence in Chronic Obstructive Pulmonary Disease

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18.1 Introduction and Context

Chronic obstructive pulmonary disease (COPD) is characterized by progressive nonreversible obstruction of airflow, and is comprised of obstructive chronic bronchitis, emphysema, or both (Parshall et al. 2012). Due to the progressive and persistent inflammation of the airways, parenchyma, and vasculature, there is obstruction of airflow, pulmonary tissue damage, and alterations in mucous secretion and clearance. Over time, airways narrow, alveoli airspaces enlarge, and mucus production increases. These physiological changes result in obstruction of small airways, impaired ventilation and gas exchange, and a chronic productive cough, which is often ineffective to clear the thicker secretions. The individual's work of breathing increases, yet the increased effort is ultimately ineffective to sufficiently reward an increase in alveolar ventilation.

With increased severity and progression of disease, gas exchange is impaired and arterial blood gases altered. Hypercapnia usually occurs first due to insufficient alveolar ventilation, and is accompanied by hypoxemia when impaired ventilation and alveolar diffusion further worsen gas exchange. Due to these alterations in lung function, ventilation, and gas exchange, the person with COPD often experiences dyspnea, particularly upon exertion. Dyspnea is defined as "a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity" (American Thoracic Society 1999, p. 322).

The primary cause of COPD is the persistent and altered inflammatory and immune responses to inhaled noxious particles or gases, including cigarette smoke, biomass fuels, and occupational agents or dust (Vestbo et al. 2013). Cigarette smoking is the greatest risk factor for individuals in most countries. Between 85 and 95 % of persons with COPD are either current or previous smokers; moreover, cigarette smokers have more symptoms, greater lung abnormalities, greater decline in lung function, and a higher mortality (Kohansal et al. 2009).

COPD creates a considerable burden on both individuals and societies. It is a leading cause of morbidity and mortality across the globe (Vestbo et al. 2013), and is the third to fifth cause of death in North American and West European countries. The economic and social burden includes impacts on workplace, home, disability, and medical costs (Vestbo et al. 2013). Persons with COPD have a high incidence of comorbidities, including

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heart failure, and are at high risk for acute exacerbations of respiratory distress, which are often triggered by infection, pollutants, or acute inflammation (Vestbo et al. 2013). Acute exacerbations and events often result in emergency visits and acute care admissions, and at times are the cause of death.

Despite its prevalence, COPD is underdiagnosed, often diagnosed late in the course of the disease, or misdiagnosed as asthma or another disease process (Soriano et al. 2009; Vestbo et al. 2013). Recently, the Global Society for COPD recommended that a clinical diagnosis should be considered for any person "who has dyspnea, chronic cough, and/or sputum production, and a history of exposure to risk factors for the disease," following which spirometry be done to confirm the diagnosis and evaluate the severity of airflow limitation (Vestbo et al. 2013, p. 350).

There is no cure for COPD, therefore the focus is on managing symptoms and limiting the progression of the disease. The particular management strategies vary depending on the individual, the symptoms, and the severity of the disease; the approach is to decrease inflammation, minimize symptoms, and optimize a healthy lifestyle. Inhaled medications used to decrease inflammation and increase airflow include bronchodilators, beta-adrenergic agonists, and corticosteroids (Parshall et al. 2012). Smoking cessation is important because it decreases symptoms and complications, and slows the progression of the disease. Avoidance of environmental irritants and protection from weather extremes, such as the use of a scarf in winter or staying indoors in hot, humid weather, may decrease shortness of breath and bronchospasm (Parshall et al. 2012). Psychological, physical, and social rehabilitation is best individualized to meet the specific needs of persons with COPD as well as their spouses, partners and other family members. Breathing exercises and physical conditioning are targeted to reduce ventilatory effort and maximize oxygen consumption. Supplemental oxygen may be prescribed for intermittent or continuous use, most commonly through nasal cannula. Lung reduction or transplant surgeries are alternatives for a limited number of persons with severe disease.

Despite the prevalence of COPD, and its significant impact on individuals and societies, little was reported in the literature regarding the experiences of persons having COPD prior to 2000. The majority of the literature on COPD focused on quantitative assessment of dyspnea, including development and evaluation of scales such as the Modified Borg Scale and the Visual Assessment Scale. The Borg Scale, which is a category scale developed initially to evaluate physical exertion and effort during exercise (Borg 1982), was readily adopted and subsequently adapted to 'measure' numerous aspects of dyspnea. Two difficulties ensued. First, the scale was used without consistency between the intent and the descriptors. Second, contrary to Borg's assertion that, "numbers should be anchored by verbal expressions that are simple and understandable by most people" (1982, p. 380), verbal descriptors are usually omitted. Gift (1989) also noted this inconsistency with regard to differences in descriptors of, and intensity rating in, the use of visual analogue scales for shortness of breath and other symptoms.

It was recognized that experiences of persons with COPD were not well understood nor were the descriptors or "qualitatively distinct sensations" of dyspnea (Moy et al. 1998, p. 749). Govindaraj (1987) called for "information on the subjective aspect [and the] possible differences in the sensation experienced by subjects in different types of dyspneic states" (p. 64). Initial qualitative inquiries with this population were reported in the 1990s, and expanded over the next two decades. In this chapter is an overview of the qualitative research literature conducted with persons with COPD, their caregivers, or both that focused on exploring their experiences.

18.2 Overview of the Qualitative Literature for the Persons with COPD

An in-depth search for qualitative research studies was conducted in diverse electronic data bases: CINHAL; Medline; PsycINFO; AnthroPlus; Philosopher's Index; and Humanities & Social Sciences Index Retrospective (HSS).

The search was limited to studies in English that were published in peer-reviewed journals. Due to the known scarcity of qualitative literature for this population, a broad inclusion of search terms was used without limitation of dates. Search terms were "COPD" OR "chronic obstructive pulmonary disease" AND "qualitative research" OR "phenomenology" OR "grounded theory" OR "focus groups." The exception of these search terms were the AnthroPlus and HHS, in which only "COPD" OR "chronic obstructive pulmonary" AND "research" were used, and the Philosopher's Index in which only "COPD" OR "chronic obstructive pulmonary" were used. The special limiter "Research Article" was used within the CINHAL database. Studies located in each of the AnthroPlus and HHS databases were duplicated within the MEDLINE and CINHAL, that is, there were no unique findings in these databases. Two studies were located within the Philosopher's Index: one was a description of method and another was a duplicate of one located within the CINHAL search.

This broad search resulted in 3197 publications. Criteria for inclusion for this review were: first, the focus of the study was on persons with COPD or their family or other informal caregivers; second, there was intention to collect and analyze descriptive data through a planned qualitative approach. The search was subsequently limited to publications that reported experiences or perceptions of persons with COPD, their family members/informal caregivers, or both, based on the keywords, title, or abstract. Excluded publications were those that had qualitative data not analyzed or intended as a qualitative study or approach, and those that were not focused on the person with COPD or caregiver. For example, studies that explored health care professionals' experiences of caring for persons with COPD were excluded.

Abstracts were individually reviewed to determine the focus of study and the qualitative method. When the abstract was not available and the title lent to uncertainty for inclusion or exclusion, the full text of the article was reviewed, such as two publications: "Living with a chronic illness: the experience of women with chronic obstructive pulmonary disease (COPD)" by Sexton and Monro (1988), and "Evaluation of a multimodal grounded theory approach to explore patients' daily coping with breathlessness due to chronic obstructive pulmonary disease" (Jørgensen et al. 2013). Both were excluded: the former used an open ended mailed questionnaire with limited analysis; the latter reported on the methodology rather than the findings.

After articles were obtained and reviewed, a hand search was conducted of their reference lists. In addition, the references of three meta-syntheses were examined: "Patient experiences of depression and anxiety with chronic disease" (DeJean et al. 2013); "Experiences of persons with advanced COPD" (Disler et al. 2014) and "Experiences of an acute exacerbation" (Harrison et al. 2013). A systematic review of the qualitative literature on breathlessness from 1989 to 2005 was also examined, in which 19 of the 22 studies were experiences of persons with COPD (Gysels et al. 2007).

The quality, depth, and scope of the studies varied. For example, some authors reported grounded theory as their method, yet limited their approach and analysis to the use of components of grounded theory. It was not the intent to evaluate the quality of studies that had been peer-reviewed and accepted for publication. The search was to enable a broad and diverse overview of the literature for this population and topic.

After consideration of inclusion criteria, 152 publications were included in the review for this chapter. The majority of the studies focused on experiences and perspectives of persons with COPD, some of whom were identified as having either moderate to severe COPD or advanced COPD. The qualitative method and number of participants were diverse across settings and disciplines; consistent with qualitative inquiry, most studies had five to 30 participants. More than half of the publications cited a descriptive approach, with use of thematic or content analysis; some used a framework for the analysis, whereas others described use of qualitative or interpretive description. Either grounded theory or a phenomenological approach was cited by more than another third of the authors. The remainder used either a narrative approach or focus groups, with the exception of individual studies that used ethnography, action based research, conversation analysis, critical psychology, and interpretive outcome research.

The majority of the findings were reported in the last 5 years; none were located prior to the 1990s and six publications were from the 1990s. The latter used a qualitative approach with thematic or content analysis, and were conducted by nurses in either the USA or Canada (Berg 1996; Devito 1990; Leidy and Haase 1996; McBride 1994; Small and Graydon 1993; Small and Lamb 1999). Each of these studies was unique in its contribution at the time, but not unique compared to the collective findings over time, with regard to symptoms and experiences of living with COPD.

Devito (1990) interviewed 96 participants with COPD about their recall of feelings associated with shortness of breath during hospitalization, and revealed the fear associated with an acute episode. Fatigue was identified as a symptom experienced by persons with COPD (Leidy and Haase 1996), and linked to labored breathing (Small and Lamb 1999). The burden, embarrassment, and isolation that are commonly experienced with COPD and its management were first described at this time, as were the necessary and frustrating limitations in activities (Berg 1996; Leidy and Haase 1996; McBride 1994; Small and Lamb 1999). Berg (1996) noted that most of her seven participants "described a life which grew increasingly inactive" (p. 38). In addition to shortness of breath and fatigue, activities were noted to be limited by challenges of time, effort, weather, and uncertainty of illness (Berg 1996; Leidy and Haase 1996; McBride 1994; Small and Graydon 1993; Small and Lamb 1999). Oxygen was described as both a help and a hindrance to activities and daily living, but interfered with travel (Berg 1996; Leidy and Haase 1996). Breathing strategies, pacing, not rushing, energy conservation, normalizing and planning were identified as strategies to maintain exercise and activities (Leidy and Haase 1996; McBride 1994; Small and Lamb 1999). Despite use of these strategies, roles were relinquished, many participants spent most of their time alone and homebound, and symptoms interfered with activities they wanted to perform.

Over the next two decades, qualitative research expanded in this area of inquiry, with an increase over each five year span from 2000 to 2004, 2005 to 2009, and 2010 to 2014. Professional perspectives, diversity of method, and countries of origin also increased. Although the majority of the total numbers of publications continued to be authored by nurses, there are numerous studies by physicians, multidisciplinary teams, and occupational or physical therapists. As anticipated in a search that was limited to English, studies of origin were primarily in the USA, Canada, the UK and Ireland, Eastern Europe, Australia, and New Zealand. However, studies were also located that were conducted in China (two), Malaysia, Taiwan (two), Thailand, Turkey, and Uganda.

The research was primarily conducted in community settings, with interviews in participants' homes. Participants were recruited from community and home settings, home care services, pulmonary rehabilitation programs, outpatient clinics, or physician services. Few studies were conducted with participants while they were in hospital (e.g., Bailey 2001, 2004; Heinzer et al. 2003; Jensen et al. 2013; Lomborg and Kirkevold 2005, 2008).

18.3 Living with Chronic Obstructive Pulmonary Disease: Experiences and Perceptions

As described, this review focused on experiences and perceptions of persons with COPD, and their caregivers. Descriptions are described from the review and subsequent identification of six perspectives: distressing symptoms; embodied experiences; caregiver experiences; management of illness, symptoms, and activities; guilt, beliefs, and stigma associated with smoking; and perceptions of illness and advance care planning.

18.3.1 Prevalent and Distressing Symptoms

Persons with COPD report numerous symptoms that are troublesome, prevalent, and distressing: dyspnea, fatigue, cough, pain, depression, anxiety, fear, loss of appetite, and sleep disturbances (Avsar and Kasikçi 2010; Bailey 2001, 2004; Dunger et al. 2014; Gardiner et al. 2009; Gysels and Higginson 2011; Hasson et al. 2008; Heinzer et al. 2003; Kessler et al. 2006; Kvangarsnes et al. 2013; Lohne et al. 2010; Odencrants et al. 2005; Pooler 2014; Shackell et al. 2007; Stridsman et al. 2014; Willgoss et al. 2012). Dyspnea is the most prevalent and distressing symptom reported, has diverse descriptors, and is not necessarily correlated with objective findings such as oxygen saturation or respiratory rate. For example, descriptions of everyday breathing by participants with moderate to advanced COPD in one study included: working really hard; really lost my breath; short of breath; gasping; breathing shallow; breathing fast; tight; and so much trouble breathing (Michaels and Meek 2004). Participants in other studies described sensations such as being unable to breathe and not able to get air (Bailey 2001; Hasson et al. 2008; Pooler 2014).

Other symptoms and experiences of distress commonly occur with dyspnea, including anxiety, pain, fatigue, panic, and fear of dying or suffocation (Bailey 2004; Gardiner et al. 2009; Hasson et al. 2008; Kessler et al. 2006; Lohne et al. 2010; Stridsman et al. 2014; Victorson et al. 2009). Indeed, dyspnea may initiate and exacerbate other symptoms, such as the dyspnea–anxiety–dyspnea cycle described by Bailey (2004) and "vicious COPD circles" of pain, breathlessness, sleep disturbance, and anxiety described by Lohne et al. (2010, p. 232). The uncertainty and fear experienced when unable to get a breath is described by this participant: "You're fighting for your life and it's scary, the more you try to calm yourself down and regulate your breathing to get the deep breaths in, it's like trying to choke yourself at the same time" (Hasson et al. 2008, p. 529).

Challenges for persons with COPD include the diversity in types and patterns of dyspnea as the disease progresses; they may experience both predictable and unpredictable episodes of dyspnea (Simon et al. 2013; Pooler 2014). At these moments in time, they cannot rush or even pace their activities (DeVito 1990; Heinzer et al. 2003; Lomborg et al. 2005; Pooler 2014). The person may need to stop abruptly, such as this participant with severe COPD described: "So just walking from the front door to the elevator, I have to stop. I get halfway! I don't have a choice but to stop. Completely. Whatever I'm doing, I gotta, I have to stop." (Pooler 2014, p. 8).

There is significant psychological and emotional distress experienced with dyspnea, which may be worsened by the person feeling rushed, or asked to use energy when they need to conserve it for breathing. Some participants reported that they needed to concentrate on their breathing; having others hovering worsened the sensation: "They want to help but […] you gotta do it yourself" (Fraser et al. 2006, p. 553). Yet they may not appear distressed to others; stoic in their suffering, some participants purposefully concealed their distress to maintain their integrity and dignity (Chan 2004; Dunger et al. 2014; Jørgensen et al. 2013; Lomborg et al. 2005; Pooler 2014). It is not only dyspnea and its distress that are concealed. Stridsman (2014) reported that fatigue is challenging and may become overwhelming when experienced with dyspnea, yet it is often unexpressed to either health care professionals or family members.

Strategies for management of symptoms, including dyspnea, anxiety, and fear, were described. These included strategies for everyday management to minimize or avoid dyspnea, and strategies to manage the onset of dyspnea and the accompanying anxiety and distress. Thomas (2009) described four categories for immediate management of dyspnea: changing activity; relaxation; medications; and breathing. Participants reported stopping or decreasing the activity, trying to stay calm, using an inhaler, and concentrating on breathing. These strategies are comparable to coping strategies described by O'Neill (2002): breathing; medications; rest; and avoidance measures.

18.3.2 Limitations of the Body and Life-World

Persons with COPD reported increased physical limitations as their disease progressed and symptoms worsened; many described being homebound and socially isolated, were unable to engage in daily activities or hobbies, and were dependent on others (Barnett 2005; Ek et al. 2011; Fraser et al. 2006; Gullick and Stainton 2008; Guthrie et al. 2001; Pooler 2014; Williams et al. 2011). Ek et al. (2011) described practical problems, restrictions, and challenges of persons with advanced COPD who were dependent on oxygen and lived alone: although there was freedom with independent living, stress, anxiety, and fear were also expressed. Persons with COPD often use two strategies to minimize dyspnea and conserve their energy: they take more time to do ordinary activities, such as having a shower or getting dressed; and they do less, such as getting help with cleaning the house or shopping for groceries (Habraken et al. 2008; Pooler 2014; Victorson et al. 2009):

> At one time I used to walk to […] but then it got to where I was stopping nine times just going down the road and then it all started closing in. […] At one time I'd be alright in certain weather conditions, but now even brewing up [making a cup of tea] is a labour.
> (Clancy et al. 2009, p. 81)

Participants often expressed a desire to be more active and engaged, not taking on the roles of feeling or being ill. However, there is a body–mind mismatch between that which they would like to do and that which they are able to do as they were inhibited by both the sensation and fear of breathlessness (Gullick and Stainton 2008; Jones et al. 2004a; Pooler 2014; Williams et al. 2011). For example, one participant described wanting to do some gardening and being unable to do so: "It's not wanting to do it, it's just that your body says you can't do it" (Williams et al. 2011, p. 1243). Furthermore, losses of their abilities to participate in activities were often unpredictable and frustrating (Barnett 2005; Corcoran et al. 2013; Fraser et al. 2006; Guthrie et al. 2001; Habraken et al. 2008; Pooler 2014).

> I can't plan anything. It depends on what sort of night I've had. I avoid anything-early mornings because I can't do it. That can be frustrating sometimes. I wish I could put my coat on and go. I'd like to go on holiday with my family and go shopping.
> (Barnett 2005, p. 810)

> It's hard to explain. Sometimes, I am working in the garden without any problems. After a while, I come into the house and boom, it's over. Suddenly I'm exhausted, I can't do anything. That's hard to explain. She [my wife] sometimes doesn't understand. But I don't even understand! Because one moment, I'm working and the next, I can't do anything anymore. It's hard to explain because you can't see any difference, I still look the same.
> (Habraken et al. 2008, p. 847)

Limited by the inability to get air and restricted by their distressing symptoms, persons with COPD live in a "shrinking life-world shaped by breathlessness" (Gullick and Stainton 2008, p. 605). Many participants describe being homebound and socially isolated due to the inability to breathe and the distressing symptoms that limit their activities. In addition, both stigma and embarrassment contribute to the social isolation that many experienced (Berger et al. 2011; Goldbart et al. 2013; Guthrie et al. 2001; Halding et al. 2010). The disease may also contribute to isolation by the very nature of the inflammation and symptoms, including increased mucous production, coughing, noisy breathing, and the risk of infection (Berger et al. 2011; Ek et al. 2011; Goldbart et al. 2013; Gysels and Higginson 2008; Halding et al. 2010; Pooler 2014). Halding et al. (2011) described the burden of self-blame and stigma as being "exiled in the world of the healthy" due to a self-inflicted disease (p. 102). Although COPD is an invisible disease, it is made visible by the use of inhalers, walkers, or oxygen that may lead to embarrassment for some (Arnold et al. 2011; Berger et al. 2011). For example, one participant described: "That's embarrassing, using the inhaler in front of people. It's okay if I'm […] by myself, but when I'm with people and trying to get some of that phlegm up." (Berger et al. 2011, p. 924).

Conversely to those who struggled with severe restrictions and were homebound, others were determined to live as normally as possible, even though the unpredictable and acute events created numerous challenges (Duangpaeng et al. 2002; Fraser et al. 2006). These participants acted normally, concealed their oxygen, used breathing strategies, and paced themselves to preserve their sense of control, integrity, and energy (Fraser et al. 2006; Jørgensen 2013; Pooler 2014). Participants were creative to accommodate their hobbies, adapt their homes, and maintain connections. Tailoring their activities and energy to their social, existential and physical priorities was of benefit (Ek and Ternestedt 2008; Williams et al. 2007). They minimized their symptoms and conserved their energy by taking more time or modifying their activities, not just avoiding the task (Habraken et al. 2008; Pooler 2014). And when they had a good day or afternoon, they took advantage of it when they could.

> If I'm doing something in the house it takes me quite a while. I just go slow. When I get tired I just sit down for a minute. Two minutes. Get up and get at it again, as soon as I catch my breath. I take a long time to do it!
> (Pooler 2014, p.4)

> On a good day me and my wife we go for walks in South Bank, we walk around the markets we go down for a meal we take the ventolin and the breathing spacer. Mandy (wife) puts it in her purse.
> (Milne et al. 2009, p. 302).

For persons with COPD, there was a reduction in activity over time, which was accompanied by a persistent increase in the severity of symptoms (Jones et al. 2004a). Many participants expressed frustration with these limitations, which were often dramatic, unpredictable, and socially isolating.

18.3.3 Caregiver Experiences

There were few publications within this body of literature that included caregiver perspectives; of these, most reported studies conducted were with persons with COPD and their caregivers. Six were limited to family members of persons with COPD (Bergs 2002; Elkington et al. 2004; Hasson et al. 2009; Huniche et al. 2013; Simpson et al. 2010; Spence et al. 2008), of which two were with bereaved caregivers. Two publications reported multiple perspectives of patients, family members, neighbors, registered nurses and physicians (Pinnock et al. 2011; Small et al. 2012).

Care and support for persons with COPD was primarily provided by family members, most often by their spouses who may also have health or mobility concerns, and share both personal and social losses, including restricted activities, sexual intimacy, and isolation (Booth et al. 2003; Boyle 2009; Gullick and Stainton 2008; Gabriel et al. 2014; Lindqvist et al. 2013a, b; Pinnock et al. 2011; Reinke et al. 2008; Spence et al. 2008). Spouses of persons with COPD had additional secondary losses, including employment, lifestyle, retirement and travel plans, and personal freedom, plus the anticipated death and ultimate loss of the spouse (Boyle 2009).

> We don't have the life we thought we'd have. We can't have guests anymore. We can't go out […]. Things that I ordinarily would have enjoyed doing. The quality of his life is horrible. I'm healthy, but the quality of my life is not nearly what I hoped for.
> (Boyle 2009, p. 278)

Many family members reported experiencing physical and emotional distress, including fatigue, frustration, fear, and uncertainty (Bailey 2001; Bergs 2002; Booth et al. 2003; Gabriel et al. 2014; Kanervisto et al. 2007; Lindqvist and Hallberg 2010; Spence et al. 2008; Warner 2008). Caring for the family member who was breathless was described as terrifying, and sometimes spouses lay awake worried about the breathing (Booth et al. 2003). The trajectory of the illness and onset of exacerbations was one of uncertainty and anxiety for both persons with COPD and their family members, although monitoring was also described as an important role by some spouses (Boyle 2009). Acute events often seemed to take both patients and family members by surprise and there was uncertainty about when to seek care (Bailey 2001; Boyle 2009). Family members indicated that they both valued and needed support, including after bereavement, yet few formal support groups or resources existed for them (Booth et al. 2003; Boyle 2009;

Elkington et al. 2004; Gysels and Higginson 2009b; Hasson et al. 2009; Spence et al. 2008).

Bergs (2002) reported that wives of COPD patients were worn out, felt isolated, and had losses in self-identify and quality of life; although they identified they needed support, they found it hard to ask for help and "Instead, they keep on struggling on their own" (p. 617). As the severity of illness progressed, caregivers became increasingly vulnerable in their coping capacity, requiring additional support which they may not seek (Simpson et al. 2010). Asking or seeking help was of increased complexity when the illness narrative became normalized within the context of aging and smoking: debilitating symptoms and everyday limitations may be perceived as normal rather than being ill or having COPD, and options are not perceived to help or improve their well-being (Elkington et al. 2004; Habraken et al. 2008; Jones et al. 2004b; Pinnock et al. 2011; Pooler 2014).

> But he wouldn't accept help, he didn't want help from anybody. He didn't like going to the doctors, we had to really force him to go to the doctors you know.
> (Elkington et al. 2004, p. 443)

> It just goes so slowly. We don't really notice but other people do. They see that he can no longer do things that he could a year ago. For us it's just normal.
> (Habraken et al. 2008, p. 847)

> We're not really ill. It may sound funny, but a COPD patient is not ill. He is breathless. Whenever I get an infection, a bacterium, then I'm ill. But like now, I'm not ill because I can eat properly, I can still laugh, I still have fun in my life.
> (Habraken et al. 2008, p. 847)

Some persons with COPD and their spouses learned to judge whether and when to contact a health care professional who was available (Huniche et al. 2013; Jonsdottir 2007; Wang et al. 2012). Jonsdottir (2007) conducted participatory action research through family nursing partnerships with couples, and reported that:

> […] learning to listen to any physical changes in the body and learning to discern between the kind of attention that were needed to respond to the respective symptoms at any given time was an important task and bolstered feeling of security.
> (Jonsdottir 2007, p. 453)

Support and information was important for feelings of safety after early discharge when provided in the home through telephone consultation for patients and family members: "The more you know, the safer you feel. You are not so frightened when you know what is what and get a proper explanation of this [disease]" (Wang et al. 2012, p. 3).

18.3.4 Management of Illness, Symptoms, and Activities

Management of COPD was explored directly and indirectly revealed through this body of qualitative research. The disease controls peoples' lives on a fundamental level (Jonsdottir 2007). The need for information and education about the diagnosis is evident in this literature, through descriptions such as "grappling in the dark" (Hyde et al. 2013, p. 275). Many participants described not knowing the cause of COPD or being familiar with the term (Gardiner et al. 2009; Jones et al. 2004a; Rodgers et al. 2007; Wilson et al. 2011). For example, Jones et al. (2004a) reported that only a few of their participants knew the name COPD for their lung disease, although there was "a universal understanding that their disease was serious and unlikely to improve" (p. 151). Conversely, other participants were able state the name but had little knowledge or understanding of their illness: "When you are first diagnosed they say 'Oh yes, you've got COPD,' but that's the end of it, nobody tells you or explains anything to you." (Wilson et al. 2011, p. 1706).

Participants feared acute events and struggled extensively with symptoms (Gruffydd-Jones et al. 2007; Gysels and Higginson 2009b; Jeng et al. 2002; Pooler 2014). Concern about the harm of dyspnea and uncertainty of the benefit of exercise was reported (Jones et al. 2004a). Unaware that their symptoms might be alleviated through management of their illness and modification of health behaviors, participants integrated both the illness and the symptoms into their lives (Barnett 2005; Chen et al. 2008; Cicutto et al. 2004; Knauft et al. 2005). Many times, their day-to-day experiences of symptoms and limitations were reported as anticipated or normal events:

> Any exertion causes breathlessness, which at times can be painful. Bending down in particular can take my breath away. Any sudden movement can do the same. Some days are fine and I can go up and down the stairs fine, other days I have to stop half way to get my breath.
> (Barnett 2005, p. 808)

Cooney et al. (2013) described the fragile balance of living with COPD as hiding and battling: strategies for hiding are sputum clearance, breathlessness management, and smoking cessation programs access; battling strategies are energy conservation, recognition of normal, optimization of health behaviors, avoidance of stress and anxiety, and promotion of independence. There were few participants with moderate to severe COPD who controlled their symptoms; well-being was described as a "precarious balance" which needed skillful maintenance, hard work, and "insightful daily management" (Gysels and Higginson 2009a, p. 139).

Huniche et al. (2013) used critical psychology to evaluate self-management strategies in which readings to monitor their ongoing condition were reported to produce a sense of security, although some participants experienced the readings as worrisome and disturbing. Although persons with more advanced COPD are vulnerable to acute exacerbations and hospitalizations, it is at the same time challenging for many to recognize the seriousness of the events and cues (Bailey 2001; Kvangarsnes et al. 2013; Wilson et al. 2007). Patients may feel they are discharged after an acute exacerbation before they are ready, with sensations of uncertainty as to how they might manage, and perceived needs for discharge planning, practical assistance, and physical care (Clarke et al. 2010; Gruffydd-Jones et al. 2007).

Pulmonary rehabilitation programs are established in many countries to provide education and monitor exercise. Several factors are linked to enrollment and attendance, including support, concern about symptoms, stigma regarding their illness, and need for understanding of their unpredictability of their physical capacity; both peer and professional support was described to be important for adherence to exercise maintenance and pulmonary rehabilitation (Chan 2004; Fischer et al. 2007; Halding 2010; Hellem et al. 2011; Hogg et al. 2012; O'Shea et al. 2007; Rodgers et al. 2007; Thorpe et al. 2014). Conversely, lack of social support at home was cited as a factor for non-adherence for attendance to pulmonary rehabilitation (Arnold, et al. 2006).

It is valuable to understand the barriers and benefits to pulmonary rehabilitation programs that participants described. Concerns were expressed related to symptoms with exercise, stigma and shame, and feasibility such as travel and inclement weather (Harris et al. 2008; Moore et al. 2012; Toms and Harrison 2002). Moore et al. (2012) reported that pulmonary rehabilitation programs may be declined due to perceptions that could be addressed, such as this participant who initially declined but later completed the program: "[…] and when I got the letter and it said bring trainers and loose clothing I thought oh it must be exercise so that's really what made me not go" (p. 5). Another participant described her skepticism, which perhaps indicated the need for clarity:

> Levels of activity go up and down, my lungs do not stay the same all the time […] you can't just say this regimen is going to work, because in three weeks, three hours, your breathing could be completely different.
> (Hogg et al. 2012, p. 193)

Participants described numerous benefits of pulmonary rehabilitation programs: regained hope and confidence; increased activities; reduced or managed dyspnea; being active in a safe, secure, and understanding environment; increased knowledge; and engagement with others in social setting with peer and professional support (Harris et al. 2008; Milne 2009; O'Neill 2002; Rodgers et al. 2007; Toms and Harrison 2002; Wilson et al. 2007). Wilson et al. (2007) reported that participants preferred group information with knowledgeable people who would provide information regarding the disease, dyspnea management, medications, and acute exacerbations.

18.3.5 Guilt, Beliefs, and Stigma Associated with Smoking

Although many persons with COPD acknowledged the negative implications of smoking, others contested it as the single or primary cause, and identified external factors out of their control instead of—or in addition to—smoking, including mining, welding, air pollution, aging or even chance (Bailey et al. 2009; Boeckxstaens et al. 2012; Caress et al. 2009; Hansen et al. 2007; Rodgers et al. 2007; Schofield et al. 2007; Small et al. 2012). This skepticism possibly alleviated feelings of stigma and blame but also influenced beliefs and success of smoking cessation, such as these participants stated:

> It's a load of bunkum about fags though. I admit they don't help but it's no use saying it's fags all the time because it isn't […] there's plenty of people got this complaint that's never ever smoked in their lives.
> (Rodgers et al. 2007, p. 200)

> Well every time you go to a doctor they tell you that smoking is not good for you, but well I think it is more of an age thing.
> (Hansen et al. 2007, p. 741)

Others recognized that smoking had contributed to their disease; they lived with guilt and self-blame as well as blame from others, including family and health professionals. Many tried to quit but were unable to do so (Jónsdóttir and Jónsdóttir 2007; Lundh et al. 2012). Even when "told" to stop smoking, some believed the damage was done, some were uncertain of the ongoing harm, and others lacked the inner power to stop (Bailey et al. 2009; Jones et al. 2004a; Hansen et al. 2007; Lindqvist and Hallberg 2010; Wilson et al. 2011). Participants expressed dismay and frustration with the label of being a smoker and being constantly reminded of the link to COPD by health care professionals and others, regardless of their current smoking status, the length of time they had quit, or even if they had never smoked (Bailey et al. 2009; Hellem et al. 2012; Jónsdóttir and Jónsdóttir 2011). For example, this participant described:

> When I talk about having COPD, everyone asks if I've been a smoker. That's the first question they ask. If you've smoked, it's kind of like being convicted […] You've done this to yourself […] You shouldn't have done that!
> (Hellem et al. 2012, p. 212)

Participants described the difficulty of quitting, wanting to make the decision on their own, and the need for support; criticism by family or a health care professional were noted to be harmful (Eklund et al. 2012; Jónsdóttir and Jónsdóttir 2011; Lundh et al. 2012). Conversely, individualized and positive outcomes of smoking cessation, such as seeing their grandchildren grow up, were noted to be constructive (Schofield et al. 2007). Small et al. (2012) recommended engaging a social narrative to enhance the uptake of smoking cessation, and encompassing aging and the industrial past or other perceived factors, rather than just a singular cause for blame and guilt.

18.3.6 Perceptions and of Illness and Advance Care Planning

Despite the daily precarious balance, acute symptoms and hospitalizations, and the progressive nature of the disease, persons with moderate to severe COPD often had a poor understanding of the illness trajectory and eventual outcome (Gysels and Higginson 2010; Gardiner et al. 2009; Hakkak et al. 2014; Hall et al. 2010; Jones et al. 2004b; Kessler et al. 2006; Knauft et al. 2005; MacPherson et al. 2013; Pinnock et al. 2011; Seamark et al. 2012). Some linked it to aging or felt fortunate that it was COPD rather than another illness.

> These lungs won't get any better. That's something you need to accept. Well, compared to other people […] everyone has got something at my age! I feel lucky to have what I have.
> (Habraken et al. 2008, p. 847)

Pinnock et al. (2011) described living with COPD as a "chaos narrative" of illness, without a clear beginning or anticipated end (p. 1). There is uncertainty with the course of the disease and little understanding of its progressive nature (Chan 2004; Gardiner et al. 2009). In acute events, there may be recognition that death may occur, but the focus is on striving to breathe and survive, as described by this participant:

> When you have an attack, then you only think about getting air or breathing. And then I just think that it will go one way or the other. You couldn't care less about which way it goes as long as it goes one way. It's unbearable.
> (Lomborg et al. 2005, p. 268)

Some participants lived with the understanding that COPD is a chronic disease: not recognizing that they could die of COPD, they did not discuss end of life (Gardiner et al. 2009; Gysels and Higginson 2010; Hakkak et al. 2014; Hall et al. 2010). Even so, many participants expressed fears of dying of breathlessness or suffocation in the interviews, although they had not relayed these concerns to health care professionals and some were reluctant to do so (Gardiner et al. 2009; Hakkak et al. 2014; Hall et al. 2010). For example, these two participants expressed concerns of dying while not being able to breathe: "the thought of dying through not being able to breathe, that was a little bit of a shaker, I didn't know you could die through this," and 'My current concern is […] well, dying. I'm not afraid of dying, I'm afraid of the way I will die, I don't want to die in agony like I am if I've got one of them attacks" (Gardiner et al. 2009, p. 695).

There was noted variability for participants to discuss end of life or advance care planning. There was an unwillingness of some to contemplate the future, whereas others were interested in a general conversation of preferences for care (Jones et al. 2004b; MacPherson et al. 2013; Seamark et al. 2012). Jones et al. (2012) noted some participants were ambivalent about discussing the future: "Sometimes I would, sometimes I wouldn't. When I'm feeling alright I feel great and I don't care but […]" (patient does not finish sentence) (p. 311), whereas others were unwilling: "Well, I suppose people think I should know a bit more about what I've got and that but I just don't want to dwell on anything like that" (p. 312). This ambivalence occurred even though many knew that their condition was incurable: "If it [the illness] carries on deteriorating at the rate it has done over the last couple of months then I can't see much future beyond that" (Jones et al. 2012, p. 212). Participants demonstrated a need for knowledge about their severe or advanced disease, and recommendations were made to discuss end of life care (Gysels and Higginson 2010; Jones et al. 2004b; Kessler et al. 2006; Knauft et al. 2005; MacPherson et al. 2013; Seamark et al. 2012). The timing, person, and place are noted to be important for the discussion, which may not be best suited in hospital at the time of an acute exacerbation, but instead with a known care provider at a later date (Seamark et al. 2012).

18.4 Understandings for Practice

The participants' voices and analysis in this body of literature have increased our understanding of the perceptions and experiences of persons living with COPD, and their caregivers. This literature provided a breadth of meanings, interpretations, and perspectives experienced by persons with COPD, including symptoms, perceptions, limitations, barriers, challenges, strengths, and capacities. There are descriptions that call us to be empathic and sensitive to persons who experience COPD, and practical recommendations for support and education.

18.4.1 Prevalent and Distressing Symptoms

Prior to the 1999 definition by the American Thoracic Society, there was no consensus regarding a definition of dyspnea (Govindaraj 2002; American Thoracic Society 1999), and there is still no consensus approach to readily quantify or describe it (Bausewein et al. 2008; Jablonski et al. 2007; Meek et al. 2012; Parshall et al. 2012). Despite the intensity of language that persons with COPD use to describe their shortness of breath, clinicians describe and document patients' experiences as "dyspnea" or "shortness of breath." However, participants have revealed the distress, frustration, and desperation that may be experienced with shortness of breath or dyspnea in COPD. Numerous descriptions of both sensations and perceptions of breathing have affirmed that dyspnea is a "composite of several sensations" (Simon et al. 1990, p. 1012). Feeling short of breath was described by participants with COPD as not being able to get enough air in, despite extensive effort, and at times with feelings of panic, distress, and desperation (Bailey 2004; Hasson et al. 2008; Pooler 2014). However, the term dyspnea does not necessarily relay the individual perceptions of frustration and embarrassment when difficult breathing, coughing, wheezing, or rapid breathing occurred.

Through language we may unintentionally minimize experiences by translating the diversity of sensations into one word, that is, dyspnea. Health care providers are advised to attend to these nuances, when documenting or relating patient experiences into a word or phrase with our individual assumptions and understandings. Instead of a single or precise definition, overt recognition of the diversity of experiences and meanings of both dyspnea and shortness of breath is beneficial (Carling Elofsson and Öhlén 2004). Comparable to pain and other symptoms, assessment of dyspnea is most reliable by asking the patient. Distressing and uncomfortable sensations of breathing cannot be assumed to be absent when the person does not “complain” or has “normal” vital signs or oxygen saturation. Although it is appropriate and essential to ask the person, further research is needed to provide insight as to what we ought to ask and how we might attain descriptions of their breathing, and how best to assess in times of severe shortness of breath.

Asking if the person is feeling “short of breath” or to provide a numerical indicator of their shortness of breath is inadequate to capture the range of experiences, descriptors, and perceptions. We increase our competency of assessing “dyspnea” by using language that is meaningful to the individual. Potential descriptors revealed in these studies included tightness, pressure, coughing, drowning, suffocating, difficult, nausea, almost a panic, frustration, desperation, and very, very tired (Avsar and Kasikçi 2010; Bailey 2001, 2004; Dunger et al. 2014; Gardiner et al. 2009; Gysels and Higginson 2011; Hasson et al. 2008; Heinzer et al. 2003; Kessler et al. 2006; Kvangarsnes et al. 2013; Lohne et al. 2010; Odencrants et al. 2005; Pooler 2014; Schackell et al. 2007; Stridsman et al. 2014; Willgoss et al. 2012). Descriptions of dyspnea revealed through this qualitative research has led to further exploration and understanding including physiological states, suffering, definitions, categorizations, assessment, and management (e.g., Bausewein et al. 2010; Currow et al. 2013; Jørgensen et al. 2014; Simon et al. 2014; Williams et al. 2010b). For example, patients with chronic obstructive pulmonary disease surveyed reported severe and intensive distress; 23 of the 30 patients indicated that they “experienced such severe breathing distress that they thought they would suffocate” (de Souza Caroci et al. 2004, p. 106).

Qualitative research also revealed that persons with COPD have multiple symptoms in addition to dyspnea, including fatigue, anorexia, pain, sleeplessness, and anxiety (Bailey 2004; Gardiner et al. 2009; Hasson et al. 2008; Kessler et al. 2006; Lohne et al. 2010; Stridsman et al. 2014; Victorson et al. 2009). This increased awareness of the high symptom burden experienced by this population has led to an interest in systematic assessment of symptoms, not just dyspnea (e.g., Bentsen et al. 2013; Eckerblad et al. 2014), and recommendations to address the physical symptoms and psychological distress to improve quality of life (Blinderman et al. 2009; van der Molen et al. 2013). Further qualitative and quantitative research is needed to further explicate the perceptions, experiences, and management strategies of symptoms experienced by persons with COPD.

18.4.2 Limitations of the Body and Life-World

Participant experiences in these studies are consistent with findings that many persons with COPD have “frequent symptoms of breathlessness, coughing , and wheezing that limited their ability to carry out everyday activities” (Chapman et al. 2003, p. S24). When the physical body is limited by breathing, it is no longer continuous with self. Self in the body becomes aware of the body and of breathing; body and self in the world is constrained by breathing. Still themselves, and yet not quite the same self, many felt held back and constrained by their breathing and their bodies. COPD has clearly been identified to be more than a pulmonary disease; it is experienced by the individual within the physical, social, and emotional aspects, and may extend to their family, friends, and neighbors. No longer are persons with COPD defined and assessed by objective measures, because of this qualitative literature, there is a recognized need to consider multiple symptoms and quality of life (Jones et al. 2012; Slok et al. 2014).

It is important for nurses and other health care providers to recognize that exertion is severely limited with exacerbations of COPD or in moments of acute dyspnea. Patients require a slower pace and intervals of rest to recover their breath. Persons with chronic obstructive pulmonary illness often restricted their activities, in part to minimize sensations of the body and to limit anxiety (Gullick and Stainton 2008; Habraken et al. 2008; Pooler 2014; Victorson et al. 2009). There is a physical imperative related to insufficient energy and the work of breathing; not only is air obstructed, so too are actions and activities. However, this decrease in activities comes with a risk of deconditioning, further limitations in activities, and decreased quality of life. Braido et al. (2011) demonstrated the relationship of dyspnea with decreased ability for independent activities of daily living, lower levels of well-being, and higher levels of distress.

Strategies such as pacing, focusing on activities that are meaningful, and maintaining health behaviors to optimize physical function should be taught to minimize frustration, create meaning, and prevent deconditioning and worsening of symptoms (Fraser et al. 2006; Habraken et al. 2008; Jørgensen 2013; Pooler 2014). Management of symptoms should also be addressed to promote activity, including dyspnea, pain, and anxiety (Parshall et al. 2012). Furthermore, linking information and support to maintain physical activity, engage in pulmonary rehabilitation, and encourage smoking cessation may be beneficial to optimize symptoms and quality of life. This may include a practical discussion of the benefit of their oxygen or walkers, which may have been seen as embarrassing, stigmatizing, or challenging (Arnold et al. 2011; Berger et al. 2011; Earnest 2002), and strategies to manage seasonal barriers and risks (Donaldson et al. 2012).

Although several studies described the energy, limitations, activities, and isolation, few addressed the time required for moving through the world. Gullick and Stainton (2008) discussed the conscious management of the body that required longer periods of time; Pooler (2014) described slowing down, doing less, and having to stop; Victorson et al. (2009) noted the modification of activities. This is an area for further exploration, considering the fatigue and the energy required for moving through the world that have also been described. For example, Jowsey et al. (2014) found that people with COPD spent a substantial amount of time on home, clinical, and nonclinical activities, which constitutes as work, is disruptive in daily life, and "robs the individual of time they could otherwise spend on other valued activities in other aspects of their lives" (p. 93). These activities were required by persons who have limited energy, describe themselves as fatigued, frequently experience breathlessness and pain, and need to pace themselves. Furthermore, these activities did not include time in hospital or other health care settings, which are also common and most probably both time and energy consuming.

18.4.3 Caregiver Experiences

COPD is most often diagnosed midlife or later, and is associated with limited activities, being homebound, numerous hospitalizations, and a high mortality rate over a five to ten year span (Lange et al. 2012; Vestbo et al. 2014). It is not therefore surprising that many COPD patients have informal caregivers, nor that they are often the spouse who is also older. For example, Gauton et al. 2011 reported that about 70 % of patients with COPD had one or more informal caregiver, the majority of whom were spouses.

Although there is less qualitative research that includes the caregivers of persons with COPD, the research has showcased the important role, considerations, and need for their inclusion in assessment, care planning, and education. These informal caregivers most often provide direct care and support at home, despite demonstrated gaps in knowledge and services (Gardiner et al. 2009; Pinnock et al. 2011). Caregivers of persons with COPD reported numerous concerns, including restricted activities, secondary losses, and both physical and emotional distress (Elkington et al. 2004; Habraken et al. 2008; Simpson et al. 2010). Indeed, the distress, burden, and worry of family caregivers for persons with COPD are reported to be higher than those caring for persons with heart failure or renal failure (Gauton et al. 2011; Janssen et al. 2012). Compared to those caring for patients with cancer, more caregivers of COPD patients were not working, had greater impairments of activities of daily living, and reported a greater desire for more help from friends and family (Burton et al. 2012; Garlo et al. 2010). However, this research suggested that caregivers may be reluctant to ask for help, although it may be desired and needed (e.g., Bergs 2002; Simpson et al. 2010). Some people are reluctant to seek help; others may not perceive that they need it because of their perceptions of COPD, smoking, aging, and health care services. Therefore, it is important that health professionals take the initiative to provide information and resources, such as symptom management strategies and available health services.

Participants, including caregivers, reported a sense of security and safety when education and support were provided (Jonsdottir 2007; Wang et al. 2012). It is recommended that there be consistent information, individualized care, and clear professional support structures and services provided to persons with COPD and their caregivers.

18.4.4 Management of Illness, Symptoms, and Activities

As noted earlier, COPD is a progressive disease with uncertainty, unpredictability, and variability (Vestbo et al. 2014). Not being able to breathe was perceived as a threat to life (Bailey 2004; Gardiner et al. 2009). However, it is not just a stressor: insufficient alveolar ventilation and gas exchange threatens the person's air, well-being, and life itself. Therefore severe shortness of breath, distress, difficulty, and insufficient air is not a just psychological stressor but also a physiological threat (Rotondi et al. 2002). It is important to not minimize these sensations of insufficient air, for fear and panic may be important warning mechanisms to seek assistance such as medications or emergent care. In an acute episode, the decision to seek treatment must be made while experiencing distress of not being able to breathe, severity of tightness and wheezing, or persistent coughing. Despite life-threatening circumstances and severity of sensations, the decision to seek help is complex and without clear or consistent indicators.

Distraction, a strategy recommended in the coping literature, was ineffective in acute moments of being unable to breathe; instead of distracting themselves from breathing sensations, participants described the importance of focusing on breathing (Lomborg et al. 2005). When shortness of breath is severe, attempts to control breathing with distraction may increase frustration, anxiety, or distress (Bailey 2004; DeVito 1990; Gosselink 2003; Logan and Jenny 1997). The person with acute distress may isolate themselves or withdraw emotionally from others to focus on their breathing and try to interrupt the cycle of not getting air in. Instead of distraction, family members or health care providers need to enable the person's focus on breathing, perhaps breathing with the person to audibly hear and slow down each breath. The quiet presence and reassurance of another person enabled many to move breathing to the conscious, voluntary level and interrupt the downward spiral of the anxiety felt with being unable to breathe. Health care professionals can provide a sense of security by being present and quiet, minimize energy requirements by not asking open-ended questions or requiring movement, and facilitate medications and rest, such as providing a walker or chair. These strategies can be taught to individuals and their family members in a formalized plan of care.

For persons with severe or advanced pulmonary disease, not even an extremely sedentary lifestyle prevented the reoccurrence of distress. COPD was not portrayed as something that could be controlled, predicted, or fixed. There are major disruptions and losses for persons with COPD and their caregivers, encompassing limitations to activities, role reversals, functional decline, uncertainty, and fear related to distressing symptoms, particularly dyspnea. When persons with moderate to severe pulmonary disease forget or don't think about breathing, and start to move quickly, they are slowed down or stopped by the incapacity of their lungs. They may feel embarrassed, inform others, slow down, or avoid the activity. Some stopped or slowed down because they were distressed with feeling short of breath; others limited their activities because they were worried about the sensation and their health. These modifications have an impact on their family, spouses, and others. It is less clear from this literature that symptom pairs or clusters—such as dyspnea and pain or dyspnea, fatigue, and cough—influence activities and choices.

The complexity of decision-making and need for information and support is evident for both persons with COPD and their caregivers. Individual perceptions, preferences, and beliefs should be explored when providing information, such as smoking cessation, referral for pulmonary rehabilitation, and options such as oxygen therapy. In an acute event, the decision to seek treatment must be made while experiencing the distress of not being able to breathe, severe wheezing, or persistent coughing. Yet, despite life-threatening circumstances and intensity of sensations, the person with chronic obstructive pulmonary disease may not perceive the threat or seriousness of their breathing difficulty. The decision to seek help is complex and without clear or consistent indicators. They may wait, uncertain about whether their breathing will resolve, and end up much more ill than they would have been if they had sought help earlier. Some participants in the studies included in this review expressed not knowing when to go to hospital, as they did not have typical indicators of respiratory distress. Further research is indicated on the decision-making and support needed for early recognition and intervention in acute exacerbations.

Findings from the literature included understanding beliefs and perspectives of exercise and activities, use of medications and oxygen, smoking and cessation, and recognition of acute exacerbations. These strategies are important, yet extremely challenging to implement across the illness experiences. That which is more predominant and known is how the illness controls and overwhelms the person and family members, as discussed earlier. The need for information and education is a predominant theme for support, management, and well-being. As the disease progresses, there are increased challenges in self-management due to both the severity and unpredictability of acute exacerbations. Qualitative findings have been a base for much of the integrated models of care that recognize the complexity, uncertainty, and unpredictability of self-management of COPD (Bourbeau et al. 2013; Crawford et al. 2013; Fromer 2011).

18.4.5 Guilt, Beliefs, and Stigma Associated with Smoking

There is a strong correlation of smoking with COPD, emphysema, and chronic bronchitis in much of the developed world. Breathing problems, wheezing, and "smokers' cough" may be experienced for many years by persons who smoke, without being interpreted as a disease or experienced as illness (Vestbo et al. 2013). Smoking cessation is one of the most important yet misunderstood and complex strategies to promote well-being for persons with COPD, although it is not necessarily perceived as having this importance. The complexity and challenge of quitting smoking is described within a context of self-blame and addiction. Few participants in these studies were completely successful in their attempts to stop smoking; barriers included both the powerful addiction and beliefs about harm and benefit (Bailey et al. 2009; Hansen et al. 2007;

Jones et al. 2004a; Jónsdóttir and Jónsdóttir 2007; Lindqvist and Hallberg 2010; Wilson et al. 2011).

Importantly, information needs to be tailored to persons with COPD about smoking cessation, particularly about the potential benefits rather than just "being told to quit" and the focus on blame (Eklund et al. 2012; Schofield et al. 2007). For example, Hilberink et al. (2006) found that more than 50% of the smokers with COPD were amenable to smoking cessation support; those motivated to quit had more severe dyspnea and chronic sputum burden, and addressing those complaints increased motivation. They recommended tailoring counseling to two distinct groups: discussing advantages of quitting with unmotivated smokers and developing an action plan with smokers who were motivated to quit. Questions for further research include the effects of smoking cessation on the decrease of symptoms and restrictions of illness, decrease in emergency visits and hospitalizations, decrease in the progression of disease, and perception of symptoms, including cough, shortness of breath, and fatigue

Strategies for self-management require both tailored information and support from health care professionals and caregivers. Although it is important to inform the public about the harms of smoking and benefits of cessations, these narratives provide understanding of the complexity and challenges of dependency, addiction and stigma. COPD has physical, emotional and social consequences, and some persons may perceive the damage as having been done. Positive encouragement and participation in management of symptoms and activities may facilitate smoking cessation. Persons may benefit from a multicausal and individualized approach to smoking cessation in combination with other actions for lung health and comfort, including avoiding triggers or irritants such as smog, humidity, dust or heavy scents. It is important that health care professionals combine a thoughtful and non-judgmental stance when discussing smoking history and cessation strategies.

18.4.6 Perceptions of Illness and Advance Care Planning

There is a paucity of literature with regard to the perceptions, understandings, and preferences for care for those who live with COPD. Persons with COPD may not understand their disease or the nature of the illness (Gysels and Higginson 2010; Gardiner et al. 2009; Hakkak et al. 2014; Hall et al. 2010; Jones et al. 2004b; Kessler et al. 2006; Knauft et al. 2005; MacPherson et al. 2013; Pinnock et al. 2011; Seamark et al. 2012); many do not recognize that they will likely die of COPD and have not discussed their preferences or end of life care with their physician or other health professionals (Gysels and Higginson 2010; Jones et al. 2004b; Kessler et al. 2006; Knauft et al. 2005; MacPherson et al. 2013; Seamark et al. 2012),

Compared to persons with cancer, persons with advanced and end stage COPD experience a prevalent and multiple symptom burden, including: pain, dyspnea, and fatigue which are often not systematically assessed or managed (Bausewein et al. 2010; Solano et al. 2006); lower quality of life (Habraken et al. 2009); and lower physical, social, and emotional functioning (Gore et al. 2000). Yet persons with COPD often do not have their symptoms systematically assessed or managed, have access to social support, or other comparable access to palliative services (Lanken et al. 2008; Patel et al. 2012).

Barriers identified by health care professionals to discussions of end of life or advance care planning include uncertainty of the course of illness, lack of consensus re the person to initiate the conversation, connotation of comparing COPD with cancer, conflicts with goals of chronic disease management and lack of understanding of end of life for individuals with COPD (Gott et al. 2004; Knauft et al. 2005). Patient-related barriers include assumptions that clinicians will initiate discussions when needed, assumptions that the deterioration is normal part of aging, and guilt because of the smoking-related disease (Knauft et al. 2005; Patel et al. 2012). Little is known about the preferences of patients and their caregivers for their end of life care and their preferred place of death. Furthermore, the ambivalence and variability may be based on assumptions about need to be discussed and clarified. For example, Fried and Bradley (2003) found that participants with COPD wanted to avoid imposing caregiver burden and financial hardships on others and valued quality of life, yet none identified treatment burdens as so undesirable that they would reject them, which were based on incorrect assumptions about the outcomes of those interventions, including intubation and resuscitation. Home may be associated with a good death, but older persons may be concerned about caregiver burden and adequate symptom relief, and hospital may be the preferred place of death (Gott et al. 2004; Hall et al. 2010)

Although it is important both to create and attend to opportunities to discuss end of life, it is important that health care professionals first clarify what persons with COPD understand about their illness and trajectory, including fears or beliefs. Those persons with more advanced or severe disease may not initiate the discussion, but find it comforting to know that there are strategies to alleviate the distress and discomfort at end of life as they may have fears of agony of suffocation (Gardiner et al. 2009). Although the SUPPORT study (Claessens et al. 2000) demonstrated that patients with COPD were comparable to patients with lung cancer with their preferences regarding comfort-focused care and unwillingness to have prolonged mechanical ventilation, patients with COPD who died were more likely to receive ventilation (70.4 % for COPD vs. 19.7 % for lung cancer) and resuscitation (25.2 % vs. 7.8 %). Therefore, it is important that persons with COPD share their wishes and goals with both their family members and health professionals while they are able to speak for themselves.

18.5 Conclusion

In chronic obstructive pulmonary illness, there are multiple interactions and complex interrelationships that influence not only perception but also interpretation of sensations, and subsequently the illness experience. Feeling short of breath in everyday activities was described as distressing and frustrating for many persons with COPD. Acute exacerbations or infections were unpredictable and sudden; signs were interpreted by both self and others to determine whether to self-medicate or seek interventions. Although defined as chronic and delineated as pulmonary, COPD is experienced as chronic, acute, and life-threatening, and experienced in the body, by the person, with and among caregivers, friends, family, neighbors, and others. Distressing sensations are at times unpredictable and sudden; other times they are anticipated and alleviated.

For persons with moderate to severe COPD, actions and plans are disrupted and control is seldom attained. Physical restrictions of the body and breathing limit possibilities to "adapt" or "cope" with this progressive illness. There are few emotional, social, and existential elements that are untouched for persons with COPD and their family and friends. Extensive energy and work are expended to maintain the precarious balance of their physical, emotional, social, and mental well-being, with significant reliance on family members, who are often older caregivers. They and their caregivers often suffer but maintain endurance to preserve dignity and self (Morse 1997, 2001), as they live with a disease that is invisible and yet has stigma attached. They endure day-to-day, but also often live in the moment with uncertainty, as they experience various dilemmas and threats with a disease that is unpredictable. Vulnerable to acute exacerbations and with a progressive disease trajectory, persons with COPD greatly need and benefit from the supportive care of health care professionals and services.

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19

Qualitative Evidence in the Study of HIV/AIDS and Sensitive Topics: The Contribution of Online Qualitative Research

Guendalina Graffigna

19.1 Introduction

The study of socially sensitive topics related to health is complex and underlines the role of specific meaning-making processes resulting from multilayer interactions between individuals. To cast light on the symbolic processes at the base of health and illness representation is crucial in order to understand barriers to illness prevention and potential drivers to motivate people to practice safe conduct. In this regard, qualitative research is receiving enhanced recognition across disciplines, thanks to its ability to grasp the inner dynamics of social phenomena and to give voice to individuals about their experiences, feelings, and doubts related to health and illness.

On the basis of these premises, in this chapter, we move from the definition of what we consider a social constructivist position, to the study of health-related problems and to then define qualitative evidence from a socio constructivist perspective. Given these premises, we emphasize the value of opting for qualitative research to explore HIV/AIDS and we underline how this approach is receiving increased recognition across disciplinary fields by commenting on recent publication trends. On the basis of this literature review, we discuss the *pillars* of qualitative research evidence in the sector of HIV/AIDS, together with the main methodological challenges that are still topics for debate in this area.

Additionally, we will show how interpersonal exchanges in occidental societies, particularly those mediated by the Internet, deserve increased attention from qualitative researchers involved in the field of HIV/AIDS, due to their pervasiveness in the daily life of the individual and their influence on health related beliefs, attitudes, and behaviors.

19.2 The Social Construction of Health and Illness

According to a constructivist paradigm (Reardon and Rogers 1988), reality is socially constructed through a dialectical interaction between the physical world and the existence of the individual (Cline et al. 1990). The social construction of reality is mediated by language: interpersonal communication creates the world and its meanings (Sharf and Vanderford 2003). From this perspective, even if material reality exists independently from social interaction, it would not have meaning if separated from symbolic interpretation (Railsback 1983). Social reality, being inter-subjective, is constantly reinforced by interpersonal interaction and, due to its symbolic form, is objectively experienced by individuals

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and becomes the template of their behavior (Berger and Luckmann 1991). Globalization and the consequent increase of cross-cultural exchanges among humans have further fostered this concept of the symbolic representation of the world, showing how meanings are the product of an individual's conversations in a specific culture and how the individual's behavioral answers to the context in which they find themselves are framed by their cultural lenses (Kleinman 1975).

19.3 A Definition of Qualitative Evidence in the Socio-constructivist Framework

The idea of a symbolic and interpersonal construction of reality is particularly pregnant when sensitive topics related to health and illness are taken into consideration. In this frame, the research approach that aims to cast light on this complex process of reality construction needs to be ductile, insightful, and able to catch any nuance of the phenomena under investigation. This is one of the reasons why qualitative research is receiving more and more recognition across disciplinary fields, for instance, as a promising approach to studying socio-sensitive phenomena related to health. As a matter of fact, qualitative research appears to be the most suitable lens with which to explore the symbolic complexity that underlies the social construction of the reality of health and illness, in particular when sensitive topics are concerned. From this perspective, research approaches that are less structured, normative, and standardized than traditional neo-positivistic quantitative methods are needed in order to be more sensitive to the meaning transactions connected with daily life. Exploration of the ways that people experience and make sense of their world is crucial, and an essential source of knowledge in the field of health management.

Thus, from this perspective, to produce evidence means developing the ability to fine-tune a person's way of seeing their health and illness experience; it is to be able to see the world through their eyes. As it is conducted, qualitative research is an inquiry strategy that gives significance to the words people use to describe their experience: in other words, it helps researchers "know the stories behind the numbers" (Mayan 2009, p. 9). As a matter of fact, qualitative research across its different delineations and epistemological roots is configured as a research strategy that is tailor-made, close to context, and made *with* people, as opposed to forced *upon* people. The process of meaning making by individuals, drawing on their experience and on their reference context, is therefore a crucial source to grasp the dynamics at the basis of healthy or unhealthy conduct in the scope of HIV/AIDS treatment and prevention.

19.3.1 The Need for Qualitative Lens When Studying the Social Construction of HIV/AIDS

We searched Scopus—one of the broadest scientific databases, which indices contributions from several disciplines—by limiting our inquiry to peer reviewed, English language research related to HIV/AIDS in the last 20 years, and the results were quite impressive. There were 34,100 papers that reported the results of different types of research, conducted across a wide range of health and social disciplines. This search also highlighted the important increase of contributions in the last decade: the number of papers went from only 485 published in 1990–1832 published in 2013 (and others will probably appear soon, since the year 2013 had not ended at the time this paper was written). In this literature debate, it is interesting to notice that the presence of qualitative research pertaining to HIV/AIDS was marginal at the end of the past century, and has dramatically increased in the last 5 years.

By narrowing our literature search to only papers related to qualitative research,[1] the results

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[1] In this section we comment on publications retrieved in the Scopus database with a query that crossed key words linked to qualitative research (i.e.. *qualitative research* or *qualitative inquiry* or *qualitative study* or *grounded theory* or *ethnography* or *phenomenology* or *narrative* or *conversational analysis* or *discourse analysis*), with the key word *HIV/AIDS*. We restricted our search to only peer reviewed journals and to sources written in English. The choice of Scopus, instead of other databases, was related to its broader spectrum and coverage of different disciplinary domains in the health and humanities sector.

were very different in terms of numbers, but not in overall trend: in total, Scopus indexed 2135 qualitative research papers published in the last 20 years. It is interesting to note that only three of these articles were published in 1990, whilst the current year (2013) had 223 papers already published, with others likely to appear before the end of the year (see Fig. 19.1).

The trend of new publications related to qualitative research about HIV/AIDS exemplifies the increased recognition that qualitative research is receiving. Although fewer in comparison to scientific papers related to quantitative research conducted on this topic—qualitative research represents only the 6 % of the entire amount of research published in this area—the growth rate is indicative of an increased openness and attention to the evidence produced in this research approach. Furthermore, it is important to point out that this increased recognition is happening in parallel across different disciplines, and particularly within the medical sector: about 56 % of qualitative papers about HIV/AIDS published in the last two decades appeared in medical journals; 21 % of papers were published in the domain of social sciences; 9 % in the area of psychology; and 8 % in nursing. Other sectors involved, although marginally, are business and economics, immunology, biology and chemistry, arts and humanities, and even agriculture (see Fig. 19.2).

It is indubitable that the problem of the HIV/AIDS epidemic requires multidisciplinary research and approaches. It is a healthy sign, then, that qualitative research evidences have been achieved across different disciplines, thus addressing different angles of the problem. Qualitative research evidence can be considered a shared language and sensibility that may sustain the dialogue among different disciplines, with the common goal of producing usable knowledge to solve applied problems.

It is also important that this trend of qualitative research recognition appears to be global and, although primarily covered by authors from the USA and UK, is increasingly applied by other countries, such as South Africa, Canada, Australia, Brazil, Uganda, Kenya, and northern European Countries. Less present in the debate so far are southern European and Asiatic countries, although they are not entirely absent.

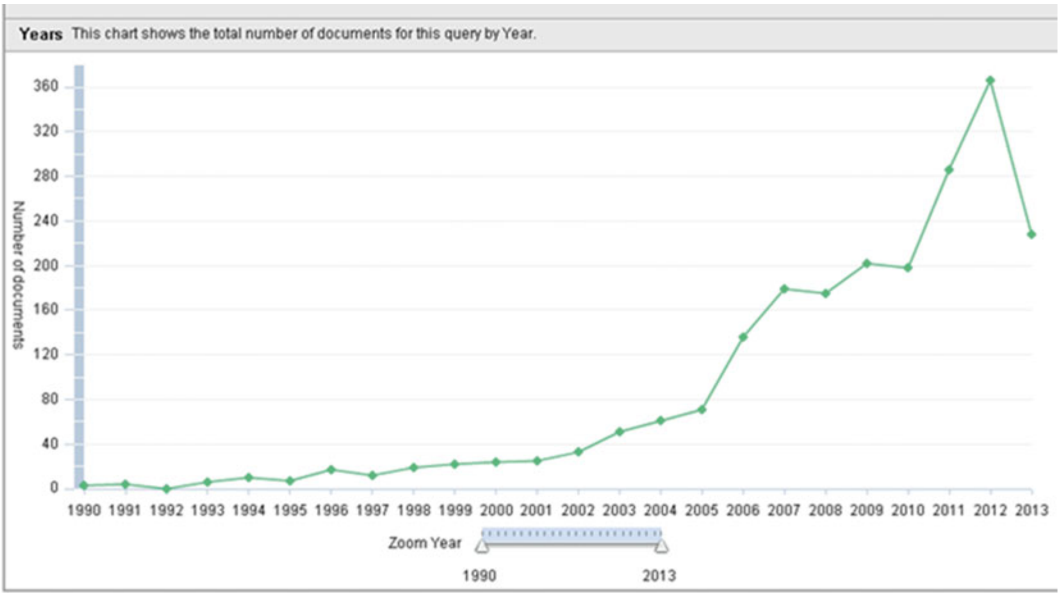

Fig. 19.1 The increasing trend of qualitative research in the field of HIV/AIDS

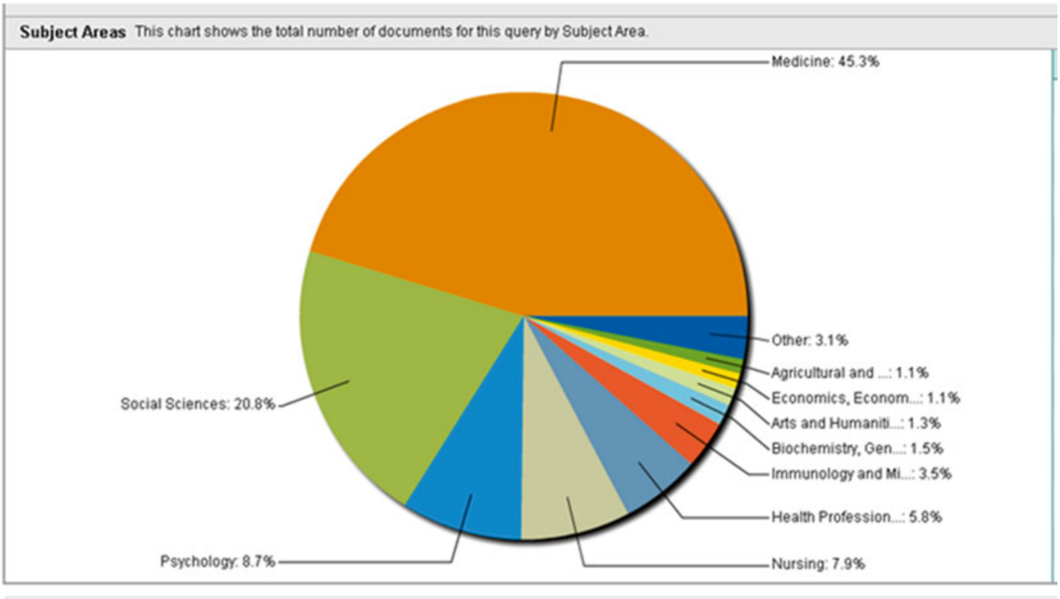

Fig. 19.2 The disciplines involved in qualitative research publications about HIV/AIDS

19.4 Main Topics Covered by Qualitative Research in the Area of HIV/AIDS

The issues addressed by qualitative research appear to be broad, covering different aspects of the diagnosis, prevention, and caring processes for different target populations affected by the HIV/AIDS epidemic. Across all of the different focuses and knowledge objectives, the qualitative research retrieved in this literature review shares a strong applicative nature and has the final aim of producing situated insight for orienting interventions in specific social contexts. The qualitative research retrieved appeared to be best articulated in a conceptual map, driven by two thematic axes (see Fig. 19.3).

The first axis in Fig. 19.3 articulates the type of problem dealt with by the study, from a focus on preventive practices, to a focus on the treatment and management of HIV/AIDS. The second axis articulates the level of reality addressed: it encompasses the main interests of both the individual and his/her psychological functioning, such as the final driver of societal change and, at the opposite end of the spectrum, a focus on the collective structure of society, which is considered to be the fundamental element that influences the attitudes and behaviors of the individual, and thus health practice.

Within this general framework, the majority of retrieved qualitative research contributions seem to mainly share a prevention perspective, aimed at stopping the HIV/AIDS epidemic. The main target populations in these studies appear to be those primarily at risk of HIV/AIDS; namely the most out-of-reach, vulnerable, unrepresented, and generally less powerful in their social context. Interestingly, qualitative research in this domain seems to act as an important vehicle to give voice to the often neglected, less trendy, and less easily studied aspects of the HIV/AIDS prevention process.

In this regard, the published qualitative research addressed: local populations in underdeveloped countries (Abraham et al. 2011; Jack et al. 2011; Page 2005; Wagner et al. 2011); generally marginalized targets of the population, such as injection drug users (Brown and Hill 2005; Mosack et al. 2005; Ntata 2007); alcohol addicted populations (Brems and Dewane 2007;

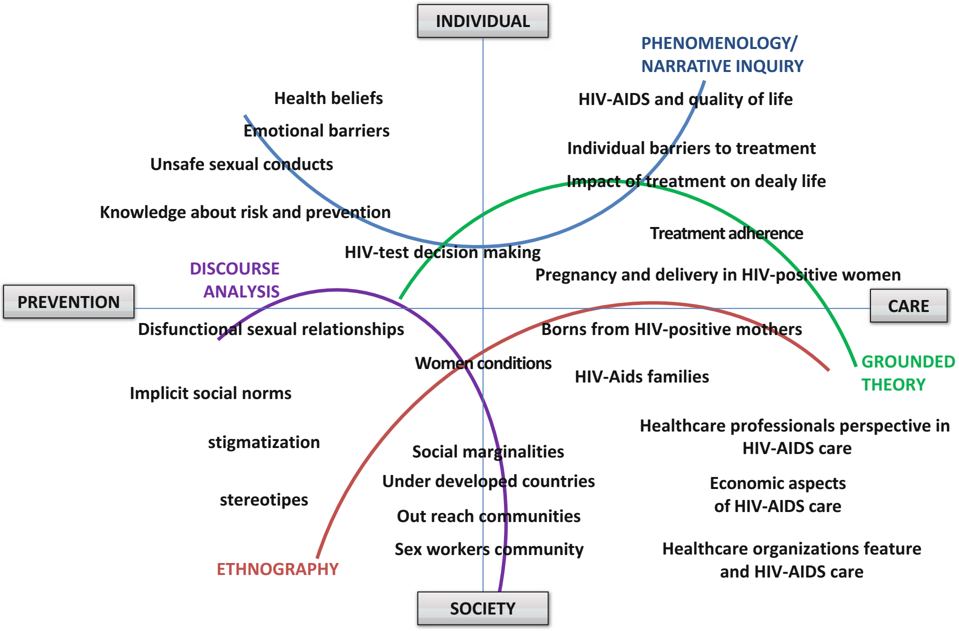

Fig. 19.3 Thematic and methodological articulation of qualitative research evidence in the area of HIV/AIDS

Essien et al. 2005; Mutinta et al. 2013; Phorano et al. 2005); sex workers (Aral et al. 2005; Sherman et al. 2011; Van Blerk 2007; Whitaker et al. 2011); and GLB communities (Brooks et al. 2011; Clark et al. 2013; Hubach et al. 2012).

19.4.1 At-Risk Behaviors

For instance, Needle et al. (2008) conducted a qualitative research study based on interviews, focus groups, and on site observations with drug injectors in order to deeply explore their habits, beliefs, and routines related to drug assumptions and at-risk sexual behaviors. Their study highlighted that, in this population, drugs play a central role in structuring behavioral patterns and daily routines related to buying, selling, and using of drugs. They also underlined how, in this population, behavioral patterns across drug and sexual risk networks were frequently mixed, thus underlining the high potential to spread HIV/AIDS in these scripts of habits. Similarly Phorano et al. (2005) unveiled the link between alcohol abuse, gender-based violence, and HIV/AIDS. Furthermore, they cast a light on how gender-based violence is often perpetuated by cultural practices. Their findings also offered important practical guidelines for orienting gender-based prevention programs. Thanks to its flexibility and its "ecological" approach to problems, qualitative research in these areas has allowed scholars to grasp the inner, complex, often ineffable and invisible barriers that hinder safe behaviors, and that sustain the life of the HIV/AIDS epidemic, both at the level of an individual's way of functioning and with community structures and cultural norms.

19.4.2 Couples and Partner Relationships

With regard to individual functioning, some studies analyzed the cognitive, emotional, and behavioral components of human experiences related to sex behaviors, to couple and partner relationships (Benoit et al. 2012; Harman et al. 2007; Harris and Rhodes 2013; Kaljee et al. 2007; Lesser et al. 2007) and to health management in general (Miller and Rubin 2007). In particular, the knowledge gaps and the relational norms and beliefs related to unsafe behavior that may lead to transmission of HIV have been addressed. For instance, Smith and Watkins (2005) illuminated the evolution of HIV/AIDS risk perceptions and the beliefs of men and women in rural Malawi. Interviews and diaries collected in this study showed that HIV/AIDS and strategies to prevent it were a frequent topic of conversation amongst married Malawians, increasingly in more recent times, although women and men expressed different sensibilities and priorities. In particular, extramarital behaviors of men were the key object of worries both for women, who consider their husbands as a possible source of infection, and for men, who worry about their extramarital partners.

19.4.3 Translation of Health Knowledge

The symbolic meaning, intrinsic contradictions, and consequences on the intimate attitudes and behaviors of the individual have been discovered, casting light on the reasons for the inapplicability and unacceptability of certain preventive messages and educational programs in specific local contexts (Busulwa et al. 2006; de Cortazar et al. 2009). In this regard, Graffigna and Olson (2009) conducted a qualitative study designed according to Discourse Analysis to unveil the complex psychosocial processes that underlie the translation of health knowledge about HIV/AIDS disease and infection into safe practices, often reducing the impact of preventive campaigns about HIV/AIDS. Their results confirm the role of young people's interpersonal exchanges in determining HIV/AIDS preventive conduct and show the importance of social discourses about HIV/AIDS in mediating the impact of preventive campaigns on young people's attitudes and beliefs.

At the community level, culturally based practices and norms, as well as stigmatization processes and prejudices, have been observed and uncovered by qualitative research, which is particularly sensitive in understanding the concerns of ethnic and cultural groups (Chinkonde et al. 2009; Mahendradhata et al. 2008). This branch of qualitative study has helped in putting the individual's way of functioning into perspective, in the more complex and systemic scenario of anthropological and sociological processes that root groups and peer networks.

19.4.4 Gender-Based Health Inequalities

Thus, specific nuances of the HIV/AIDS problem, in the light of certain sociocultural, relational, and historical contexts, have already been researched and described. A significant amount of attention in the qualitative research debate has been devoted to the condition of women, which is considered to be a particularly delicate and risky situation in certain cultural groups (Clum et al. 2009; McCall et al. 2013; Medley et al. 2009; Norris et al. 2005). The development of a feminist analysis of the problem, in order to underline dangerous and unequal power dynamics, is well documented. For instance, Gahagan et al. (2011) conducted a qualitative research study on gender-based health inequities in relation to HIV, including HIV testing as well as different challenges in accessing HIV care, treatment and support programs, and services when testing HIV-positive. Their findings showed that gender is a key determinant of health in relation to HIV, and that it relates to health equity issues such as access to HIV testing, stigma, discrimination, sexual behaviors and relationships. Furthermore, Christofides and Jewkes (2010) showed with their study that often women who are aware of their HIV risk feel powerless to discuss condom use, HIV testing, and infidelity with their male partners. Women directly relate such experience of gender power inequality to HIV risk. These findings were important to orient counseling to approach HIV risk reduction.

In this context, the contribution of qualitative evidence is outstanding, since qualitative research, by challenging the dominant logic of analysis and intervention in local contexts, has shed light on different aspects of the problem and generated key insights towards radical social change. These studies have also contributed to a revision of cultural stereotypes of the HIV carrier—often maligned and condemned to suffer the consequences of his/her "deviant behavior"—who has been reassigned by qualitative evidence to a more natural role as a "victim" of dysfunctional contexts and relationships (Deng et al. 2007).

19.4.5 Adherence to Treatment

As anticipated, qualitative research evidence has also contributed to knowledge about the care and treatment for HIV/AIDS, particularly in addressing its main problems, unmet needs, and changing priorities. Here, the discussion is flourishing and articulated, and some studies focused on the emotional and cognitive barriers to patient adherence to antiretroviral therapies (Biadgilign et al. 2009; McClelland et al. 2011; Murray et al. 2009; Reback et al. 2004). For instance, Ushie and Jegede (2012) conducted qualitative research to examine the role of family support in treatment adherence of patients affected by HIV/AIDS. They found that family support does not necessarily promote treatment adherence in infected patients: it seems to have a negative effect on adherence when the recipient perceives that the support is given with ulterior motives (e.g., gossiping about them; becoming indebted to the support givers), and when the recipient is the primary breadwinner and feels that this role is being undermined. The authors thus advocate for a context-specific evaluation of the role of family support, in which effectiveness depends on the patient's subjective interpretation of the support givers' motives.

The impact of treatment on an individual's quality of life and routines has been studied, together with the level of acceptability of antiretroviral therapy in the specific psychological context of different patient targets (Alfonso et al. 2006; Van Der Elst et al. 2013). For instance, Mohammadpour et al. (2010) conducted a phenomenological study to understand what may hinder or sustain patients' adherence to antiretroviral therapy. They discovered four pivotal elements that appear to play a crucial role in therapeutic adherence: the patients' active choice of living, and thus the perception of therapy as rescuing; the patients' ability to develop strategies for adhering to the regimen and managing the side-effects; the quality of relationships with healthcare providers; and the appraisal of medication effectiveness as a motivator to continue one's adherence to the regimen. These results were important in order to suggest new clinical insights and strategies to enhance patients' adherence to highly active antiretroviral therapy.

19.4.6 Pregnancy

Another important branch of contributions focused on the issues related to pregnancy and delivery in women affected by the virus (Brickley et al. 2009; Kelly 2013; Rujumba et al. 2013). The emotional and clinical sensitivity of this condition has also been addressed (Stoebenau et al. 2011). Important insights have been produced about the condition, the problems, and the needs of affected women in different countries and healthcare systems, in order to support a more sensitive and patient-centered type of care (Laws et al. 2011; Rossi et al. 2011). For instance, Cooper et al. (2007) investigated the influencing factors for HIV positive individuals' reproductive intentions in Cape Town, South Africa. They discovered that being HIV-positive modified but did not remove reproductive desires, particularly for women. Strong desires to experience parenthood, mediated by prevailing social and cultural norms that encouraged childbearing in society more broadly, were highlighted by the study. Furthermore, the research revealed that HIV positive women tend to not discuss their reproductive desires and intentions with health care providers in HIV care or general health services because of anticipated negative reactions. These findings highlight the need for dedicated policies and interventions to create safer and healthier reproductive options for HIV-positive individuals in this region of the world, which is particularly affected by the HIV/AIDS epidemic.

19.4.7 Family

The entire social network and, in particular, the whole family group of a patient affected by HIV/AIDS has been explored in order to uncover experiences and needs (Li et al. 2008; Salter et al. 2010). The situation of children growing up in the family of HIV-positive patients, and, more often, the children born to an HIV-positive mother, has captured the attention of qualitative researchers in different countries over the years (Fetzer et al. 2011; Giles et al. 2009; Marhefka et al. 2011; Vreeman et al. 2010). For instance, Rochat et al. (2013) conducted a qualitative study in order to test and sustain the development of specific intervention programs dedicated to HIV families with HIV-negative children. This was in order to best orient and support the process of HIV-positive mothers' disclosure of their health status to their HIV-negative children and to sustain psychological elaboration and adaptation of children in such difficult family situation.

19.4.8 Organizational and Professional Issues

Finally, in the context of HIV/AIDS care, a more recent trend in the research zeroes in on the organizational and professional issues related to the delivery of care. Professional attitudes, skills and experiences are discussed, in order to give voice to the difficulties and emotional burdens present in this area (Everett et al. 2005; Södergård et al. 2005; Stein et al. 2007). Qualitative research also addressed the knowledge and educational needs of the different healthcare professionals involved in HIV/AIDS care, with particular reference to nurses, midwives, and social workers, thus contributing to the development and sharing of best practices in the HIV/AIDS domain (Chetty and Maharaj 2013; Evans and Ndirangu 2011; Solomon et al. 2006). This branch of the literature is particularly interesting because it addresses the subjectivities and the situation-specific problems and lack of resources experienced by professionals in dealing with such a difficult epidemic. Additionally, the problems of care responsibility, psychological tenure, professional identity, and professional role negotiations have been addressed, although marginally so far (King and McInerney 2006).

In this regard, the purpose of Guenter et al. (2005) study was to understand the culture, values, skills and activities of staff involved in education and prevention activities in community-based AIDS Service Organizations (ASOs) in Ontario, Canada. Important cultural conflicts were unveiled as crucial obstacles to the best functioning of the service and practical insights for organizational change were advanced and then implemented. In addition, Lester et al. (2010) study evidence highlighted that the main barriers to the widespread use of isoniazid preventive therapy (IPT) for HIV prevention in Gauteng province, South Africa were primarily due to healthcare workers misrepresentations and attitude towards this service. In particular, they unveiled how the lack of experience among physicians was one of main deterrents to the good delivery and implementation of IPT. These authors advised change in healthcare worker perception, recurring to local clinical opinion leaders to educate and sensitize clinicians, in order to sustain the best development of IPT programs in the area.

Still sporadic, but interesting, is qualitative research oriented to a more economical and marketing perspective, as well as to a political science perspective, related to the discussion of global economics and power dynamics that seem to aid or hinder the progress of this ongoing epidemic (Casais and Proença 2012; Cerdeño et al. 2012; Holloway et al. 2012).

19.5 The Methodological Choices of Qualitative Research on HIV/AIDS

With the richness of issues covered by qualitative studies across disciplines and geographical regions, the qualitative methods employed are certainly varied. Although the literature was often only generically related to the data construction techniques used in the research—

mainly interviews, but often focusing on groups and ethnographic observations—many contributions showed an advanced methodological reflection and consistency with the chosen methodological foundation.

Method choice varied according to the focus of the research, and is outlined in the conceptual thematic map previously described (Fig. 19.3). Numerous ethnographies were conducted in order to deeply explore norms, values and behaviors of different cultural groups and how these hinder prevention (Crane et al. 2006; Lopez et al. 2013; Mbuagbaw et al. 2012). Ethnography was also a frequently chosen method when the study of the conduct of health professionals was concerned in the management of HIV/AIDS care. Less frequent, but still significant, was the use of grounded theory, which appears to be the approach of choice to describe decision-making processes leading to adherence to, or avoidance of, HIV testing, the cessation of unsafe behaviors, and asking for assistance and treatment (Alvarez et al. 2006; Guarino et al. 2012; Sherman et al. 2011). Phenomenology and narrative inquiry more deeply explored the inner experience of the disease, and cast light on the delicate conditions related to inequality, marginality and the deprivations of specific target groups (Chetty and Maharaj 2013; Mohammadpour et al. 2010; Molzahn et al. 2012; Pienaar and Visser 2012). This is particularly true in the case of the condition of women. Finally, also frequently used is discourse analysis (in prevalence, critical discourse analysis and feminist discourse analysis) to analyze barriers to preventive communication and to uncover implicit factors that, at the individual and interpersonal levels, seem to foster incorrect assumptions about the virus and its conferred risk (Körner et al. 2011; Mankayi and Naidoo 2011; McInnes et al. 2011). Furthermore, more recent qualitative research in this domain has assumed the participatory action research paradigm, by proposing to overcome the boundary between research and action. This is accomplished by the conceptualization of the inquiry process, a place of intervention itself, as a place to engage different stakeholders, in order to raise awareness of the HIV/AIDS epidemic and to orient change and interventions aimed at prevention (Al-Iryani et al. 2010; Burkhalter et al. 2013; Rhodes et al. 2012).

19.6 Future Directions for Qualitative Research in the HIV/AIDS Arena

As discussed in this chapter, although broadly, the focus of the qualitative research conducted in the last 20 years on HIV/AIDS has moved away from the perspective of deficit, where it principally analyzed problematic situations. Less attention has been paid to low risk target populations, in order to implement prevention strategies in this sector of the population.

However, current HIV prevention work indicates that HIV transmission is a concern even in more developed countries, that information about the virus and its contraction has not been sufficient to modify unsafe attitudes and behaviors in this area, and that there are more complex processes at work behind the elaboration and reception of a preventive message (Hoosen and Collins 2005). Interpersonal communication appears to influence the explanation of prevention messages and to mediate the impact of a health campaign on an individual's attitudes, beliefs and behaviors (Kitzinger 1994). In this regard, the internet offers an interesting alternative to face-to-face exchanges, allowing people to share knowledge about sensitive issues. In fact, many authors have shown how the anonymity guaranteed by this medium allows for more thorough disclosure of experiences, feelings and doubts, particularly related to health risks (Powell and Segrin 2004; Rideout 2002). However, at present, the role of internet exchanges in influencing the HIV/AIDS epidemic has not been fully explored, and only a few qualitative studies have been conducted in this domain (Graffigna and Olson 2009; Muzyka et al. 2012; Zukoski et al. 2011). From our perspective, online peer-to-peer exchanges in low risk populations are assuming major importance in HIV/AIDS prevention and deserve increasing attention in the future. The internet is a powerful tool, with which individuals can build relationships, exchange empathy and mutual empowerment, and obtain advice on improving their wellbeing. Interpersonal exchanges on the internet have the same level of interactivity as face-to-face conversations, but the e-environment makes it possible to overcome traditional interpersonal communication barriers. Geographically distant individuals can talk synchronously, as if they were in each other's presence. An effective exchange can also take place asynchronously, without it being necessary for the individuals to be online at the same time.

Online exchanges about HIV/AIDS are therefore, from our perspective, an interesting opportunity for observation in the arena of risk prevention and qualitative research. Given its flexibility and anonymity, the internet may even be the most suitable approach with which to explore such dynamic and subtle processes as the sharing of knowledge between patients and caregivers. In this regard, among the numerous methodological and technical options offered by qualitative research, internet-mediated forms of qualitative research are particularly interesting and warrant closer attention from a health research perspective, not only because they enable the study of new evolving phenomena but also because they can sustain the development of new forms of intervention (Graffigna 2009).

19.6.1 The Lesson Learnt: The Characteristics of Qualitative Evidence About HIV/AIDS

As described in this chapter, the majority of qualitative contributions to HIV/AIDS research are devoted to giving voice to local experiences, with the aim of detecting insights about the HIV/AIDS epidemic and to better orient intervention strategies. The literature review conducted in this chapter reflects four crucial *pillars* that constitutively result in a body of qualitative evidence.

1. Qualitative evidence are *situated*, namely, be able to give voice to local, peculiar and sometime less evident experiences; it must be grounded in the social context and offer an "ecological perspective" on the phenomena under investigation.
2. Qualitative evidence are *usable*: as we have discussed in this chapter, qualitative research in the HIV/AIDS domain should focus on real problems determined by the local social context and seek to produce directly applicable knowledge, in order to orient change and solutions. In other words, qualitative research in this domain usually aims at reaching results with a high level of pragmatic relevance, which is both applied and usable.
3. Qualitative evidence are *insightful:* thanks to its great sensitivity regarding context, qualitative research in HIV/AIDS investigations offers a divergent perspective on the research object that allows for new visions and interpretations. The creativity implied in the research process is a shared characteristic across all of the qualitative research we reviewed: qualitative evidence contributes to new ways of seeing the problems and, thus, how to handle them. Furthermore, qualitative studies are a source of insight during the research process itself, not only for the researcher, but also for the research participants. It can thus be seen as a new knowledge horizon; this type of research is, for participants, an important source of new awareness about themselves and their own contexts.
4. Qualitative evidence are *engaging:* another peculiar ingredient of qualitative research is the great level of involvement that it demands, both during the research process between the researcher and the research subjects, and also at its end, at the moment of evidence delivery and deployment. Qualitative research is impactful, self-explicative, and often able to engage clients and stakeholders, making it easy to apply in orienting health practices. Qualitative research evidence directly drives empathy towards the object of the study and its features; it is subjective and about subjectivities, and thus is able to speak about and to human beings.

From our perspective, these four characteristics constitute the minimum common denominator of qualitative research evidence really able to have an impact in a real social context and to sustain healthcare interventions and innovations in the area of HIV/AIDS management. They may be regarded as suitable pillars to developing the best design and to implementing qualitative research that is able to produce relevant knowledge in the field.

19.6.2 Open Challenges for Qualitative Evidence in the Field of HIV/AIDS

These crucial characteristics of qualitative study designs in HIV/AIDS research also suggest some general challenges that, although not new to qualitative research methodology, need to be continuously considered and addressed. First, if we said that qualitative research in the area of HIV/AIDS is mainly devoted to giving voice to situated and local experiences and perspectives, then the problem of accessing the field is crucial in this type of research. Research aimed at studying the lived experiences of outreaching communities, of minorities and, in particular, of high-risk targets of the population face important pragmatic barriers to access the field. The problem of language is also crucial, particularly when researching in a social and cultural context different from the researcher's own. Methodological pitfalls related to translations, interpreters, and cultural mediators involved in the research have been pointed out and deeply criticized.

Another crucial concern related to qualitative research in this field is the ethics of investigation practices. To study delicate and neglected aspects of the HIV/AIDS epidemic elicits several ethical concerns, such as how to balance the researchers' personal curiosity and interests with a vocation to social change and the elimination of inequality. Moreover this type of research often implies stressful and emotionally loaded exchanges during the data collection process, so the problem of how to equally reward participants for the courage of participating in the study and for disclosing their perspective is another issue to consider. Additionally, the problem of how to maintain the promise that the study will contribute to change and improvement must be addressed. And finally, the study must take into consideration a plan with which to preserve the researcher's emotionality when being engaged in such a stressful field of work.

A final methodological concern related to qualitative HIV/AIDS research is the level of generalizability of qualitative evidence. This is a tormenting refrain for qualitative researchers, and is broadly discussed in the literature, but it is one that becomes particularly challenging in this branch of research, which, as we have seen, is particularly devoted to producing situated insights to solve real and applied social problems. In other words, achieving generalizability while simultaneously maintaining the situated sociocultural relevance of the results is vital.

All of these important challenges emphasize the necessity of sustaining the highest levels of reflexivity and rigor during the whole methodological process. Research practices should be mastered by the researcher in order to ensure the proper method is chosen and the study is correctly managed. To be reflexive regarding one's own research practices in this field does not simply mean avoiding biases and external influences on the research process, but also means becoming engaged in a critical appraisal of one's own research practices and epistemological assumptions, in order to maintain methodological coherence and soundness during the entire research process. Although reflexivity is not a simple answer to the challenges exposed by the HIV/AIDS domain, it certainly may be an antidote to some common errors and pitfalls.

19.7 Chapter Summary and Conclusions

Qualitative research has greatly contributed to the understanding and management of the HIV/AIDS epidemic in the last 20 years in different cultural contexts and different at-risk groups. The research covers a variety of issues, displays the continuous development of qualitative evidence in HIV/AIDS research, and shares the goals of being oriented toward problem solving and deeply linked to the specific context of the analysis.

On the basis of the main characteristics of the qualitative research that we retrieved and analyzed, and moving away from a socio-constructivist paradigm, we listed the aspects that better define the nature of qualitative research evidence in the domain of HIV/AIDS at the end of this chapter. These elements imbue qualitative research methods in this sector with powerful potential, and, from our perspective, guarantee their increase and diffusion across disciplines and countries. However, intrinsically linked to the peculiar strengths of qualitative research in the area of HIV/AIDS are also some important challenges. These, although neither new nor uniquely related to HIV/AIDS qualitative research, need to be addressed and discussed further, in order to enhance the applicability of qualitative research and its credibility in the overarching research arena.

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Qualitative Evidence in Suicide Ideation, Attempts, and Suicide Prevention

Jennifer White

20.1 Background

The scholarly study of suicidal behaviors (i.e., ideation, plans, expressions of suicidal intent, attempts) has long been associated with quantitative research. The important contributions that such studies have made to the field of suicidology[1] are beyond dispute. For example, epidemiological studies have informed our understanding of the patterned distribution of nonfatal suicidal behaviors by age and sex, across time periods, and between jurisdictions. Surveys have told us about the number of people who consider suicide, the number who attempt suicide, and the proportion who seek professional help following an attempt within a given catchment area. Suicide prevention programs have also been extensively studied and numerous evidence-based reviews have been completed (Katz et al. 2013; Mann et al. 2005). Several programs and strategies appear to hold promise, including physician education, gatekeeper training, and means restriction (Mann et al. 2005). Without undermining the value of these contributions, it is important to acknowledge that within the field of suicidology, a persistent positivist bias has resulted in an intellectual culture that has historically undervalued qualitative research. This was noted by Range and Leach back in 1998 when they recommended that greater methodological diversity and a more reflexive and humble posture toward knowledge generation (exemplified by many feminist and qualitative research frameworks) are needed to be seriously considered if the field of suicidology was to advance in any meaningful way. Ten years later, Hjelmeland and Knizek (2010) conducted a rigorous review of all of the research articles published in the main suicidology journals over the period 2005–2007 and found that less than 3 % were based on qualitative methodologies. Meanwhile, the editor of a leading suicidology journal recently suggested that an “insistence on the rigorously and quantitatively scientific” (Joiner 2011, p. 471) will provide the necessary conditions for the field to advance.

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[1] Suicidology is the study of suicide, suicidal behavior, and suicide prevention. In the United States, suicidology is strongly associated with the work of Edwin Shneidman and Norman Farberow who began publishing research on suicide in the 1950s and 1960s (Spencer-Thomas and Jahn 2012). While the scholarly study of suicide goes back centuries, Laird (2011) notes that suicidology is a distinctly modernist movement that emerged in the 1960s based on the growing prominence of the social sciences, particularly psychology, sociology, anthropology, and statistics.

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Not surprisingly, the overreliance on a narrow range of positivist methodologies exerts a powerful influence over what is to count as knowledge and whose knowledge counts. As others have argued, the rationalist biases, privileging of randomized controlled treatment (RCT) designs, and the largely atheoretical, technical orientation of the evidence-based practice (EBP) paradigm have collectively contributed to an overly scientific understanding of human experience within the broad field of mental health (Brophy and Savy 2011; Kirmayer 2012; Thomas et al. 2012). Many of the relational, contextual, and historical factors which are relevant for understanding human suffering and suicidal despair are not easily amenable to categorization, measurement, or replication (Fitzpatrick 2011; White in press), and, as a consequence, most traditional evidence-based reviews leave readers with an incomplete understanding of suicidal behaviors and a rather limited vocabulary for conceptualizing and representing prevention practices. While there have been a few clear voices advocating for greater methodological diversity (Hjelmeland and Knizek 2010; Kral et al. 2012; Leenaars 2002; White 2012), it is fair to say that the most significant contributions to the qualitative evidence base on suicide ideation, attempts, and suicide prevention have been made from outside mainstream suicidology, with scholars from nursing, counseling, social work, as well as health and social care fields, furnishing the bulk of this material.

All research questions are predicated on particular values and assumptions, and all are driven by specific ontological and epistemological commitments (including the stance of so-called value neutrality), even though they are not always explicated. Instead of viewing qualitative and quantitative methodologies as singular or static entities that are in a hierarchical or opposing relationship to one another (which can lead to polarizing debates such as the “science or paradigm wars”), they should be more properly judged on how well they answer the particular research questions being asked, using criteria that are commensurable with the underlying theoretical and philosophical assumptions (Caeli et al. 2003). Ultimately it is the question at hand that should be driving the choice of methodology (Fitzpatrick 2011; Polkinghorne 2005). In short, if we want to adequately engage with the multiplicities, complexities, and uncertainties that characterize our social worlds, including experiences of suicidal despair and the contexts that surround its emergence, and work toward the development of ethical, effective, and culturally responsive approaches to suicide prevention, then multiple paradigms and diverse research, policy, and practice frameworks will need to be mobilized (Fitzpatrick 2011; Goering et al. 2008; Gould 2006; Rogers 2003).

The main purpose of this chapter is to bring to light the significant contributions that qualitative researchers have made to the evidence base on suicidal behaviors[2] and suicide prevention. The remainder of the chapter has been organized into three main sections. First, the context will be set for understanding the significance of suicidal behaviors as a major health and social problem. Some of the challenges associated with defining suicidal behaviors will also be introduced here. Second, the burgeoning qualitative research literature on suicidal behaviors and suicide prevention practice will be discussed. The majority of this work has been published since 2000, attesting to the relatively recent contributions that qualitative researchers have made in this area. In the final section, the practical implications of this body of evidence for health practitioners, policy makers, and researchers will be discussed.

20.2 Setting the Context

Most countries have clear classification systems in place for defining and tracking deaths by suicide over time (DeLeo et al. 2006). Despite general

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[2] Suicidal behavior is an all-encompassing phrase that includes suicidal thoughts, feelings, attempts, and communications.

common sense understandings of suicide (i.e., self-inflicted, intentional death), scholars and researchers continue to revisit and debate existing terminology and definitions (DeLeo et al. 2006; Silverman et al. 2007) suggesting that the matter of what counts as a suicide death is not as self-evident as it might seem. Meanwhile, determining how many individuals think about suicide (suicide ideation) and/or engage in nonfatal suicidal behaviors in any given year is even more challenging given the difficulty of defining terms like suicide ideation or suicide attempt with any precision. Multiple, overlapping categories and conflicting terms have been proposed, including suicide attempt (with or without injuries), deliberate self-harm, and parasuicide, with different regions/countries favoring different terms (DeLeo et al. 2006). Some terms and concepts have been critiqued for their pejorative implications (e.g., suicide gesture) (Heilbrun et al. 2010). This line of critique is especially relevant when studying the lives and identities of girls and women, whose suicidal behaviors have often been construed as "passive," as "not serious," or as "cries for help" (Canetto 2008; Jaworski 2003; Range and Leach 1998).

Ascertaining intention and agency have become central preoccupations in the effort to classify a behavior as a "suicidal act," and this of course relies on human judgment, cultural context, and interpretation. On top of the multitude of challenges associated with trying to establish another person's "true" intentions (which must include an acknowledgment that multiple and contradictory intentions can coexist) (DeLeo et al. 2006), many people attempt suicide without coming to the attention of a formal service provider, which means there is no opportunity for these behaviors to be systematically counted and tracked through existing public health surveillance systems.

As this brief overview shows, far from being timeless, self-evident, universal categories, suicide and suicidal behaviors carry multiple meanings that are historically contingent and contextually specific. For example, throughout human history, suicidal behaviors have been variously conceptualized as a sin, a crime, an honorable action, a philosophical question, and an illness (Canetto 2008; Marsh 2010). Such cultural variations, unstable meanings, and the social processes that bring suicidal behaviors into existence as objects of study are ripe for qualitative investigation and analysis.[3]

While recognizing the unstable and historically contingent character of these terms, for the purposes here *suicide ideation* will refer to thoughts of killing oneself, while *suicide attempt* will refer to "self- inflicted, potentially injurious behavior with a nonfatal outcome for which there is evidence (either explicit or implicit) of intent to die" (Silverman et al. 2007, p. 273). *Suicidality/suicidal behaviors* will refer to all aspects of suicidal thoughts, behaviors, and actions (Bridge et al. 2006).

In general, suicide ideation and attempts are far more common than deaths by suicide. Cross-national lifetime and one-year prevalence rates of suicide ideation and attempts have been calculated (Borges et al. 2010; Nock et al. 2008). Average lifetime prevalence rates across 17 countries were 9.2 % for suicide ideation and 2.7 % for suicide attempts (Nock et al. 2008). Among American adolescents (aged 13–17), lifetime prevalence rates were 12.1 % for ideation and 4.1 % for attempts, highlighting the fact that nonfatal suicidal behaviors are typically more common among the young (Nock et al. 2013). Besides being young, a number of other factors have also been correlated with suicide ideation and attempts. These include: being unmarried, female, and less educated and having a history of a mental disorder (Nock et al. 2008).

Interestingly, in these studies, "risk factors" such as gender, age, and marital status are typically treated as discrete and static entities. Very little attention is paid to how existing social arrangements (Scourfield, et al. 2012) might actually produce vulnerability and suicidal despair among those who are the most powerless

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[3] As just one example, the social and bureaucratic processes through which coroners and medical examiners come to classify a death as a suicide were the focus of an interesting ethnographic study by Timmerman (2005).

(Canetto 2008). In other words, these large-scale epidemiological studies tell us something important about the magnitude of the problem and the factors that are most strongly associated with suicidal behaviors, but they are clearly limited in their ability to tell us anything about *how* specific factors are linked to suicidal behaviors (Hjelmeland and Knizek 2010). For the most part, standardized clinical interviews that rely on dichotomous (yes/no) variables are used to determine a past history of suicide ideation or attempts. In most cases, this leads to relatively simplistic and decontextualized understandings of suicidal behaviors. Complex, ambiguous, or contradictory narratives are typically overlooked (Kidd 2004). As Hjemeland and Knizek argue,

> The linear cause-and-effect thinking that focuses only on one or a few variables is too simplistic, too reductionist; it does not take the whole individual and his or her surroundings into consideration at the same time, which is necessary if we want to understand why that particular person at that particular time in his or her life is considering to or actually has carried out a suicidal act. (p. 77)

Particularity, context, narratives, and meaning making are the raison d'être of qualitative research. The next section provides an overview of the recently published qualitative research literature.

20.3 Mapping the Landscape

At least two previous reviews of the qualitative research literature addressing suicidality have been undertaken. For example, Lakeman and FitzGerald (2008) conducted a systematic review and thematic analysis of qualitative studies that explored how people live with, or recover from, being suicidal. Meanwhile, Han et al. (2013) reviewed the qualitative research literature addressing suicide and suicidal behaviors among East Asian populations. The current approach will be guided by a much broader question: what is the extent and nature of the qualitative research evidence pertaining to suicide ideation, suicide attempts, and suicide prevention?

Despite its broad focus, the following topics will be *excluded* from consideration: qualitative studies of suicide deaths (which are the focus of another chapter in this volume), qualitative studies of non-suicidal self-injurious behaviors[4] (which are behaviors that are categorically defined by an absence of suicidal intent), and mixed-method designs (unless a subset of qualitative data was analyzed and reported on separately). Only peer-reviewed studies (excluding books) published in English have been included.

The following databases were searched: MEDLINE, CINAHL, PsycINFO, Social Work Abstracts, Web of Science, and Academic Search Complete. Search terms included: "qualitative research," "qualitative evidence," "suicidal behaviors," "suicide attempts," "suicidal ideation," and "suicide prevention." The following journals were also hand searched: *Qualitative Health Research, Archives of Suicide Research*, and *Suicide and Life Threatening Behavior*. After reading all of the abstracts that were generated by the search process, discarding those that were duplicates or irrelevant, and setting a firm end date (December 2013), just over 75 published (English language) articles were identified.

The material has been sorted into three broad, overlapping categories: (a) lived experience of suicidality and healing, (b) practices and perceptions of care and treatment for suicidal individuals, and (c) conceptualizations of suicidal behavior and suicide prevention.

20.3.1 Lived Experience of Suicidality and Healing

The concept of "lived experience" comes from phenomenology where the focus is on studying everyday experiences as lived by particular

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[4] Since terms like deliberate self-harm (DSH) are used in multiple and inconsistent ways by researchers (i.e., inclusive of suicidal actions in some cases, but not always), some relevant studies may have been inadvertently excluded.

human beings (Van Manen 1990). Over half [5] of all of the qualitative studies identified through this review addressed the lived experience of suicidality (i.e., suicide ideation and/or attempts) and/or healing, making this by far the most common focus of qualitative investigations. Most of these studies were published in the last 10 years. These studies, which feature the insights and voices of those who have lived through a suicidal crisis, have typically been published within the broad health and social care literature.

20.3.1.1 Survivors of Near-Lethal Suicide Attempts

Rosen (1975) published one of the earliest qualitative studies examining the lived experience of suicidal behavior. He interviewed seven of ten known individuals who all survived near-lethal attempts following a jump from the Golden Gate or Oakland Bridges in San Francisco. The main purpose of his study was to "learn more about the nature of suicidal behavior by jumping and its alleged impulsive and ambivalent qualities" (p. 289). Interestingly, the term "qualitative research" is never used by Rosen to describe his work and the details regarding his approach to analysis are minimal. However, his use of structured interviews, the reading across informant accounts, and the reliance on direct quotes to bring the material to life are emblematic of qualitative research. Rosen's findings suggest that survivors of a near-lethal suicide attempt did not appear to go through a stage of "resistance" or "life review" at the time of their jump. The participants did however all appear to go through a stage of "transcendence," which Rosen characterized as an experience of submission or surrender. Almost all of the attempt survivors reported that the choice of the Golden Gate Bridge as the site of their jump was associated with the special and symbolic significance of the bridge. This led Rosen to recommend that a concerted campaign to "deromanticize" suicide, especially its link to the Golden Gate Bridge, and the building of a barrier be pursued.

Over three decades later, qualitative researchers from the UK investigated the experiences of those who survived near-fatal suicide attempts. Specifically, Biddle et al. (2010) interviewed individuals who survived a suicide attempt by hanging. Participants in their study acknowledged that hanging was their preferred method of suicide due to its expected association with certain death and its overall ease and accessibility. This raises challenges for suicide prevention and means restriction campaigns. Another study explored how individuals who survived a near-fatal attempt came to choose particular suicide methods. Television, news stories, the Internet, and past experiences were cited as the most influential information sources (Biddle et al. 2012).

20.3.1.2 Youth and Young Adults

Young people (ranging in age from 11 to 24) who recently made a suicide attempt, or adults who had experienced a suicidal crisis in their youth, were a common focus of qualitative researchers' attention at the start of the twenty-first century. Through the use of in-depth interviews, researchers explored participants' experiences of suicide ideation and attempts. Researchers also elicited narratives of healing and highlighted processes of recovery. Grounded theory and basic qualitative thematic analyses were the most commonly used methodologies.

The lived experience of suicidal ideation was rarely a singular focus of attention among this group of researchers (see Paproski 1997 for a rare exception). More commonly, those young people who had made one or more previous suicide attempts and those with a history of "suicidal behaviors" (which included thoughts, feelings, and actions) were recruited as research participants. In some cases individuals were asked to reflect back to a time (within the past 3 years) when they had made an attempt or been suicidal in their youth (Bostick and Everall 2006, 2007; Everall 2006a, b). In these studies, participants reported experiencing several, deeply felt, negative emotions as part of becoming suicidal, which

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[5] Multiple published articles can emerge from a single study, and different members of a research team can analyze and report on different aspects of a large qualitative dataset.

sometimes left them feeling out of control. For example,

> I was a ticking time bomb really. I could at any moment cry, scream, have explosive anger. It came out at strange times. It was lonely, scary, because you don't trust anyone but you don't trust yourself either. It's isolating. (Bostick and Everall 2006, p. 280)

In other cases, previously suicidal individuals were interviewed after they had received a therapeutic intervention (Bergmans et al. 2009a, b) or within a year following the suicide attempt (Bennett et al. 2002). In one case, adult First Nation women, aged 30–45, reflected back on the experience of living with suicide ideation in their youth, and the subsequent processes of healing (Paproski 1997). Young people who were being treated by a mental health team following a suicide attempt (Anderson et al. 2010) and nonclinical populations (Gair and Camilleri 2003) were interviewed about their experiences.

In another set of studies, young female Latina adolescents (as well as their parents in some cases) were interviewed following the young person's suicide attempts (Hausmann-Stabile et al. 2013; Nolle et al. 2012; Zayas et al. 2010). By situating their study of suicidal behavior within a familial and cultural context, these researchers were able to highlight some of the unique challenges that these youth faced as they attempted to reconcile their own needs with their family's expectations. For example, one 15-year-old girl of Mexican descent attempted suicide following her parents' separation and she blamed herself. When asked to give an account of her suicide attempt, she said,

> Like, I blamed the things on me. Like, if I would've done things differently, what if my father–what if I didn't argue so much with my father? My parents would still be together. If I was different, my father would've been different, and my sisters would've been different, and it would have been a whole different situation. (Nolle et al. 2012, p. 324)

Reading across these studies, a few noteworthy findings are worth highlighting. First, suicidal thoughts and behaviors among young people typically occur in dynamic sociocultural contexts, where individual vulnerabilities, relational identities, cultural and familial expectations, and normative discourses intersect in highly complex and conflicting ways. For example, young people are often faced with managing multiple and competing expectations which can sometimes lead to intense and difficult emotions, and under certain circumstances of escalating stress, this can contribute to negative identity conclusions such as worthlessness (Everall 2006a, b) or burdensomeness (Nolle et al. 2012). This could include, for example, living in the midst of irreconcilable tensions between individual and family aspirations (Hausmann-Stabile et al. 2013) or failing to live up to their own or societal expectations. Navigating such contradictory demands can sometimes lead to a "fractured reality" (Anderson et al. 2010). Latina adolescents, with a strong commitment to "familism," for example, may attempt to resolve this crisis by sacrificing themselves for the benefit of their families (Nolle et al. 2012). Second, the emotional experience of suicidality is fluid, complex, and layered. Experiences of overwhelming despair, self-loathing, alienation (Everall 2006a, b) as well as guilt and remorse following a suicide attempt (Zayas et al. 2010) were commonly reported by participants. Third, turning points, relational connections, and multiple pathways were prominent in the narratives of healing and recovery. Paths to healing were characterized by nonlinear "pockets of recovery" (Bergmans et al. 2009a, b) that were culturally and spiritually meaningful (Paproski 1997), which included feeling cared for and having significant relational connections to others (Bostick and Everall 2006; Everall 2006a, b; Gair and Camilleri 2003) and which enabled young people to feel protected and nurtured while, at the same time, allowing possibilities for self-determination (Bennett et al. 2002).

20.3.1.3 Individuals Living with Mental Health Problems

Adults who had received service from a mental health or crisis response team, who had recently been admitted to hospital for suicidal behavior (frequently referred to as "suicidal patients" or "psychiatric inpatients"), or who were living with depression or another mental health problem were another commonly studied population. These studies were all published within the past 10 years and were conducted in a diverse range of geographical locations, including: Italy (Ghio et al. 2012), Norway (Vatne and Naden 2012), Iran (Keyvanara and Haghshenas 2010), Poland (Mandal and Zalewska 2010), Brazil (Neto et al. 2012), Canada (Oliffe et al. 2010), Sweden (Pavulans et al. 2012), and Switzerland (Valach et al. 2006). In-depth interviews and focus groups were the most commonly used methods for eliciting first-person narratives.

From these studies we learn that suicide attempts cannot always be rationally explained (Ghio et al. 2012; Pavulans et al. 2012), although in some cases people described their suicidal actions in ways that the researchers characterized as "goal directed" (Valach et al. 2006). There is frequently a paradoxical quality to suicidal ideation. For example, "the thought of being able to put an end to one's suffering if it should become unbearable, is comforting and makes it possible to endure suffering" (Vatne and Naden 2012, p. 308). Holm and Severinsson (2011) put it this way, "finding the meaning of one's desire for death might offer a possibility to escape and gain freedom, while at the same time helping one to hold on to life" (p. 171). Participants in the Swedish study spoke about the double meaning of a suicidal act (Pavulans et al. 2012). Specifically, a suicide attempt was equated with "being in want of control" which suggests being out of control and wanting control simultaneously. Finally, Valach et al. (2006) offer the example of the research participant who, "… described cutting herself without wanting to kill herself and then, in the course of cutting, she suddenly cut herself in a manner that endangered her life" (p. 359). These complex narratives hint at the limits of traditional approaches to understanding suicide ideation and attempts that rely on binary (yes/no) answers to questions about suicidal behavior.

As these studies further attest, qualitative researchers can also bring the sociocultural contexts, the dominant discourses, and the historical and political conditions that contribute to the emergence of suicidal despair into sharp relief (Neto et al. 2012). For example, qualitative studies can illuminate how gendered discourses, including cultural expectations regarding the performance of masculine identities (i.e., stoicism, independence, commitment to action), are relevant for making sense of men's suicidal thoughts and behaviors (Oliffe et al. 2010). Other studies shine the light on women's lives, as they attempt to negotiate their identities as mothers, wives, friends, and productive citizens in the midst of changing social norms, asymmetrical power relations, and competing cultural narratives (Keyvanara and Haghshenas 2010). For many women who engage in suicidal behavior, experiences of victimization, and violence were highly salient in their narrations of suicidality (Holm and Severinsson 2011; Mandal and Zalewska 2010). These qualitative accounts offer richer, more complicated, and deeply contextualized views of men's and women's lives, especially when compared with approaches that seek to isolate particular variables (i.e., depression or history of violence) as risk factors for suicidal behavior. From these studies we also learn that change and recovery from suicidal despair is clearly possible (Holm and Severinsson 2011) and it is evident that involving service users in decisions about heath care is an ethical and useful practice in its own right (Ghio et al. 2012).

20.3.1.4 Other Specific Populations

A number of other studies explored the experience of suicidality among specific populations. These included: older persons (aged 55–98) (Crocker et al. 2006; Haight and Hendrix 1998; Moore 1997; Wu et al. 2012), individuals with substance-use problems (Miller 2006; Spence et al. 2008), immigrant populations (Biong and Ravdnal 2009; Chung 2012), individuals with a history of suicidal behavior who posted to an online community (Benson et al. 2013; Dodemaide and Crisp 2013), sexual minority populations (DiStefano 2008; McAndrew and Warne 2010), female veterans (Gutierrez et al. 2013), and farmers from Manitoba (Sturgeon and Morrissette 2010).

20.3.2 Perspectives on Care and Treatment for Suicidal Persons

Approximately 30 % of the published qualitative literature identified through this review examined individual, family, and professional perspectives on the care and treatment of suicidal individuals. All of these studies are relevant to the prevention of suicide. Three different perspectives could be discerned: (a) professionals' views, (b) suicidal individuals' views, and (c) combined views. Almost all of these qualitative studies were published within the past decade.

20.3.2.1 Professionals' Views

Professional perspectives on care for suicidal persons included the views of psychiatric nurses and mental health clinicians (Aflague and Ferszt 2010; Webster et al. 2012), counselors and youth workers (Popadiuk et al. 2008; Ranahan 2013; Slovak and Singer 2012), physicians (Vannoy et al. 2010), hospital emergency department medical staff (Pallikkathayil and Morgan 1988; Redley 2011; Senarathna et al. 2013), and trained suicide prevention gatekeepers (Evans and Price 2013).

In an early qualitative study, Pallikkathayil and Morgan (1988) interviewed emergency department nurses about their previous encounters with suicidal patients. Findings revealed that caring for a suicidal person was highly stressful and was often associated with a sense of loss of control. Anger toward the suicidal person and frustration over a lack of resources were prominent feelings reported by nurses doing this work. Suicidal behaviors often elicited conflicting feelings from nurses who understood their responsibilities as saving lives. Individuals who presented at hospital having made a suicide attempt appeared to have a destabilizing effect on nurses' professional identities. The authors describe how this constellation of factors can potentially lead to avoidance, distancing, and disengaging practices on the part of nurses.

A later study by Ranahan (2013) also raised important questions about the potential for standard suicide prevention practices to have the unintended effect of creating distance between the professional and the suicidal person. Specifically, using a grounded theory methodology, Ranahan interviewed child and youth care practitioners, supervisors, and educators about working with suicidal youth. A consistent finding was the belief that once suicidality was suspected, a series of action steps would need to be activated, including a practice that Ranahan called "flooding the zone," whereby the professionals "… overpower the likelihood of the adolescent dying by suicide by surrounding the adolescent with services and other helping professionals" (p. 144). This study surfaced important ethical considerations regarding the practice of "flooding" suicidal young people with a barrage of services, often without their input or against their own preferences.

Several other innovative methodologies were used to explore professionals' views and a few are worth highlighting here. One study focused on the vocabulary and narrative context for inquiring about suicide risk among primary care physicians based on an analysis of transcripts from previously recorded patient visits (Vannoy et al. 2010). Researchers found most of the physician responses to potential suicide risk among patients to be appropriate, contextually sensitive, and supportive. A small minority of physicians inquired about suicide in a manner that was found to be inhibitive of patient disclosures. These unhelpful responses included: failing to place the inquiry in context, asking yes/no questions, or using a "no-problems-expected phrasing" (e.g., "you're not feeling suicidal are you?").

Aflague and Ferszt (2010) initially observed nurses conducting suicide risk assessments with adult patients in a psychiatric hospital setting. This was followed by a research interview with the nurse participants. Using a methodology called phenomenography, these researchers sought to better understand how nurses think about and perform suicide risk assessments. They write that, "[u]nlike phenomenology, which searches for the essence of phenomena, phenomenography focuses on the different ways people experience, conceptualize, perceive, and understand various aspects of phenomena in the world around them" (p. 249). When coming to their formulations regarding suicide risk, the researchers noticed great variability among the nurses. At the same time, nurses relied on a combination of knowledge (e.g., risk factors), process skills or "methods" (e.g., active listening), and a "reference dimension" (e.g., stories, cases, or previous experiences).

In another innovative approach, Popadiuk et al. (2008) used a focus group to engage suicide prevention counselors in a discussion regarding the challenges of working with suicidal individuals. They also introduced the counselors to a "self-confrontation procedure," which is a practice that involves counselors videotaping their counseling sessions and then, at regular intervals, stopping the tape and playing segments back for the client, as a way to invite client reflections and generate new insights. Following the initial focus group, counselors were encouraged to consider how the self-confrontation technique might be useful with their own clients. A follow-up interview was scheduled to discuss their impressions one month later. What made this study unique, apart from the important findings it generated about the unique stressors counselors face when working with suicidal individuals, was the process. Specifically, it began with counselors' experiences and provided them with the opportunity to critically reflect on the strengths and limitations of the self-confrontation technique, using an experiential learning format. This provided a stimulating site for joint learning and knowledge creation.

Two recent studies considered the important role of social dynamics, practice cultures, and organizational influences on suicide prevention practices. First, Senarathna et al. (2013) used the treatment of acute self-poisoning cases as a site for studying the social dynamics among rural hospital staff in Sri Lanka. Focus groups were held with doctors, nurses, and other nonclinical hospital staff. Findings suggested that a self-poisoning episode typically brought hospital staff into extensive contact with family and community members. For example, according to one doctor,

> The whole village rushes in to the hospital, because we do not have a security guard here. Removing those people [from the ward] is a big issue for us. It is quite disturbing to have them around [the patient]. A whole village present here crying and weeping. This is my main issue here. First of all [before I start treatment], I chase them away. (p. 1484)

Such vivid accounts invite a much more complicated understanding of what is at stake in these particular moments than studies that focus more narrowly on identifying risk factors or evaluating standardized interventions. Findings from the study by Senarathna et al. (2013) show how the social and cultural dynamics surrounding episodes of acute self-poisoning place unique demands on rural hospital staff in Sri Lanka. Several implications for future practice were noted, including the need to develop more effective communication mechanisms to support constructive interactions between staff and family members and the need for higher levels of collaboration and cooperation across all members of the healthcare team.

Second, Evans and Price (2013) examined the role of organizational culture on the uptake of suicide prevention gatekeeper skills within specific workplaces. Through a series of interviews and focus groups with individuals who had recently participated in a suicide prevention gatekeeper training workshop, they learned that current training efforts needed to move beyond "…a reductionist approach and the focus on individual competencies" (p. 223). Specifically, an ethos of collective responsibility, enhanced opportunities to intervene, and development of a positive organizational context were identified as key enabling conditions that could make a positive difference in advancing the goals of suicide prevention.

20.3.2.2 Suicidal Individuals' Views

The views and experiences of suicidal individuals who have accessed formal mental health services have been well documented by qualitative researchers in recent years (Paulson and Worth 2002; Samuelsson et al. 2000). As one example of the important contribution that such studies can make to the current evidence base, Cutcliffe et al. (2006) interviewed adults who had received care as a result of a suicide crisis from the emergency psychiatric services. They sought to understand how psychiatric nurses work with suicidal patients and learn what was most meaningful from the patients' perspective. Based on an analysis of patient accounts, the researchers theorized that the caring processes that nurses engaged in to facilitate movement from a "death-orientated position" to a "life-orientated position" could be best captured through the idea of "reconnecting the person with humanity," which included several overlapping processes. Specifically, nurses were able to cultivate and restore trust, facilitate insight, provide a bridge back to humanity, and ultimately support patients to learn to live again. These practices of care, which are predicated on a human, close relationship, were set against some contemporary approaches to treating suicidal persons, which are often based on being "treated mechanically" or placed "under observation" (Cutcliffe et al. 2006, p. 802).

Interestingly, an earlier qualitative study by Cardell and Pitula (1999) suggested that even practices of "constant observation" can embody many of the human, caring qualities recommended by Cutcliffe et al. (2006). Specifically, Cardell and Pitula interviewed "suicidal, psychiatric inpatients" who had received constant observation within the previous 2 weeks. They found that when the "observers" engaged them as persons, participated in conversation and distracting activities, showed friendliness and optimism, and provided emotional support, the benefits to patients were perceived to be extremely positive. On the contrary, when observers lacked empathy, failed to acknowledge the person, provided little to no information about what was happening, and invaded the personal space of the person under observation, the effects were experienced as extremely upsetting and negative.

Another study examined the specific experience of young men who had been actively suicidal at some point in their lives and who had accessed formal or informal (mental) health services for support (Jordan et al. 2012). Aspects of care that were considered the most meaningful were elicited from participants through open-ended interviews. These included: having flexible program mandates to enable wide access to services, more proactive outreach, and increased opportunities for more informal types of support. Participants also spoke about the limiting effects of traditional notions of masculinity on help seeking and envisioning possible futures for themselves. When opportunities were created for these men to explore these issues with others who were facing similar challenges and when they were given the chance to challenge some of the limiting and unhelpful assumptions about "being a man" in an open and trusting environment, participants reported feeling less alone, less stigmatized, and increasingly understood. Finally, having a relational connection with an open-minded, empathic, and caring mental health professional made a meaningful difference in the lives of these men.

One study in this group was unique in that it sought out the views of parents and carers whose children had expressed suicide ideation or engaged in self-harm (Byrne et al. 2008). Through a focus group methodology, the researchers met with parents and carers whose children (16 years and younger) had engaged in self-harm and/or expressed thoughts of suicide within the past 3 years. Findings indicated that parents/carers have a high need for particular kinds of support when dealing with a son or daughter who is thinking about suicide or engaging in self-harm. Specifically, parents expressed a need for emotional support for themselves and their families, parenting information, especially parent-child communication, and general knowledge about managing self-harm.

20.3.2.3 Combined Views

A small number of studies examined the combined views of suicidal persons *and* professionals or caregivers (Cooper et al. 2011; Sun and Long 2012; Sun et al. 2008). This is a research orientation that nicely exemplifies the point made by Cutcliffe et al. (2006) that "[t]he practice of providing care for the suicidal client clearly involves at least two people" (p. 793). As just one example of this approach, Bergmans et al. (2009a, b) interviewed repeat substance abusing suicidal male clients and hospital emergency department (ED) personnel about their interactions and learned that there were a number of potential "disconnects" between the two groups. The two groups often had different ideas and expectations regarding reasons for seeking care, the role of the emergency department, and the availability of community-based resources. For example, participants said they attended the emergency department to get help with their emotional distress. Once in the ED, however, they faced long waits, had to endure multiple interviews, and felt an overall loss of control. Many participants also said that they expected to encounter negative interactions, as exemplified here:

> Well I notice a big difference if I'm coming in for a medical reason than if I'm coming in for a psychiatric reason… I get the feeling like oh they feel that I'm just a revolving door client… it's just a total different way of treatment. Um, it's almost like they're fed up with me. (p. 424)

Meanwhile, ED staff were often faced with highly agitated and frustrated patients, who would occasionally become aggressive once they learned of the long waits in the ED. One staff member said, "Do people like having them as patients? Not when they're spitting on you and punching you" (Bergmans et al. 2009a, b, p. 425). Several practical recommendations emerged from this study, including the creation of high-functioning, interprofessional teams within the ED. Establishing a clear role for the hospital social worker, who can serve as a patient advocate, provide a reassuring presence, support patients throughout their time in the ED, and liaise with outside resources, was also recommended. Finally, alliance-building efforts, validation strategies, and emotional de-escalation techniques were identified as important skills that could contribute to supporting these clients to feel safer and more grounded while in the ED.

Two studies examined the *interactions* between suicidal persons and trained helpers. In one case, researchers listened to telephone-based crisis response calls with older adults (65 and older) in addition to interviewing the telephone counselors (Deuter et al. 2013). In another study, postings made to an online community for distressed adolescents (Greidanus and Everall 2010) were the focus of qualitative inquiry. What is unique about these two studies is the way they afforded researchers an opportunity to attend to how meanings and identities were negotiated through conversational practices, within real-world helping contexts.

20.3.3 Conceptualizations of Suicidal Behavior and Suicide Prevention

In this final group of studies, local understandings of suicidal behavior and practices of suicide prevention were the primary focus of analysis. Not surprisingly, close attention is paid to language, discourse, cultural contexts, and social processes of identity construction and meaning making. Representing approximately 20 % of the total number of qualitative studies identified in this review, these studies represent a growing area of interest. What sets these studies apart from those reviewed in previous sections is that for the most part, *non-suicidal* individuals and groups are typically engaged to find out how suicide risk, resilience, and practices of prevention are conceptualized within their own particular contexts and cultural communities.[6] It is worth mentioning at this point that the categories of "suicidal persons," "non-suicidal persons," and "professionals" are themselves highly problematic for the ways in which they imply that these identity categories are final, singular, and stable, as opposed to emerging, multiple, fluid, and overlapping. It is this very attention to received under-

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[6] An exception is the study by Horne and Wiggins (2009). They used a discursive psychology framework to analyze how individuals worked up an "authentic" suicidal identity in an online forum for those with suicidal thoughts. They also examined how others responded to these particular identity constructions.

standings of the social world that many of the studies included in this section set out to disrupt.

A diverse range of communities and social groups were consulted to better understand how they conceptualized suicidal thoughts and practices of suicide prevention. They included: young people (Bennett et al. 2003; Coggan et al. 1997; Fullagar et al. 2007; Kidd 2004; Molok et al. 2007; Roen et al. 2008; White and Morris 2010; White et al. 2012); sexual minorities (Fenaughty and Harre 2003; Roen et al. 2008); Indigenous community members (Decou et al. 2013; Kral 2013; Strickland et al. 2006; Wexler 2006); key informants from Ghana and Uganda, including students, laypersons, and professionals (Hjelmeland et al. 2014; Knizek et al. 2011; Mugisha et al. 2013; Osafo et al. 2011a, b); and healthcare practitioners working in specific cultural contexts (Anderson et al. 2005; Hagaman et al. 2013).

For example, Anderson et al. (2005) used a social semiotic framework to analyze how doctors and nurses working in a hospital context in England made sense of young people's suicidal behavior. These researchers were able to highlight the complexities, ambiguities, interactive qualities, and unspoken meanings embedded in the nurses' and doctors' accounts of suicidal behavior. They called attention to the broader social environments within which to make sense of youth suicidal behavior as well as the culturally mediated systems of meaning that participants relied on to conceptualize young peoples' suicidal behaviors.

Other researchers focused their analyses on the cultural resources that young people drew upon to make sense of suicide (Bennett et al. 2003; Fullagar et al. 2007; Kidd 2004; Roen et al. 2008; White and Morris 2010; White et al. 2012). For example, Kidd (2004) interviewed street youth living in Vancouver and Toronto and found that the theme of "being trapped" featured prominently in street youths' understandings of why they, or others, might become suicidal. Kidd also pointed to a recurrent narrative of social exclusion and stigmatization in the accounts of street youth and suggested that more socially responsible forms of engagement, including family support, media education, and legal interventions, would be necessary to challenge harmful stereotypes and provide meaningful opportunities for street youth to participate more fully in the life of the community. The findings from Roen et al. (2008) amplify the findings from Kidd's study in important ways by highlighting how "suicidal identities" are often saturated with moral judgments, which construct the suicidal person as other. Working in the context of England and Wales, they traced young peoples' (16–24) understandings of suicidal behavior. These discursive practices

> […] locate suicide as being against the community's religious beliefs, as not happening in 'normal families', but as being something that is more expected from 'druggies' and not in 'nice streets'. In a sense reproducing through suicidal discourses a moral order. (p. 2091)

Other studies focused on conceptualizations of suicide risk among sexual minority populations (Fenaughty and Harre 2003; Roen et al. 2008; Scourfield, Roen & McDermott (2008)). Through focus groups and interviews with young people who self-identified as lesbian, gay, bisexual, or transgendered (LGBT), as well as with youth whose sexual identity was not specified, Roen et al. (2008) explored a range of issues, including how young people negotiate distressing environments and how struggles around issues of sexual and gender identities were potentially implicated in young peoples' understandings of suicidal behavior. They highlighted some of the ways that LGBT youth deal with overt homophobia and more subtle forms of stigma and discrimination. The researchers also highlighted the ways in which young people drew on available cultural discourses to make sense of suicidal behavior among LGBT youth, including seeing it as a response to isolation, homophobia, and the stress of coming out.

Another group of qualitative researchers have recently begun to explore understandings of suicide within African contexts, specifically, Ghana (Hjelmeland et al. 2014; Osafo et al. 2011a, b) and Uganda (Knizek et al. 2011; Mugisha et al. 2013).

What these researchers have helpfully pointed out is that meanings of suicide are culturally specific and any suicide prevention program that is developed must take local understandings into account. Across the continent of Africa, there are many different tribal groupings, religious practices, and cultural norms and thus there is a need to study meanings of suicide within particular community contexts. Given the influential role of religion in many African peoples' lives, Mugisha et al. (2013) utilized focus groups and key informant interviews to learn more about religious views on suicide among the Baganda people of Uganda. A prominent finding was that suicide represents a serious breach of the religious order. While there were some divergent views, the researchers noted that for the most part, "[o]ur informants considered suicide as a breach of God's rules by violating the doctrines of sacred life, by violating the commandment thou shall not kill, and by violating the rule of agape" (p. 351). This dominant view has clear implications for how suicidal persons are treated and points to the need to engage with religious discourses as part of any suicide prevention effort in this particular context.

Others have examined North American Indigenous community members' understandings of distress, suicide, and healing (Decou et al. 2013; Kral 2013; Strickland et al. 2006; Wexler 2006). For example, Wexler used a participatory action research (PAR) methodology to engage Inupiat community members in ongoing and transformative conversations about youth suicide. By trying to better understand how community members made sense of youth suicide and by eliciting dominant cultural narratives of the problem, she set the stage for collective critique and social action. In another participatory research design, young people were taught how to create digital stories as part of a larger youth suicide prevention initiative in Northwest Alaska (Wexler et al. 2013). Drawing on a positive youth development framework, the project was designed to be strengths based, empowering, and transformative. Strickland et al. (2006) utilized focus groups and interviews to better understand parents' and elders' perspectives on colonization and the implications for youth suicide prevention in a Pacific Northwest American Indian community. Meanwhile, Kral (2013) drew on ethnographic fieldwork to better understand the disproportionately high rates of suicide and suicidal behaviors among Inuit male youth. Based on interviews with community members from Igloolik, he learned that suicidal behaviors were very often linked to disruptions in romantic and family relationships and intergenerational segregation. Kral discusses his findings in the context of colonialism and suggests that "[A]mong colonized peoples it [suicide] is viewed in part as stemming from dispossession" (p. 73).

20.4 Implications for Practice

As this comprehensive review has shown, understandings of suicidal behavior which contextualize and historicize the experience of despair and which privilege subjective meanings provide important insights into this complex human experience. At the same time, it is important to note that no matter how careful and well designed the study, it is impossible to arrive at some pure, unmediated, authentic, or final account of suicidal despair. For one thing, human beings cannot always "give voice" to every experience, emotion, impulse, or fleeting understanding they have, and many of the complexities of human existence, including contemplations of suicide, remain elusive, shifting, contradictory, and inarticulable (Polkinghorne 2005; Jackson and Mazzei 2013). Further, the active participation of the researcher in constructing the questions, designing the study, interpreting the material, and representing it on the page means that any knowledge that gets generated is always partial, situated, and strongly influenced by the researchers' theoretical lenses. This is as true for quantitative researchers as it is for those working within a qualitative paradigm. With these caveats in mind, the implications of some of these findings for future practice are discussed.

20.4.1 Lived Experience as a Source of Knowledge

Across a range of health and social care fields, there has been a strong call to include the perspectives of those with lived experience (i.e., consumers, service users, clients, patients) in the design and delivery of healthcare services (Ward et al. 2012). The work reviewed here directly responds to this call and showcases the value of a knowledge base informed by first-person perspectives. To begin, what we have learned from the rich corpus of studies investigating the lived experience of suicidality is that "being suicidal" is not a static or singular identity category. Those who have considered and/or attempted suicide are always multiply constituted and are constantly reconstructing themselves (Rogers 2003). At the same time however, there are some common threads. Specifically, the qualitative evidence has offered a thick description of the lived experience of suicidality, which includes intense suffering and struggle, hopelessness, and a strong desire to escape. Importantly, and in contrast to many other research approaches, these accounts of suffering are generated from those with firsthand knowledge and experience. As Hornstein (2013) writes, "…the categories emerge directly from the data of experience, they are not a preconceived classification system imposed on the data, regardless of how well or how poorly it fits" (p. 31). We have also learned that there is often a paradoxical quality to suicide ideation, where holding onto the idea of suicide (as a possible escape) is the very thing that allows a person to endure and go on living. Further, by situating the understanding of these behaviors within specific social and historical contexts, qualitative researchers have revealed the complex, dynamic, culturally situated, and unstable meanings surrounding suicidality (Hjelmeland 2011). Meanwhile, they have highlighted how the ongoing presence of caring others who remain engaged, communicate empathy, seek to understand, and provide opportunities for rediscovering "hidden pockets of strength" (Holm and Severinsson 2011) or "pockets of recovery" (Bergmans et al. 2009a, b) can go a long way toward reconnecting suicidal persons with the desire to live.

20.4.2 Caring Practices, Healing Contexts, and Reflexivity

This review has also showcased the invaluable contributions that qualitative evidence can make to better understanding the complex challenges involved in constructively responding to expressions of suicidal despair, across a range of health and social care settings. What we can take from these studies is the knowledge that providing a warm, caring, empathic, and respectful response, which recognizes the suicidal person as someone who is suffering, but who may not always be able to articulate what he or she needs, is a useful stance to take when doing suicide prevention work, particularly in Euro-western contexts. Further, by helping suicidal persons to see some of the cultural and social constraints that may be contributing to their despair (e.g., narrow notions of masculinity, patriarchal practices), practitioners can help individuals recognize that the challenges they are facing may not be of their own making, which is in keeping with a social justice orientation to counseling and prevention (Aldarondo 2007; Kenny et al. 2009). We have also learned through the qualitative evidence that providing care to those who have lost the desire to live can often be stressful and anxiety provoking. It seems that suicidal behavior can pose a direct challenge to many professional assumptions, identities, and discourses of expertise. Such unsettling experiences can often be an important catalyst for transformative learning (Clouder 2005), although this was not pursued as a line of investigation in the work reviewed here. We have also learned that individuals who have engaged in suicidal behavior are inevitably members of families, communities, and cultural contexts—each with their own expectations, needs, and values—and these larger relational networks and cultural norms need to be honored and mobilized when responding to, and supporting, suicidal individuals.

Finally, standard suicide prevention practices, including "constant observation" and standardized risk assessment interviews, always contain within them the potential to be dehumanizing or disengaging. Qualitative studies like those reviewed here highlight the importance of bringing a reflexive posture to our expert knowledge and professional practices so we can avoid unwittingly causing harm by adhering too tightly to a "one-size-fits-all" mentality when engaged in suicide prevention work (Rogers and Soyka 2004).

20.4.3 Politicized Research and Practice-Based Evidence

As this review of qualitative evidence has suggested, suicide prevention programs that are designed to address the disproportionately high rates of suicidal behaviors among certain groups (i.e., youth, females, sexual minorities, Indigenous peoples) can be made even more relevant by addressing some of the historical, political, and cultural forces that have contributed to oppression, marginalization, stigma, and experiences of suffering. Action research paradigms and other participatory methodologies, which are explicitly political in their aims and which involve local citizens in the design of solutions, show how social justice-oriented, decolonizing methodologies (Tuhiwai Smith 2012) can become important strategies for doing the work of suicide prevention. Such praxis-oriented research frameworks deliberately blur the distinctions between inquiry and intervention (McNamee and Hosking 2012).

A handful of studies included in this review have closely examined *how* we know about suicidal behaviors and have called attention to the ways in which dominant formulations actively shape the development of potential solutions and responses. All forms of research, knowledge, and evidence are products of particular traditions, cultural contexts, and ways of seeing (McNamee and Hosking 2012; White in press). In the future, if we want to avoid complacency and continue to produce innovative scholarship that is relevant for the times we are living in, we need to keep pushing ourselves to think within and against received assumptions about what counts as good qualitative research.

> The methodological implications of this view is that we as researchers question what we ask of data as told by participants, question what we hear and how we hear (our own privilege and authority in listening and telling), and deconstruct why one story is told and not another. (Jackson and Mazzei 2013, p. 262)

PAR, poststructural research frameworks and critical discourse analyses are generally underrepresented in the overall qualitative evidence base. A few books that draw from poststructural and critical frameworks have recently been published and point to the productive potential of these approaches for rethinking suicide prevention (Cover 2012; Marsh 2010). Such approaches may be more in keeping with what Fox (2003) calls transgressive forms of research which are defined in part by their "capacity to transgress, challenge or subvert existing conceptions" (p. 89).

20.5 Concluding Remarks

In a relatively short period of time, qualitative researchers have made several meaningful contributions to the evidence base on nonfatal suicidal behaviors and suicide prevention. Far from providing a definitive statement about the nature and meaning of suicidality, these studies have shown the complex, dynamic, context-dependent, multiple, and contradictory character of suicide ideation and attempts. Despite this variability, there are a number of very practical implications emerging from this review, which can strengthen professional practice when working with suicidal individuals. First, those with lived experience of suicidality have invaluable insights to contribute to the current evidence base on suicide ideation and suicide attempts. As David Webb recently put it in an interview with Liz Sheean (Sheean & Webb, 2010):

> I argue that you cannot hope to understand any human experience, not just suicidality, if you ignore what it means to those who live those experiences. And for this you need to hear directly from

> those who have the lived experience, there's no other way of getting this important information. (Sheean and Webb 2010, p. 28)

Second, we need to place human dignity, flexibility, and the pursuit of culturally meaningful goals at the center of any professional effort designed to support suicidal persons. To do this work well, professional practitioners will need to be supported with ongoing training opportunities that reflect knowledge generated from multiple sources, including service users, findings from qualitative research, as well as more traditional evidence-based practice guidelines. Organizational cultures that support teamwork, invite a reflexive stance toward professional practices, and promote culturally responsive and sociopolitically informed approaches to healing are strongly recommended. Third, we need to take the broader social and political arrangements into account when attempting to understand the sources of human suffering while at the same time never losing sight of the local and particular context. When research directly engages with the "*politics* of the setting which it explores" (Fox 2003, p. 96, emphasis in original), the potential for research to become a site of social justice and transformed social relations is made visible. In closing, as Van Manen (1990) observed: "We gather other peoples' experiences because they allow us to become more experienced ourselves" (emphasis in original, p. 62). Through engaging with this chapter, it is hoped that readers have not only become more experienced with the topic of suicidal behaviors and suicide prevention but also inspired to think differently about what it means to suffer, to care, and to act in ways that support suicidal people to reengage with the project of living, within a broad context of justice, cultural diversity, and ethical social relations.

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Qualitative Evidence in Suicide: Findings from Qualitative Psychological Autopsy Studies

21

Heidi Hjelmeland and Birthe Loa Knizek

21.1 Introduction

21.1.1 Qualitative Suicide Research Is Scarce

The suicide research field is—and has for decades been—heavily dominated by quantitative risk factor research and qualitative studies are few and far between (Hjelmeland in press). In the period 2005–2008, barely 3 % of the studies published in the main international suicide research journals, *Suicide and Life-Threatening Behavior (SLTB), Crisis,* and *Archives of Suicide Research (ASR)*, had used qualitative methodology and often as just a small appendix to a mainly quantitative study (Hjelmeland and Knizek 2011a). More recently, in the period 2011–2012, 5 % ($N=3$) of the publications in *ASR* and 11 % ($N=9$) in *Crisis* had used some qualitative methodology. In the most comprehensive of these journals (in terms of the number of articles published annually), *SLTB*, less than 2 % ($N=2$) of the articles published in 2011–2012 contained a small (and somewhat quantitative/unclear) qualitative component (Hjelmeland in press). In a 2011 editorial titled, "Scientific rigor as the guiding heuristic for *SLTB's* editorial stance," *SLTB's* Editor-in-Chief, Thomas Joiner, explicitly reduced qualitative studies to hypothesis-generating tools and emphasized that, "if push comes to shove – and it often does, and I expect, will continue to do so […]" (p. 472), such studies would be not be prioritized for publication. In other words, a negative attitude toward qualitative research still is explicitly visible in the suicide research field. By prioritizing to publish rather simplistic, mainly cross-sectional risk factor studies that repeatedly "find" the familiar risk factors, albeit in constantly more special/peculiar groups, these main journals do not contribute much new or useful knowledge for clinical work or suicide prevention in general (Hjelmeland in press).

21.1.2 The Importance of Context and Complexity

Findings with regard to the different risk factors vary from one study to the next. For instance, somatic illness has been found to be an important risk factor for suicide among the elderly in some studies, whereas other studies have found no difference in somatic illness between the suicide group and a control group (Kjølseth 2010).

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Then authors speculate as to what this means; how is somatic illness connected to suicide and why do results vary? However, that results of such studies vary should come as no surprise. Personal processes, "are influenced by an indefinitely high number of factors […] sensitive to outcomes and, hence, always changeable" (Smedslund 2009, p. 778). Hence, "[…] statistical methods are unlikely to produce more than local and unstable fragments of knowledge" (Smedslund 2009, p. 779). There may be cultural differences with regard to how important different factors are for peoples' lives and hence for suicide (e.g., Vijayakumar et al. 2005). There may also be individual differences both across and within cultural groups in terms of how a risk factor is perceived or experienced. For instance, the perception/experience of having to deal with a somatic illness may depend on the person's relationship with family and health personnel as well as the sociocultural conception of aging and age-related somatic illness (e.g., Kjølseth 2010). Moreover, we know that the vast majority of people suffering from or struggling with the most common risk factors do not kill themselves and that many who do have lived with a number of the risk factors for a long time prior to the suicide. Thus, it is evidently not the risk factors per se but the significance or meaning the risk factors have for the individual at the time of suicide that is of importance.

The high focus on risk factors contributes to taking attention away from other, perhaps more relevant, perspectives such as existential issues (e.g., Kjølseth 2010). Suicide is a highly complex phenomenon and we need to take more of its complexity into consideration in our research than currently is the case. In mainstream suicide research, a large focus lies on rather simplistic linear—and allegedly causal—relationships between some, or few, risk factors and suicide. Seeing as people are complex, reflecting, meaning-seeking, relational and goal-oriented beings, linear cause-and-effect thinking between some risk factors and suicide is problematic. To be able to understand *why* someone has decided to kill themselves—that is, to understand the *meaning* the suicide had for the individual person—the suicide must be viewed in relation to the person's lived experience (e.g., Kjølseth 2010). Furthermore, the sociocultural context evidently plays an important role in a person's lived experience and is therefore also crucial to take into consideration (e.g., Hjelmeland 2010, 2011). Since neither lived experience nor culture/context can be operationalized into quantifiable variables, this is where qualitative studies come to the fore (e.g., Hjelmeland and Knizek 2010, 2011a, b). Without a deeper understanding of *when*, *where, how*, and *for whom*—if at all—the common risk (or other) factors actually are linked to suicide, suicide prevention strategies may not be very effective (Hjelmeland in press; Hjelmeland and Knizek 2011a). To understand the meaning(s) of suicide, we need to answer the questions: Why suicide? Why did this person kill himself/herself at that particular point in his/her life? In other words, "Who was this person and why did they elect to die?" (Owens and Lambert 2012, p. 351).

21.1.3 Qualitative vs. Quantitative Psychological Autopsy Studies

Despite the negative attitudes toward qualitative suicide research explicitly or implicitly upheld in the suicide research field, several qualitative studies of suicidal behavior have been published to date, albeit mostly in journals outside the field. In this chapter we will limit our focus to those qualitative studies trying to answer the "why" question stated above, which means that we will focus on qualitative psychological autopsy studies (PA studies) and demonstrate how these studies have contributed to a better and even somewhat different understanding of suicide than quantitative PA studies are able to. Psychological autopsy was originally a method to clarify the mode of death in cases where it was equivocal by examining in detail factors surrounding the death and the deceased (Shneidman 1981). However, based on the medical model (Pouliot and De Leo 2006), this method eventually became the prime approach to studying risk factors for suicide

(Cavanagh et al. 2003). This is done mainly by means of interviewing one or two of those bereaved, although other sources of data (e.g., suicide notes, medical/psychiatric records, police records, coroners' reports) have sometimes also been used.

21.1.4 Problems with Quantitative Psychological Autopsy Studies

Numerous quantitative PA studies of various risk factors for suicide have been carried out to date and what is most often found/emphasized in such studies is that the vast majority of those who kill themselves suffer from one or more psychiatric disorders. For instance, in their comprehensive review of PA studies, Cavanagh et al. (2003) found this to be the case in around 90 % of the suicides. Thus, based on such studies, it is an established "truth" in the suicidological field that there is an almost 1:1 relationship between mental disorders—most often some kind of depressive disorder—and suicide and a causal link between depression and suicide has been implied (Cavanagh et al. 2003; Isacsson and Rich 2003). Isometsä (2001) even claimed that mental disorder is a necessary, though not sufficient, condition for suicide. This, in turn, has contributed to a heavy emphasis on identification and treatment of mental disorders, particularly depressive disorders, in suicide prevention (e.g., Bertolote et al. 2003; Michel and Valach 2011).

However, there is reason to question both the "truth" that almost all those who die by suicide suffer from one or more mental disorders and the causal implication between the two. In fact, from a research methodological standpoint, the "evidence base" for this truism is weak (Hjelmeland et al. 2012). The methodological problems in quantitative PA studies are many (e.g., Pouliot and De Leo 2006). In spite of this, such studies are regarded as the most direct (Cavanagh et al. 2003) as well as a reliable and valid (Kelly and Mann 1996) method to study risk factors for suicide. Recently, two comprehensive "policy papers" were published, outlining "The next generation of psychological autopsy studies" (Conner et al. 2011, 2012). In Part I of these papers, Conner et al. maintained that, "[…] the PA remains the only validated approach to explicate the psychological and contextual circumstances near to suicide" and that, "they will continue to be the primary method for assessing the causal pathways that lead to suicide for the foreseeable future" (2011, p. 595). What they recommended was somewhat refined case–control PA studies, that is, quantitative ones, in other words, more of the same and still with a high emphasis on diagnosing mental disorders. However, what none of the authors recommending continued use of quantitative PA studies seems to have taken on board is the fact that many of the questions asked to assign a psychiatric diagnosis to the deceased by means of interviewing some of the bereaved—regardless of how standardized a diagnostic manual is used—cannot be answered reliably by anyone other than the person to be diagnosed. And, if these questions cannot be answered reliably, the diagnoses cannot be valid (Hjelmeland et al. 2012). Hjelmeland et al. therefore recommended that such quantitative PA studies, at least as diagnostic tools, now should be abandoned.

Moreover, informants in quantitative PA studies are most often one or two of the closest next of kin. This may be problematic. Firstly, it is not necessarily the closest in kin who is the closest in terms of confidence or intimacy. Secondly, different informants can contribute with very different information: either due to differences in interests and expectations because of the nature of the informants' relationship with the deceased and/or due to differences in access to relevant information (Parkar et al. 2012; Scourfield et al. 2012). An example with regard to the former is that different accounts from mother and mother-in-law have been found when problems in the relationship between spouses were assumed to be relevant for the suicide (Parkar et al. 2012), and, with regard to the latter, some studies have found that friends sometimes know more than parents about substance abuse, interpersonal problems, and/or suicidal ideation (Hawton et al. 1998). This makes it crucial to know who provides the information obtained in PA studies. However, very few, if any, of the quantitative PA studies where psychiatric diagnoses have been assigned have discussed or mentioned such issues (Hjelmeland et al. 2012).

21.1.5 The Importance of Qualitative Psychological Autopsy Studies

Based on the above, we maintain that what the suicide research field needs more of at present is qualitative PA studies where several informants around each suicide are interviewed and where the relationship (and not just in terms of kin) between the informant and the deceased is taken into consideration in the data collection and analysis of information. In addition, the analysis should focus on the *complexity* involved in suicide. A few such qualitative PA studies have begun to emerge and are presented below.

First, we present findings from studies from the so-called West where there already is an abundance of research evidence from quantitative (risk factor) studies and demonstrate that qualitative studies give fuller/better and even different insights into suicide than quantitative PA studies are able to. Thus, they provide better grounds for developing targeted and context-sensitive suicide prevention strategies. Thereafter, we present findings from a qualitative PA study conducted in a so-called non-Western low-income country (Northern Uganda) where there has been little previous research on suicide. Our view is that, in such a context, it is necessary to start with qualitative research, the assumption being that importing questionnaires or structured interview guides from "the West" is problematic due to important sociocultural/contextual differences influencing reliability and validity.

21.2 Qualitative Psychological Autopsy Studies from "the West"

Although a handful of qualitative PA studies (Bell et al. 2010, UK; Fortune et al. 2007, UK; Kjølseth 2010, Norway; Orbach et al. 2007, Israel; Owens et al. 2008, UK; Rasmussen et al. 2014, in press, Norway), or quantitative studies containing a relatively small qualitative component (Séguin et al. 2011, Canada), have been conducted to date, most of them have yielded little information beyond that of risk factors. This is because the analysis mainly has been a categorization of suicide into groups based on some risk factors (often quantified), albeit that some of the studies have placed the risk factors along a life chart. Another weakness of many of the qualitative PA studies conducted to date is that only *one* informant around each suicide was interviewed (Fortune et al. 2007; Owens et al. 2008) or that the number of informants was not mentioned (Bell et al. 2010; Séguin et al. 2011). Our purpose here is to illustrate how qualitative studies can contribute knowledge about the *complexity* of suicide beyond what is possible in quantitative studies by taking context/life history into consideration in the analysis and by interviewing several informants around each suicide. We have therefore chosen to present two studies in depth rather than to provide a summary of what all qualitative studies to date have found. Where relevant, however, findings from the other studies are mentioned in relation to the studies we do present. The studies best fulfilling our criteria regarding the complexity outlined above are one study on suicide in the elderly (Kjølseth 2010; Kjølseth et al. 2009, 2010a, b) and one study on suicide in young men (Rasmussen et al. 2014, in press), both conducted in Norway. These are presented below.

21.2.1 Suicide in the Elderly

In her PA study of elderly suicides, Kjølseth (2010) critiqued previous quantitative PA studies' heavy emphasis on diagnosing mental disorders and maintained that such a focus has contributed to underestimate that we are here dealing with old people and thus that old age per se has to be taken into account in the understanding of suicide in the elderly. Her study provided not only a deeper and more comprehensive picture of how to understand suicide among the elderly, but also a different one. Through the informants' narratives, the history of the persons emerged and provided a broader understanding of the suicidal process than is possible by means of quantitative PA studies (Kjølseth et al. 2009). Often, only life events toward the end of life have been focused upon in studies of suicide among the elderly; thus, such studies have missed out on issues important to suicidality (Kjølseth 2010). Although quantitative studies have, for instance, described debilitating somatic illness or functional decline as important risk factors for suicide, it is through qualitative studies we can gain an understanding of what functional decline actually *means* for people.

21.2.1.1 The Role of Control

Kjølseth (2010) found that the suicides concerned who an individual had been, how they had lived their lives on the basis of the existing prerequisites, and how their experiences could be of significance for their encounter with old age. For instance, she found that the lives of the suicide cases in her study were characterized by extremely difficult conditions in childhood (e.g., loss of important caretakers, illness, and poverty) as well as later in life (considerable losses and challenges). The informants (who in this study were close relatives, family doctors, and home-based nurses/help of 23 deceased) described them as conscientious and very skilled in working life and as typical "action-oriented achievers" who met challenges with proactive strategies (Kjølseth et al. 2009). They were also described as emotionally distant, obstinate, and controlling, traits that could create conflict in close relationships and also made it difficult for those around to help them. Their obstinacy and controlling nature contributed to an inability to develop new strategies for adapting to age-related, and hence irreversible, losses of function. Accepting help would entail letting go of control, which they found very difficult or even impossible since it was contrary to their self-image/identity (Kjølseth 2010).

Here it seems that the characteristics constituting strength and ability to deal with problems and challenges through life made them vulnerable to suicide in old age because they were unwilling/unable to adjust to age-related losses by developing new coping strategies or accepting necessary help (Kjølseth 2010; Kjølseth et al. 2009). Due to age-related loss of function, they felt they had lost themselves since they could no longer do what they wanted or make decisions for themselves. They felt they had nothing more to live for and perceived life as a burden, a burden that increased by their inability/unwillingness to talk about it with others. They were also described as having had a realistic view of the future, that is, a future entailing more functional decline, a future they did not want. Thus, they had made an *existential choice* to end their lives and by this they regained control (Kjølseth et al. 2010a).

21.2.1.2 The Relative Insignificance of Mental Disorders

Although some were described as sad about approaching the end of life, only a few were described as showing any depressive symptoms. This is contrary to what would be expected based on findings from quantitative PA studies, in which almost all of those studied were found to have a mental disorder at the time of suicide (e.g., Waern et al. 2002). In fact, some were explicitly described as *not* depressed (Kjølseth et al. 2010a). This could indicate an overestimation of depression in quantitative studies that, when examined in depth, offers a different picture than that provided by quantitative studies.

21.2.1.3 Implications for Suicide Prevention

The findings from Kjølseth's study have a number of implications for suicide prevention among the elderly. Good contact between health workers and their elderly patients is indeed important to prevent suicide. However, the elderly in Kjølseth et al.'s (2010b) study had mistrusted the health services' ability to help them and were afraid to lose their autonomy should they become dependent on help from the health-care system. Unfortunately, their apprehensions had also been confirmed. Not only had the communication with the health personnel been poor, but they had also been unable or even rejected to provide the help the elderly had needed. The elderly had experienced a lack of understanding (Kjølseth et al. 2010b). Strongwilled and action-oriented individuals whose self-esteem very much depend on their ability to make choices and take care of themselves may easily feel degraded if met by health-care personnel that do not understand, recognize, or protect their need for autonomy when they are in need of help (Kjølseth et al. 2010b). The elderly need to be seen and understood as the persons they actually are and have been, and health-care personnel need to take time as well as have the ability and courage to talk to their elderly patients about existential issues and not just take care of their immediate medical needs, for instance, in the form of giving antidepressants (Kjølseth et al. 2010a). To be seen and accepted for whom they are and get confirmation of personal value "despite" age-related loss of function may perhaps contribute to create a basis from where it will be possible to accept help and/or develop new coping strategies (Kjølseth et al. 2009, 2010a) which, in turn, may prevent suicide.

21.2.2 Suicide in Young Men

The second qualitative PA study (which is part of an ongoing larger qualitative PA study led by Gudrun Dieserud at the Norwegian Public Health Institute) focused on young men. With the common high emphasis on the connection between mental disorders and suicide in mind, this study interestingly focused on men with *no* history of contact with mental health services (Rasmussen et al. 2014, in press). These were men who had killed themselves in the transitional phase from adolescence to young adulthood. In keeping with Leenaars (2004), Rasmussen et al. (2014) emphasized that an understanding of suicide requires studying it in a developmental, interpersonal perspective and, as also emphasized by Kjølseth (2010) above, that one has to take the whole life history of the deceased into consideration in the analysis of the suicide (Rasmussen et al. in press).

21.2.2.1 The Role of Self-Esteem as a Multidimensional Developmental Construct

Rasmussen and colleagues focused their analysis on the developmental history and identity formation of the deceased (Rasmussen et al. 2014). Using a bottom-up analysis of the narratives of the informants, the importance of self-esteem-related issues (regulation processes) to these young men's suicides emerged (Rasmussen et al. in press). In previous quantitative PA studies, normally one or two informants have been interviewed (Hjelmeland et al. 2012) and studies of self-esteem have been limited to the *level* of self-esteem connected to suicide. However, Rasmussen et al. (in press) emphasized that self-esteem should rather be studied as a *multidimensional developmental construct* and that, since an individual's self-esteem might vary by situation, relation, and context, it is important to interview several informants (such as mother, father, siblings, male friends, as well as intimate partners) because they can all illuminate different aspects of the development of self-esteem in the transitional period from adolescence to young adulthood. In their study, four to eight key informants (such as those mentioned above) around each of ten suicides (aged 18–30) were interviewed. Suicide notes were also available and analyzed for six of the suicides. None of the young men who had killed themselves had a history of previous suicide attempts or contact with the mental health services. They came from resourceful families and their living conditions were described as good and before the suicide they were reported to have functioned normally.

The findings indicated vulnerability in what the authors called the "suicidal self" due to, on the one hand, emotion regulation problems as a result of attachment experiences during the young men's developmental history (Rasmussen et al. 2014) and, on the other hand, as a perceived discrepancy between actual and ideal self (Rasmussen et al. in press). This discrepancy has been described by Baumeister (1990) and Vohs and Baumeister (2010) but has previously not been investigated closely. This study thus fills a gap in the existing knowledge base that would have been difficult, or even impossible, to investigate by means of quantitative methodology.

From the lifetime perspective, Rasmussen et al. (2014) found problematic early relationship patterns between the young men and their parents resulting in symbiotic relationships in families that, in turn, seemed to interfere with the transitional processes from childhood to adulthood. The young men seemed to have been emotionally dependent on their mothers and unsuccessful in living up to their fathers' standards, thereby complicating the adjustment to a normative masculinity centered on autonomy and individuation. The resulting emotions were frustration and shame because of the dependency and anger due to the perceived failure to live up to the standards. As they were growing up, most of the young men had aimed at traditional ideals of masculinity, such as independence, strength, rejection of weakness, and success in achievements, which may be influential—maybe even decisive—for later self-evaluation and regulation. In such a psychological constellation, there was no room for failure. However, Rasmussen et al. (in press) found that the period of transition from adolescence to young adulthood seemed to have been associated with personal defeats. They had experienced intolerable discrepancies between the ideal standards they had set for themselves and their actual performance against these standards, both in terms of relationship (i.e., love) and work-related issues. Their struggle to live up to impossible ideal expectations must be interpreted as an existential struggle.

A perceived failure to live up to one's own standards can have immense emotional significance. Whereas previous quantitative studies have suggested that it is the *size* of the discrepancy between the ideal self and the actual performance that is important for the development of suicidality (e.g., Franck et al. 2007), Rasmussen et al. (in press) found that what mattered was rather the *significance* or *meaning* that failure had for the individual. When their self-esteem was threatened (due to the discrepancy between the ideal self and their actual performance), the young men in their study were unable to tolerate any failure, large or small. Even minor setbacks resulted in extreme feelings of failure for which they blamed themselves. They became stuck in their self-blame and were unable to put things behind them and move on. It was as if, once they had exposed "their inferior self," it could never be taken back and they could not live on being, in their own eyes, such failures (Rasmussen et al. in press).

Rasmussen et al. (2014) also found that the young men's self-esteem, due to their developmental history, had a weak anchoring in their psychological makeup. Their identities seemed to be dependent upon a perfect façade and they seemed extremely dependent on how they were viewed by those they considered to be "their superior others" (Rasmussen et al. in press). They depended very much on being admired, confirmed, and guided by them. The study reported how these young men used others as models or ideals for their own behavior, as they seemed incapable or too insecure to accept themselves in their own right. They seemed to compensate for the lack of independent self-evaluation by means of successful performances and/or in a fantasy of great success. Their identity seemed to have been tied up to a very high level of activity and high achievement at work. Rasmussen et al. (in press) indicated that these men fought with a constant feeling of being worthless, due to a life history characterized by a fear of making mistakes and thus striving for perfectionism, as also found in Bell et al.'s (2010) qualitative PA study in the UK. The resulting experience of a discrepancy between what they perceived themselves to be and what they assumed they had to be led to difficult feelings like shame, anger, loneliness, and worthlessness, which the individual—due to the early attachment story—had a weakened capacity to regulate. Without being self-contained and able to maintain an identity with positive self-esteem as well as problems with regulating difficult feelings of failure, these young men were unable to deal with the increasing challenges and defeats of being a grown-up man and the norms regarding masculinity (Rasmussen et al. in press). Thus, these young men seemed to have entered adulthood with an ideal self that they were neither able to live up to nor to defy. To compensate for this, they became overachievers (Rasmussen et al. in press), a characteristic similar to what Owens et al. (2008) found in their study of young men's suicide and what Kjølseth et al. (2009, 2010a) found in their study of elderly suicides.

21.2.2.2 The Relative Insignificance of Mental Disorder

Another interesting similarity between Rasmussen et al.'s study on young male suicides and Kjølseth et al.'s on elderly suicides is the relatively little emphasis the informants put on mental disorders in their narratives about their understanding of suicide. This is in stark contrast to the conclusion in most quantitative PA studies, where an almost 1:1 relationship between mental disorder and suicide has been highlighted. Not only do such studies make mental disorder, particularly depression, one of the most important risk factors for suicide, but also even a causal relationship between the two (especially depression) has been implied (e.g., Cavanagh et al. 2003; Isacsson and Rich 2003). Interestingly, Owens et al. (2003) found a high prevalence of mental disorder (68 %) in the quantitative part of their PA study in the UK. In this part, informants had responded to binary-choice diagnostic questions. However, when the narratives of the same informants from the same interviews later were analyzed qualitatively, remarkably few were pointing to mental disorder as central to their relative's suicide (Owens and Lambert 2012).

21.2.2.3 Triggered Event, Not Impulsive Act

From quantitative studies, we have also often heard that many suicides are impulsive. However, Rasmussen et al. (2014) emphasized that the suicides in their study appeared as not so much impulsive but rather as "a 'triggered event' related to a previous significant event close in time (like a breakup with a girlfriend or a separation from family home)." As mentioned above, Rasmussen et al. also underlined the importance of interpreting these issues in light of the whole life history of the deceased in order to understand the suicides of these young men. This is exactly what Kjølseth et al. (2009, 2010a) emphasized with regard to understanding suicide among the elderly. This is something that rarely has been taken into consideration in the quantitative PA studies where the main focus often has been on precipitating factors and/or psychiatric diagnosis with little or no focus on what has led to the precipitating events "tipping the boat" or to the potential disorders. Context is rarely taken into consideration in quantitative studies.

From the description above, it is evident that Rasmussen et al.'s study has contributed to an increased understanding of the developmental and relational factors that may put some young men at risk for suicide. This contribution could only be made by the thorough exploration of both anamnestic and relational stories from different angles, thereby capturing the complexity of the developmental story and how this is inwrought with both psychological makeup and actual challenges.

21.3 Qualitative Suicide Research Where We Have Little or No Previous Research ("Non-West")

In his definition of suicide, Shneidman (1985) opened up for cultural variations with regard to what suicide is/means: "Currently in *the Western world*, suicide is a conscious act […]" (p. 203, our italics). Hence, when suicide research is to be conducted in a cultural context where little or no such research has been done before, it is important to start with qualitative studies since such research allows us to take the sociocultural context into consideration to a larger degree than what is possible in quantitative research (Hjelmeland 2010; Hjelmeland et al. 2006). Still, when research on suicide starts to appear in countries outside "the West," it is most commonly by means of quantitative studies that often use the same standardized instruments as in "the West."

With regard to PA studies, a recent example is the ongoing WHO/START Study (START stands for the Suicide Trends in At-Risk Territories), officially launched in 2006 and currently involving 18 countries in the WHO Western Pacific Region (De Leo and Milner 2010). And, this project is now in the process of expanding to include countries also elsewhere in the world, for instance, in Africa (De Leo 2012, personal communication). The study contains four components, of which number three is a PA study. The researchers explicitly acknowledge that there are vast cultural, economic, social, and political differences between the participating countries. And, many are low- and middle-income countries where little or no suicide research has been conducted to date. Still, this is a purely quantitative study using the same standardized instruments everywhere, including the Structured Clinical Interview for DSM-IV TR. Although component three also includes a community description aimed at providing a "framework for the historical, political, economic, social, and cultural contexts peculiar to the study location […] to contribute to the understanding of environmental factors influencing suicidal behaviour" (De Leo and Milner 2010, p. 103), there is no description on how this information is going to be incorporated in the analysis of the data from the PA study. The researchers and the WHO seem oblivious to the fact that cultural context, or culture, is not a measurable variable (e.g., Jenkins 1994) or that considerable problems with cross-cultural validity of the DSM-IV diagnoses have been documented (e.g., Fernando 2003). Furthermore, they are only planning to interview two informants around each suicide, whereof one will be a next of kin and the other the health-care professional who last had treated the deceased. Thereby, they are disregarding the problems connected to the relationship between the informant and deceased and its consequences for the information yielded as pointed to above. It is our suggestion that it would have been better to conduct a qualitative PA study where the cultural context to a larger degree would have been possible to incorporate into the analysis of the data. This would also have opened up possibilities for finding culturally relevant issues impossible to reveal by predefined, standardized instruments developed in "the West." An example of such a qualitative PA study is presented below.

21.3.1 Suicide in Internally Displaced Peoples' Camps in Acholiland, Northern Uganda

As far as we have been able to establish, only one qualitative PA study interviewing several informants around each suicide has been conducted in a "non-Western" country to date, namely, the study by Kizza and colleagues (Kizza 2012; Kizza et al. 2012a, b) conducted in internally displaced peoples' camps (IDP camps) in Northern Uganda (Kizza 2012). In this study, two to five informants (spouses, parents, siblings, children, grandparents, cousins, nephews, in-laws, and/or friends, totaling 73) around each of 20 suicides were interviewed. Before we present the findings, however, it is necessary to describe the context where the study was conducted.

21.3.1.1 Sociocultural Context: Civil Conflict

The study took place among the Acholi (ethnic group) in Northern Uganda. This part of the country was for two decades (1986–2006) severely affected by civil conflict between the Lord's Resistance Army (led by Joseph Kony) and the Uganda Government armed forces (Amone-P'Olak 2006; Harlacher et al. 2006). The conflict involved horrifying and dehumanizing acts, such as mass massacres, abductions, and rapes. In 1997, approximately two million people in rural areas were forced to live in IDP camps (Roberts et al. 2008), and by 2005 almost 90 % of the population in the most affected areas was living in such camps (Ministry of Health of Uganda and WHO 2005). The camps were overcrowded and the conditions dreadful and precarious. In addition, the camps did not provide the safe havens they were supposed to so people lived in constant fear of rebel attacks and abduction, as well as uncertainty with regard to the future. Peoples' lives were associated with poverty, lack of freedom, and fear of contracting HIV/AIDS through sexual assaults (Kizza 2012). The situation was desperate and characterized by despair and hopelessness; extensive alcohol abuse and reports of increasing suicide rates began to emerge (Rodriquez 2004).

21.3.1.2 Sociocultural Context: Change of Gender Roles and Responsibilities

In this context, suicide in both men and women was found to be connected to men's "loss of masculinity" (Kizza et al. 2012a, b). In order to understand what this means, it is necessary to understand how the gender roles in this community had been before the war and how the war had changed these roles and responsibilities in a way that seemed to have contributed to suicide for both men and women, albeit in different ways. Before the conflict, the ideal Acholi man was seen as a strong fighter and protector, someone who could not be defeated and who never gave up. This ideal masculine role also characterized the man as the breadwinner/provider and the one who controlled the resources in the home, including the earnings of his wife/wives; polygamy is common in this area. He was a leader and figure of authority (El-Bushra and Sahl 2005). This masculine ideal must be seen in light of traditional African masculinity: to be considered as a real man, you need to not only be financially independent but wealthy enough to be able to pay dowry so that you can marry and have children (Barker and Ricardo 2005; Dolan 2002). For the Acholi, there are thus three main tenets of the ideal masculine role, namely, marriage, provision for the household, and protection of the household (Dolan 2002). Without fulfilling these three requirements, you are not considered a grown/real man regardless of how old you are. Thus, being married and having children and being wealthy in livestock and land are part of the masculine ideal in the Acholi culture (El-Bushra and Sahl 2005).

The ideal Acholi woman before the conflict was humble, gentle, hospitable, and submissive to authority (authority here being her husband, mother-in-law, clan leaders, and/or elderly women). Moreover, she was tolerant, especially with regard to her husband (El-Bushra and Sahl 2005). Before the conflict, Acholi women were defined exclusively in relation to their reproductive role (Liu Institute for Global Issues, Gulu District NGO Forum, and Ker Kwaro Acholi 2005). Women were expected to care for the children, cook, and clean and to tend to the fields; they were responsible for production of food and could, in a way, control the food crops (El-Bushra and Sahl 2005). Since the husband had paid dowry, the wife/wives and children became his property and thus under his control (El-Bushra and Sahl 2005; Dolan 2002). Socialization into these ideal masculine and feminine gender roles begins at an early age (Liu Institute for Global Issues, Gulu District NGO Forum, and Ker Kwaro Acholi 2005) and adulthood is considered reached at the time of marriage.

These traditional gender roles were, however, in many ways turned upside down when people were forced into IDP camps. Men could not leave the camps without exposing themselves to the danger of being abducted and forced to join the LRA. Hence, they were unable to uphold their traditional role as breadwinners, a role that had to be taken over by women in addition to the responsibilities they already had. However, men maintained their role as head of the household, that is, the one making the decisions with regard to the resources there (El-Bushra and Sahl 2005; Liu Institute for Global Issues, Gulu District NGO Forum, and Ker Kwaro Acholi 2005).

21.3.1.3 Suicide in Men

In this context, suicide in men was found to be mainly related to loss of dignity and social value, no hope for the family's future, and overwhelming family responsibility (Kizza 2012; Kizza et al. 2012a).

21.3.1.4 Loss of Dignity and Social Value

The loss of dignity and social value was connected to loss of self-worth, loss of respect from others, or loss of control over their wife/wives. The two former were a consequence of the men losing face because they had chosen not to, or were unable to live up to, the cultural masculine ideals described above. This was a result of having behaved badly in some way that resulted in interpersonal conflict and public humiliation, albeit for different reasons and with different consequences for elderly and young men (for examples, see Kizza et al. 2012a). Loss of control of the wife/wives was a breach of a cultural norm as described above and was also a result of the change in gender roles due to the conflict. Since the men could not leave the camps and uphold their role as breadwinner, they became idle, and many of them resorted to alcohol abuse, gambling, and womanizing, activities perhaps meant to rebuild their pride and boost their self-esteem (Kizza 2012). To fund these activities, they were dependent on the income of their wife/wives. However, some of the wives managed to hide the food crops they had produced, thereby denying the men access to them (Kizza et al. 2012a). In this cultural context, losing control of the family resources, including the wife/wives, is perceived as an insult that may result in loss of honor, reputation, and hence masculinity (El-Bushra and Sahl 2005; Silberschmidt 2001). This in turn resulted in the man being despised by others as he was considered the "woman" of the household. In addition, because the camps were so overcrowded, it was impossible to hide this from others, which then added to the humiliation (Kizza et al. 2012a).

For some of the young men, loss of dignity and respect from others was connected to an inability to meet sanctions after having violated cultural norms. Examples here were being in an incestuous marriage and cohabiting with an underage girl. Such violations of cultural norms resulted in sanctions and necessitated cleansing rituals, both of which required money that, due to abject poverty, the men were unable to muster. This resulted in an inability to ever enter into legal marriage, which meant never being able to be considered as real men (Kizza et al. 2012a).

21.3.1.5 No Hope for the Family's Future and Overwhelming Family Responsibility

No hope for the family's future—resulting from either *perceived end of one's lineage* (because of not having a male child which in this cultural context means no social security in old age as well as the end of the family lineage) or *constrained survival means* which here was a result of loss of land due to the conflict, making the men unable to generate income that normally came from cattle—was found to be important for some of the men's suicide (Kizza et al. 2012a). Also, overwhelming family responsibility was important for some of the suicides (Kizza et al. 2012a). Due to the conflict a lot of people were killed, leaving many children orphaned. In this cultural context, it is then a moral and cultural obligation for an aunt/uncle to take care of the deceased sibling's children as her/his own (Dolan 2009). It was not uncommon in this area to find a man or woman caring for more than 20 children who had been orphaned after their parents had been murdered (Kizza et al. 2012a). The number of orphans, as well as the abject poverty in this region, made this burden impossible to carry for some of the men in this study, which meant that they were unable to fulfill the cultural ideal masculine role (Kizza et al. 2012a).

21.3.1.6 Relative Insignificance of Mental Disorder

It is noteworthy that mental illness was mentioned in the narratives of only one of the 20 suicides included in this study and then in the form of threatening and distressing hallucinations (Kizza et al. 2012a).

21.3.1.7 Suicide in Women

Having *no control in life* and *no care* were descriptions found to be central for women's suicide in this context (Kizza et al. 2012b). No control in life had to do with issues regarding distribution of labor and power, lack of right to fight decisions made by their husbands, changed roles in marriage, and issues regarding the health of themselves and their children. As described above, the long-lasting conflict had led to a change in the traditional gender roles in that women had to take on the male role of a breadwinner in addition to their own reproductive role. However, by cultural norms, men still retained their role as decision-makers; that is, it was still men that made decisions as to how the earnings brought in by their wife/wives should be spent. Above, it was described that some men resorted to alcohol abuse, gambling, and womanizing and this was often financed by their wife's hard-earned income (Kizza et al. 2012a). For the young women in this study, their husband had used their income to not only court other women but also to finance a second marriage against the first wife's will. Added to the first wife's burden was the fact that the husbands had lost their mothers and, according to cultural tradition, it is then the first wife's obligation to take on the role of mother-in-law to the second wife in terms of ushering the latter into the role of wife. That this happened at a stage where they themselves (the first wives) were young and relatively newlywed added further to their frustration.

However, according to traditional Acholi culture, a wife is the property of the husband and she has no right to fight his decisions. The young women in this study, however, in light of their new role as breadwinners, did not accept continuing subordination to their husbands. They therefore tried to fight both the second wife (literally) as well as their husband by, for instance, refusing them access to the income as well as to fulfill their marital obligations (i.e., sex), which, in turn, resulted in physical abuse from their husbands. They also took the husbands' decision to take a second wife to the elders (the mediators in such marital conflicts), who sided with the husbands since polygamy is accepted in Acholi culture. These women also did not have control over their own or their children's health. In addition to being beaten by their husbands when they refused to accept the decision to take another wife, the husbands' extramarital affairs also exposed them and their children to HIV/AIDS. Refusing to have sex with the husband is a breach of cultural norms and in these cases resulted in being beaten by the husband (Kizza et al. 2012b).

21.3.1.8 The Role of "Loss of Masculinity"

From the above, it can be gleaned that inability to cope with or adjust to changes in traditional gender roles as a result of the protracted civil conflict played an important role in the suicides of most of the men, as well as the young women in this study. For the men, these changes meant that they could no longer live up to the ideal masculine expectations; hence, they could no longer be regarded as real men, either by themselves or others. This could be referred to as a "loss of masculinity" (Dolan 2009). This "loss of masculinity" seemed to have made the males in this study disempowered and disenfranchised which, in turn, led to loss of dignity/self-worth and social value. The result was an identity crisis too heavy to cope with for these men (Kizza et al. 2012a). This "loss of masculinity" in men was also significant for women's suicide. Whereas the men seemed to have lost their power under these circumstances, the women had in a way and to an extent been empowered in that they had taken on the role of breadwinner. This made them unwilling to continue in their expected submissive role. However, challenging the traditional cultural norms led to abuse from their husbands. This was aggravated by the men's increasing alcohol abuse, perhaps in an attempt to restore their lost masculinity (Kizza 2012; Kizza et al. 2012c). They could also not leave their husbands since that would entail their parents having to pay back the dowry, which was impossible due to poverty. In other words, men's quest for their "lost masculinity" and women's attempt to fight for their rights being perceived as a cultural transgression contributed to the women's suicides (Kizza 2012). Women were trapped in, for them, unbearable circumstances, the only way out (literally) being suicide. We could therefore say that in this particular sociocultural context, men's suicide (especially the young) was related to not being *able* to live up to the sociocultural norms and expectations, whereas young women's suicide was related to not *wanting* to live up to these expectations (Kizza et al. 2012a, b). In this context, suicide in late adulthood seemed to be connected to issues of lineage continuity and lack of social security for both men and women (Kizza et al. 2012a, b); it should, however, be noted that there was only one elderly woman in this study. For the young it appeared that suicide was related to an identity crisis, whereas for the elderly existential crisis seemed to be more central (Kizza 2012).

21.3.1.9 Other Important Issues

The central issues related to suicide in this context described above are, of course, not the *whole* explanation for the suicides. Also in this context, it is important to interpret the suicides in relation to the whole life history of the deceased. Although what was found in the analysis of the informants' narratives pointed toward these issues playing the most significant role in the decision to kill oneself, there is no doubt that all the suicides in this study had a number of severe traumatic experiences from earlier in life that could have contributed to them developing a vulnerability for suicide (Kizza 2012). The armed civil conflict had gone on for most of the young suicide victim's lives and this conflict had of course also afflicted the lives of the adults. There is no space here to describe in detail the horror and atrocities connected to this conflict so for that we refer to, for instance, Dolan (2009) and Amone-P'Olak (2006), but we can mention having experienced mass massacres, including of their own family members, their lives being under constant danger of cross fire and having no food or shelter for long periods of time (Kizza 2012). Under such conditions, problems unrelated to the conflict and considered common through normal life will be more difficult to handle, deal with, or get help for, adding to the burden (Kizza 2012).

21.4 Summary and Concluding Remarks

In this chapter we have presented three different studies in depth, two from "the West" (Norway) and one from a "non-Western" country (Uganda), and we notice that *lack of control* seems central for suicide in all three studies, albeit in different ways and under different circumstances. For the elderly in Norway, a *loss of control* and the attempt to regain it through suicide was a characteristic *existential* issue. Age-related physical decline, combined with an inability to adjust to it psychologically, and contextual lack of understanding of their needs were important aspects in the suicidal process. For the young Norwegian men, suicide seemed to be connected to a *failed attempt to obtain control.* To obtain control is crucial for the development of autonomy in an individuation process; hence, this is also an *existential* issue that seemed important in the suicidal process. Also for the young Ugandan women, we saw a *failed attempt to obtain control*: they fought to *get* control over their own as well as their children's lives and health but lost against the traditional cultural norms. For the Ugandan men, we recognized both a *loss of control* (mainly in the elderly) and *failed attempts to obtain control* (mainly in the young) as central for suicidal process.

Here, we can follow the thread of existential struggle even further, in that being in control is a core pillar of hegemonic masculinity (Conell 1995). Both the Norwegian and the Ugandan men had struggled with fulfilling the demands of a hegemonic masculinity, albeit with different hindrances. In the case of the young Norwegian men, it seemed to be more about *internal* problems related to their social development and attachment history, whereas for the Ugandan men it had more to do with changed *external* conditions that made it impossible to achieve or maintain a desired masculinity. The difference between the Ugandan men and women had to do with their respective displacements in the traditional power hierarchy: the men wanted to obtain and maintain the traditional gendered cultural roles, whereas the women would not accept these. Thus, a general theme in all the three described studies seemed to be an existential struggle for control. However, how this struggle was fought in the individual cases was dependent on both the person and the action radius he/she had. Thus, the cultural context where this struggle went on is decisive.

What was evident in the qualitative PA studies both in Norway and Uganda then was that when informants were asked to narrate their thoughts about why their close ones had decided to kill themselves, existential struggles related to control seemed to permeate most of the stories one way or another, whereas mental disorders played a very minor role in the informants' narratives in both countries. This is in stark contrast to what is found in quantitative PA studies where the focus is on risk factors, and where almost all are found to suffer from some mental disorder(s), at least in "the West" (90 % in the review study of Cavanagh et al. 2003), although the proportions have been found to be lower in "non-Western" settings, for instance, in China (63 % in Phillips et al. 2002; 48 % in Zhang et al. 2010) and India (34 % in Chavan et al. 2008; 24 % in Khan et al. 2005). Existential issues, however, seem to be absent in quantitative PA studies. As mentioned above, Owens et al. (2003) and Owens and Lambert (2012) found completely different pictures within the same study: when informants had responded to binary-choice diagnostic questions, the majority (68 %) of the deceased were diagnosed with a mental disorder, but when the same informants' narratives from the semi-structured part of the interview was analyzed qualitatively, it turned out that very few of them put emphasis on mental disorders as central for the suicides. Owens and Lambert (2012) conclude that, "a preoccupation with mental illness in suicide research may have obscured other culturally normative understandings of self-accomplished death" (p. 348) and that:

> […] the 'monolithic' psychiatric discourse (Marsh 2010, p. 168) that dominates Western suicidology, and that has been built largely on the basis of psychological autopsy interviews, is not supported by a close reading of the personal narratives that are woven by bereaved kinfolk in the course of those interviews. (Owens and Lambert 2012, p. 369)

In fact, many of the traditional PA studies are conducted by means of semi-structured interviews, where diagnostic and other instruments are filled in during the course of the interview. However, most researchers, being firmly "planted" in the biomedical illness model paradigm, have so far chosen only to analyze the data from the structured instruments by means of statistics. Hence, as clearly demonstrated by Owens and Lambert (2012), there is much information in "quantitative" PA studies that never finds its way into publications from these studies.

From the above, it should be clear that qualitative PA studies have contributed both a deeper and wider, as well as a different, understanding of suicide than what quantitative PA studies have been able to. Suicide is no doubt complex and every suicide is unique (e.g., Shneidman 1985); the "road to suicide" consists of numerous lived experiences gained in a multitude of different contexts throughout life. It is high time to take some of this complexity into consideration in suicide research and prevention. For too long, the suicidological field been dominated by a narrow focus on risk factors, particularly mental disorders, with the appurtenant linear cause-and-effect thinking—as well as negative attitudes or even prejudice—toward qualitative research. Seen in light of the weak evidence base for such a preoccupation with mental disorders in suicide research (Hjelmeland et al. 2012), we maintain that it is time for a change of focus in suicide research. We need to get out of the dead end of repetitive risk factor research and start doing more qualitative research, where we have a chance to both find new and culturally relevant information, as well as to take more of the context and complexity (including dynamics/mechanisms) of suicidal behavior into consideration (Hjelmeland in press; Hjelmeland and Knizek 2010, 2011a, b).

A last point to be mentioned here is whether *psychological autopsy* study is the best term for qualitative studies where contextual (sociocultural) issues are taken into consideration. Some have criticized traditional PA studies for disregarding the social and/or cultural factors and context and have therefore conducted what they have called a *sociological autopsy* (Fincham et al. 2011; UK) or *sociocultural autopsy* (Parkar et al. 2009; India). The criticism of lack of focus on contextual issues is, to a certain extent, perhaps more relevant for quantitative than for qualitative PA studies. However, it should be noted that context seems to mean somewhat different things in studies inside and outside "the West." Outside, it is clearly about the sociocultural context where the study is conducted, whereas in "Western" studies it seems to be more about the immediate social/relational context and the life course. This is reflected in the three studies described above and, in our experience, also in reviewer/editorial comments to submitted papers. Whereas reviewers and editors often ask for a detailed description of the sociocultural context in studies conducted outside "the West," this is rarely the case for "Western" studies. Nevertheless, based on current mainstream PA studies that are firmly grounded in the biomedical illness model (Pouliot and De Leo 2006), albeit far from what Shneidman (1981) originally meant for them to be, *psychological autopsy* is perhaps now a "tainted" concept and whether to call qualitative such studies something else in the future should perhaps be discussed.

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Qualitative Evidence in Treatment Adherence

22

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22.1 Introduction

22.1.1 What Is Evidence from Our Perspective?

The evidence base for knowledge of processes in health care and for resulting good medical practice has been primarily derived from quantitative research. In this chapter we contend that qualitative research also makes important contributions to the quality of evidence-based practices and to the study of quality in health care (Ailinger 2003; Dixon-Woods et al. 2004).

The history of adherence research clearly demonstrates this point. The first decades of adherence research were oriented toward explaining variables for nonadherence, in the (vain) hope that they would lead to action that could be undertaken. Qualitative research, conducted primarily in the past decade, involved the patient directly in the research process. These resulting findings have led to new models about the complex behavior of adherence, with a focus on shared decision-making, patient involvement, and empowerment. Other forms of evidence, such as existing conceptual frameworks, social phenomena, changing images of society and evolutions in areas such as health and health delivery have also influenced and shaped these models, but in this chapter we focus on the evidence that has come from qualitative research.

In our opinion, evidence is not synonymous with proof. Rather, it is information and research-based or reflection-based material on which practices can be based. Moreover, because patient adherence is such a complex behavioral phenomenon, it will never be possible to research it by splitting the whole into its constituent parts, therefore never researched in its entirety.

22.1.2 Conceptualization of This Chapter

We chose to focus on medication adherence in this chapter because most available evidence on adherence is focused on medication adherence specifically. Also, focusing on medication adherence allows us to concretize the exact value of qualitative methods. Our premise is, however, that evidence in the field of medicine taking or following advice to prescribed treatments is transferable to other fields where adherence behavior is applicable. Adherence is a universal behavior and

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should not be narrowed to medical interventions but should be applied to all contexts in which a person is invited to adapt their behavior in order to reach new goals (Nunes et al. 2009).

In this chapter, we first illustrate the importance of adherence as a social phenomenon. In the second and third sections, we sketch the history of adherence research and—closely linked to it—focus on the terminology. Next, we present the contribution of qualitative research to insights gained in the concept of adherence that is further accentuated in an overview of the most recent qualitative medication adherence studies. In the final section we present implications for research, practice, and health policy.

22.2 The Importance of Adherence as a Social Phenomenon

Because of the difficulties in measuring adherence, no estimate of adherence or nonadherence can be generalized, but poor adherence is to be expected in 30–50 % of all patients, irrespective of disease, prognosis, or setting (Vermeire et al. 2001). Poor adherence is an ever present and complex problem, especially for patients with a chronic illness.

With increasing numbers of medications shown to do more good than harm when taken as prescribed, low adherence is a growing concern, seriously undermining the benefits of current medical care (Haynes et al. 2008; Horne 1997; Urquhart 1996). Poor adherence is also a source of ongoing frustration to health-care providers (Melnikow and Kiefe 1994) and it prevails in clinical trials too, resulting in unrecognized underdosing, which lowers the average effect of the test-drug (Melnikow and Kiefe 1994). An estimated average adherence of 50 %, rather than 100 %, in a trial would increase the required sample size fivefold in order to maintain the same power (Haynes et al. 1979). Also at the meso and macroeconomic level, nonadherence has been identified as a major public health problem that imposes a considerable financial burden upon modern health-care systems (Donovan 1995; Donovan and Blake 1992; Horne 1997; Melnikow and Kiefe 1994). This burden has been estimated to cost $100 billion each year in the USA (Donovan and Blake 1992), including 10 % of hospital admissions and 23 % of admissions to nursing homes (Donovan 1995; Morris and Schulz 1992).

The following sentence from the Haynes' Cochrane systematic review (2008) summarizes the importance of adherence and is, in our opinion, a teaser for the reader: "Increasing the effectiveness of adherence interventions may have a far greater impact on the health of the population than any improvement in specific medical treatments" (Haynes et al. 2008).

22.3 The History of Adherence Research

22.3.1 History of Adherence Research

Centuries ago, Hippocrates noticed that patients pretended to have taken their medication. At the end of the 1950s, three physicians drew attention to the adherence phenomenon in tuberculosis treatment. Around 1972, David Sackett linked unpredictable or disappointing responses to hypertension treatment to nonadherence. As the number of effective medications grew, attention to nonadherence also expanded. By the end of the 1970s, it became clear that adherence determinants were complex and poorly understood. Despite continuing research, few improvements or new insights have emerged since the 1980s due to the absence of a crucial factor: the patient's perspective.

Only in the last few decades has the complexity of adherence as a reasoned behavior been gaining acknowledgement. Donovan was the first to recognize nonadherence as a patient decision, rather than a deviance from doctors' advice (Donovan and Blake 1992). Since then, nonadherence is increasingly perceived as the result of many underlying factors, such as beliefs, patients' own frames of reference, trust in the health-care provider, side effects and so on. More recently, these factors are explored and are in fact the result of qualitative research.

22.3.2 Patient Involvement, Shared Decision-Making, Patient-Centeredness and Empowerment

Alongside the adherence research other theoretical and conceptual frameworks were developed such as: patient involvement, shared decision-making, patient-centeredness and empowerment. These movements mutually fertilized each other giving birth to the actually and generally accepted views on health professional–client relationships, and encompassing the most recent views on patient adherence.

22.4 New Terminology: "Informed Choice and Supported Adherence"

Many authors take the term adherence for granted and do not even feel the need to define it, thus impeding comparative assessment of the adherence literature (Van Camp et al. 2012; Vermeire et al. 2001).

22.4.1 Different Types of Nonadherence

Types of nonadherence include: delay in seeking care (prevention); nonparticipation in health programs (screening); breaking appointments (follow-up); and failure to follow healthcare professionals' instructions (treatment). Medication nonadherence can be situated on three levels: (1) initiation—not filling or refilling; (2) implementation—incorrect dose, wrong intake time, forgetting doses or taking drug holidays; and (3) continuation—stopping the treatment prematurely (Vrijens et al. 2012).

22.4.2 Terminology of Nonadherence

New insights (see Sect. 22.3) led to four different terms. Although often used interchangeably, they represent different conceptual frameworks.

22.4.2.1 Compliance

Compliance is "The extent to which the patient's behavior matches the prescriber's recommendations" and is a word with negative connotations, suggesting yielding, complaisance and submission. As it implies lack of patient involvement, its use is declining.

22.4.2.2 Adherence

Adherence is: "The extent to which the patient's behavior matches *agreed* recommendations from the prescriber." It has been proposed as an alternative to compliance and is widely used, as it recognizes that the patient and health professional share decision-making. Adherence emphasizes the need for agreement and implies that the patient is free to decide whether to follow recommendations and that failure to do so should not be a reason to blame patients. Throughout this chapter, we prefer to use the term adherence to incorporate the broader notions of concordance, cooperation, and partnership.

22.4.2.3 Concordance

Concordance is a relatively recent term, introduced by the Royal Pharmaceutical Society and predominantly used in the UK, meaning agreement and harmony (Marinker 1997). Its definition is "An agreement between a patient and a healthcare professional that respects the beliefs and wishes of the patient in determining whether, when and how medicines are to be taken, in which the healthcare professional recognizes the primacy of the patient's decision about taking the recommended medications." The backbone of the concordance model is the patient as a decision-maker and a cornerstone is professional empathy.

22.4.2.4 Informed Choice and Supported Adherence

Horne and Weinman (2004) introduced the concept of "informed adherence" as the behavioral implementation of a "good" and appropriate prescription. The UK NHS working group proposed "informed choice" and "supported adherence," which seem to be more comprehensive and more understandable terms (Horne et al. 2005). Both are important for interventions to facilitate medicine taking. Patients' autonomy is respected, the information offered invites patients to make a choice which encompasses the decision for action which is medicine taking, followed by a sustained support to continuing medicine taking.

22.5 The Contribution of Qualitative Research to Insights in Adherence: Patient Perspectives

Since 1975, more than 200 variables have been studied quantitatively, but none of them can be considered as consistently predicting adherence. The meeting of the Royal Pharmaceutical Society in 1995 emphasized that, although much research had been conducted, insight into the phenomenon remained superficial. Since then, approximately 100 qualitative studies with sufficient conceptual richness have contributed to the adherence evidence base, recognizing medicine-taking as a complex human behavior (Horne et al. 2005; Nunes et al. 2009). In general, complex and compound phenomena are rarely researched using a quantitative approach. Especially when studying patients' experience of medicine-taking and barriers and facilitators, qualitative research is the preferred paradigm. In this section, we present the contribution of qualitative research to insights gained in the concept of adherence.

22.5.1 Methodology

The findings in this section result from years of systematically keeping up with the literature. The search started with a backward comprehensive literature review searching a broad array of databases (MedLine, Embase, PsycINFO, Sociological abstracts, Dissertation abstracts, Eric, and the NHS, NICE, and WHO portals) from 1975 until 1999—the results of which were published in 2001 (Vermeire et al. 2001).

Beginning in 2000, the search was systematically updated, applying the same strategy, excluding Embase (because it was not available in Belgium) and including the Cochrane Library and ISI Web of Knowledge. Congruent with the evolving terminology (see Sect. 22.4), the search terms evolved from *compliance* to include *patient adherence, concordance, health beliefs, shared decision making, patient involvement, patient perspectives, medication review,* and *health behavior*. Relevant articles were classified by type (e.g., qualitative or quantitative; original research or reviews and meta-ethnographies). When identifying authors with ample research articles on adherence, their names were entered in the search field to further update the literature searches.

22.5.2 Adherence as a Planned Behavior

Adherence is considered a conscious behavior and thus behavior models can be applied, as illustrated in Fig. 22.1 (Ajzen 1991; Vermeire 2010). Like every other behavioral action, adherence is preceded by an intention: the intention to take medication. This intention is not only influenced by (1) capacities (e.g., cognitive functioning) and (2) external factors (e.g., communication or social support) but also by (3) patient perceptions (see Fig. 22.1). In routine clinical terms, the barriers included in Fig. 22.1 are either practical (external factors and capacities) or perceptual (perceptions) barriers. Unintentional nonadherence is mainly due to practical barriers, whereas intentional nonadherence is related to perceptual barriers (Vermeire et al. 2001).

22.5.3 Results from Individual Studies

In the remainder of this section we outline the results from individual studies and articles in which the results of qualitative research were synthesized.

22.5.3.1 Perceptions

Perceptual barriers/health beliefs are ways in which individual patients think about their illness or condition and treatments both in general

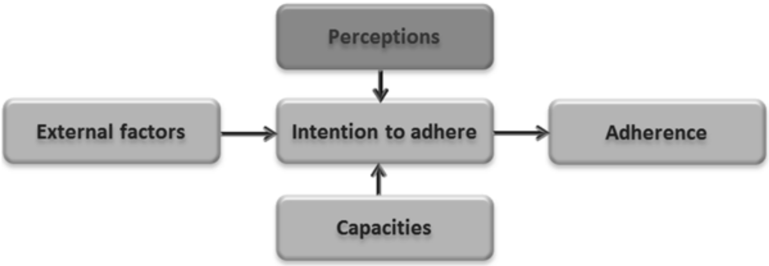

Fig. 22.1 Planned behavior applied to adherence (Ajzen 1991)

and specifically. They play a crucial role and comprise of: self-identity, patients' perception of illness, of medicine and medicines, and of the power in the consultation and the public perception of medicines (Horne et al. 2005).

Firstly, the main development in adherence-related research over the past decade has been an increasing recognition of the importance of patients' "common sense" beliefs about their illness and treatment as determinants of adherence—acknowledged as active decision-making. Qualitative research has shown that nonadherence often represents a logical response to the illness and treatment in terms of patients' own perceptions, experiences and priorities, including concerns about side effects. Patients therefore seek to balance perceived necessity and concerns and to minimize their use of prescribed medicines.

Secondly, there are the perceptions of illness in general. Patients must believe that they are vulnerable or susceptible to the disease or its consequences, that they actually have it, and that the consequences of the disease on their well-being could be serious. When they arrive at the consultation, patients already hold sets of beliefs and theories about health and illness. When confronted with a particular illness they will first try to deal with it and not yield control over their bodies to the medication regimen.

Thirdly, health beliefs about medicine in general and in medicines in particular play a role. Patients must believe that, by following a particular set of health recommendations, the threat or severity of the condition will be abolished or reduced. This is influenced by patients' knowledge, ideas, and experiences (as well as those of family and friends), perceived properties of medicines, fear of side effects, and patients' general preference for taking or not taking medication. Patients can have many fears and powerful negative images of medicines. Improving adherence requires a closer understanding of the patients' experience of their illness and medication, rather than the perceptions and expectations of health-care professionals (Vermeire et al. 2001).

Lastly, patients have necessity beliefs. Patients define adherence in terms of apparent good health and seek treatment approaches that are manageable, tolerable, and, in their view, effective. Although adherence may be a priority for health professionals, for patients concerns such as controlling symptoms, preventing medical crises, maintaining financial comfort, or enjoying a quality lifestyle may take precedence. Patients do not view all recommended treatments as necessary for their best interests (Marinker 1997; Vermeire et al. 2001).

22.5.4 External Factors and Capacities

22.5.4.1 Social Support

There are also social factors, such as a positive attitude by others in the community, that may influence adherence. Support can be both practical (e.g., seeking medication) and emotional (e.g., empathy) and can come from both informal caregivers or other patients and health-care professionals (Vermeire et al. 2001).

22.5.4.2 Continuity and Quality of Care

Next, adherence seems to be related to the quality of the interaction between the patient and health professional. It is extremely difficult to assess the nature of this interaction and to measure its components. Besides, it is well known that communication encompasses much more than the use of words; communication is about exchanging and decoding messages. The health provider–patient relationship deals with perspectives both partners have. The health professional's attitude towards the patient and their ability to elicit and respect the patient's concerns, to provide appropriate information and demonstrate empathy are of the utmost importance. A good relationship is one that offers autonomy, information and support after a successful unraveling of these perspectives. Quantitative research is extremely difficult in this area because it is impossible to reduce complex phenomena, such as communication, to a set of items that can be measured separately (Vermeire 2010; Vermeire et al. 2001).

Patients are often confronted with conflicting information. Health professionals are often not compliant with diagnostic and therapeutic standards. There is considerable heterogeneity in prescribing, with doctors drawing upon their own knowledge and understanding when they decide upon a treatment regimen. Patients should be the primary actors in medical decision-making, and health professionals should adopt a supportive role. In essence, then, adherence is an elusive and flexible goal. Patients, especially those with chronic illness, make decisions about treatments that fit into their own beliefs and personal circumstances. Health professionals need to shift the emphasis away from attempting to encourage patients into taking the medication they prescribe, towards learning how they can contribute to the decisions that patients currently make about their medications (Vermeire 2010).

Although many studies have investigated causal relationships between patient factors, doctor factors and adherence, no consistent story has yet emerged. It is possible that each condition and each patient–doctor pair involves different motivating factors that affect adherence (Vermeire 2010; Vermeire et al. 2001).

22.5.4.3 Knowledge

A major obstacle to patient adherence is ignorance about important issues, such as the nature of the disease and the nature of the treatments and how effective these can be. Only a few studies have focused on provider behaviors that would enhance patient understanding and recall through the doctor's communication style and teaching strategies.

22.5.5 Contributions from Evidence Syntheses

Equally contributing to the qualitative evidence base of adherence are meta-ethnographies. Meta-ethnography is one of the well-elaborated techniques for the synthesis of qualitative data (Britten et al. 2002; Noblit and Hare 1988). A meta-ethnography aims at reaching a deeper understanding of a phenomenon, such as adherence, through finding similarities in a series of qualitative studies (reciprocal translation), detecting differences (refutation) or reflecting on the totality (a problem, an organization, or a culture), thus making a synthesis (lines of argument synthesis) of data (Britten et al. 2002; Noblit and Hare 1988). Unlike the meta-analysis of quantitative studies, meta-analysis of qualitative studies is interpretive rather than aggregative, requiring the researchers to compare and analyze reports in an axial process, creating new interpretations in the process. This leads to third-order interpretations which are the translations (by the reviewers) of second-order key concepts/themes (by the individual authors) of the first-order text fragments (by patients) (Britten et al. 2002; Noblit and Hare 1988).

Four examples are given of systematic reviews in the area of adherence (Mills et al. 2006; Munro et al. 2007; Pound et al. 2005; Vermeire et al. 2007). The first is the synthesis of a phenomenological focus group research into obstacles to adhere to treatment regimens in people living with Type 2 diabetes in seven European countries (Vermeire et al. 2007). Table 22.1 synthesizes the key concepts and the so-called third-order interpretations, which result from an axial process. The themes derived from each study

Table 22.1 Synthesis, including key themes and third-order interpretations (Vermeire et al. 2007)

Key concepts	Third-order interpretations
The course of diabetes	Diabetes is a "problem" until there are complications, then becoming a "disease"
Information	Nonadherence is to a large extent determined by the lack or un-transparent information
Person and context	Coping with diabetes depends on social support, personal attitude towards a healthy life-style and health beliefs
Health-care provider	Does not assess health beliefs, does not tailor recommended treatment
Body awareness	Imperceptible treatment effects. Self-regulation is keeping in touch with the body, to see how it functions with or without recommended regimen

were tabulated in a list of key themes identified in the initial Flanders study. These themes were discussed by the researchers until agreement was reached on how far the concepts relating to the themes could, in fact, be translated from one study into another, and whether this led to richer explanations. The process requires returning repeatedly to the original data from each country to verify, contradict, or enrich interpretations in an axial process of coding and recoding in the context of the different studies, guided by the research questions.

The second example is a synthesis of medicine-taking, conducted using meta-ethnography (Pound et al. 2005). The findings of the synthesis fall into three parts: (1) the way people evaluate their medicines and the difficulties they encounter in doing this (trying out medicines and weighing up the costs and benefits, adverse effects, acceptability of regimen, weighing and balancing, stopping the medicine and seeing what happens, observing others, obtaining information, objective and subjective indicators, difficulties in evaluating medicines, worries about medicines that lay testing and evaluation cannot resolve); (2) the interaction between medicines and patient identity (non-acceptance, disclosure and stigma); (3) the ways people take their medicines (motivation to minimize intake, to decrease adverse effects and addiction, to make the regimen more acceptable, for financial reasons, using medicine symptomatically, using medicine strategically, replacing and supplementing medicines with non-pharmacological treatments, doctor–patient communication about regimen modifications, imposed compliance).

The third and fourth examples are systematic reviews of barriers and facilitators for individuals in medicine-taking (Mills et al. 2006; Munro et al. 2007). Both reviewers draw similar conclusions and find eight themes: (1) organization of treatment and care, treatment requirements, and relationship with the provider; (2) interpretation of illness and wellness; (3) financial burden; (4) knowledge, attitudes, and beliefs about treatment; (5) law and immigration; (6) personal characteristics and adherence behavior; (7) side effects; (8) family and community.

This narrative illustrates consistently the role and the input of qualitative research methods in the building of a qualitative evidence base.

22.6 Recent Qualitative Adherence Research from Different Stakeholders

22.6.1 Introduction

The understanding of the complexity of nonadherence resulted in a rise of qualitative research on the topic from many different stakeholders. This section overviews the last 5 years of qualitative studies on nonadherence, focusing specifically on medication nonadherence. The aim is to examine which valuable insights in medication nonadherence were gained through qualitative research from the different professions, illustrating the value, if not the need, of qualitative techniques to gain insights in nonadherence as a concept. At the end of the section, we broaden the focus from medication adherence to treatment adherence in general and in various disciplines.

22.6.2 Methodology

First, we checked with experts from different professions to see whether they were familiar with the term "adherence." We contacted research groups from social work, preventive medicine, general practitioners, pharmacy, nursing, sociology, psychology, epidemiology, and physiotherapy. All of them were familiar with the term "nonadherence" and had in their training been presented with techniques to enhance the extent to which patients follow their instructions.

We then conducted a literature search on PubMed combining the MeSH-terms "medication adherence" and "qualitative research." The search was limited to studies published in the last 5 years (2008–2012). Articles had to study medication nonadherence using qualitative research methodology. Although not all qualitative studies appear in peer-reviewed journals, we deliberately chose to search PubMed. This was done to illustrate the evolution, from Dr. Sackett's literature survey in the seventies yielding few to no research articles (nor quantitative nor qualitative), over the appearance of mainly quantitative results, to the many recently published qualitative articles on which we report here.

22.6.3 Results

22.6.3.1 Search Tree

The search strategy resulted in 109 articles, 50 of which reported on results from qualitative research in the domain of medication non adherence (Al-Qazaz et al. 2011; Arrivillaga et al. 2011; Awiti Ujiji et al. 2011; Axelsson et al. 2011; Badahdah and Pedersen 2011; Banbury et al. 2008; Biadgilign et al. 2009; Blake et al. 2010; Chong et al. 2009; Curioso et al. 2010; Dickson 2009; Fetzer et al. 2011; Garavalia et al. 2009, 2011; Grant et al. 2008; Groh et al. 2011; Gusdal et al. 2011; Haberer et al. 2010; Hawkings et al. 2008; Iversen et al. 2011; Kizub et al. 2012; Kreps et al. 2011; Lacey et al. 2009; Landier et al. 2011; Lewis et al. 2010; Marshall et al. 2012; Marx et al. 2011; Michaud et al. 2010; Mishra et al. 2011; Mohammadpour et al. 2010; Moses 2011; Murray et al. 2009; Nyanzi-Wakholi et al. 2012; Plummer et al. 2010; Regnier Denois et al. 2011; Rongkavilit et al. 2010; Ruppar and Russell 2009; Sale et al. 2011; Salt and Peden 2011; Sanjobo et al. 2008; Starks et al. 2008; Swanlund 2010; Tong et al. 2011; Tordoff et al. 2010; van Elsland et al. 2012; van Geffen et al. 2011; Van Tam et al. 2011; Wasti et al. 2012; Williams et al. 2008, 2009). Forty-six articles were not on medication adherence (e.g., on the experience of living with chronic illness or adherence to other therapy aspects such as inhalers or insulin). Another 13 articles did not use qualitative research methods. From one article, the full text could not be retrieved. Hence, the yield of relevant articles amounted to 49.

22.6.3.2 Professions Publishing Qualitative Research on Medication Adherence

Table 22.2 shows that the majority of articles on qualitative research on medication adherence were written by nurses (13) or public health

Table 22.2 Different professions publishing qualitative research on medication adherence

Profession	N° of articles
Nursing	13
Public health	10
+Medicine	*+3*
+Medicine + epidemiology	*+1*
+Medicine + preventive	*+1*
+Sociology	*+1*
+Pharmacology	*+1*
Sociology/social work	5
+Preventive medicine	*+1*
Pharmacy	4
Medicine	3
Preventive medicine	2
Physical therapy	1
Communication	1
Government	1
+Ethics + psychology	*+1*

workers (10). On top of the ten articles by public health workers, there were seven articles that were the result of collaboration between the public health sector and preventive medicine, epidemiology, sociology or pharmacology (see Table 22.2). Sociologists and social workers published six articles, one of which was in collaboration with a preventive medicine research team. Pharmacists wrote four articles.

Only one article was published by a physical therapist. One article was written by a communication specialist and two research studies were led by the government, one of which in collaboration with an ethical specialist and psychologist. Except for this one latter study, none of the authors included a psychologist.

22.6.3.3 Topics Covered by Recent Qualitative Research on Medication Adherence

The different topics covered are shown in Table 22.3. The vast majority studied determinants of medication nonadherence, mainly from the perspective of the patient (36). We identified two reviews on the latter subject. Two articles described the determinants according to health-care providers and four articles included both patients and health-care providers to investigate nonadherence determinants. One study also interviewed informal caregivers.

Table 22.3 Different topics addressed through qualitative research on medication adherence

Topics	N° of articles
Facilitators and/or barriers to adherence	43
According to patients (of which two reviews)	*36*
According to health-care providers	*2*
According to patients and health-care providers	*4*
According to patients and informal caregivers	*1*
Patient experiences with/vision on adherence	3
Identifying types of adherers	2
Describing the process of adherence	1

Three articles were on patient experiences with, or their vision of, adherence. Another two studies described different types of adherers and one article described the process of adherence.

More than half of the articles (20) concentrated on persons with HIV/AIDS. In six articles, patients with different conditions were followed (e.g., elderly, persons with various conditions, persons with an unspecified chronic condition). Five studies focused on persons with hypertension or cardiovascular conditions. The researchers of the remaining articles interviewed persons suffering from Type 2 diabetes, asthma, chronic pain, infection, osteoporosis, tuberculosis, glaucoma, leukemia, psychosis, depression, kidney failure, and rheumatic arthritis, with one or two articles per topic.

22.6.3.4 Lessons Learned from the Recent Qualitative Research on Medication Adherence

Table 22.4 summarizes all the determinants of nonadherence mentioned in the articles. Because almost every article mentioned several barriers or facilitators, their numbers may exceed the number of studies. The adherence barrier most frequently mentioned was related to the drug treatment itself and included side effects, pill burden, and intake timing. Financial burden was also a main adherence barrier, be it the cost of the medication itself or having no money to buy food or water to swallow the drugs or not having or being able to afford transport to health-care centers. Other main barriers were a bad relationship with the health-care provider, knowledge deficit, stigma, and forgetfulness. Not being convinced of the advantages or efficacy of the drug treatment was also often mentioned.

These barriers were echoed or complemented by the adherence facilitators mentioned. Having social support, being convinced of the drug treatment advantages and using aids such as a reminder or cue-dosing (routine) were the most frequently described adherence facilitators. Learning to cope and developing self-efficacy was the third most mentioned facilitator.

Table 22.4 Determinants of nonadherence

Barriers to adherence	N° of times mentioned in articles	Adherence facilitators	N° of times mentioned in articles
Side effects, pill burden, timing	22		
Finances (medication cost, transport, no food or water to swallow medication)	21	Financial support	1
Health-care provider (no trust, no consistent information, not providing information)	14	Trust in health-care provider	2
Knowledge deficit	12	Education	4
Stigma (mainly in HIV/AIDS)	10		
Forgetfulness (mainly because of activities)	10	Reminder or routine	10
		Learning to cope/ self-efficacy	6
Not convinced of advantages/ effect drugs	8	Convinced of advantages	12
Mental suffering (depression, drugs, alcohol)	5		
Disturbed routine (e.g., going out)	4		
No social support	3	Social support	12
No symptoms	3		
Frustration/fed up with therapy/not motivated	3		
Alternative treatment	3	Faith	4
Inability to trace nonadherence	2	Follow-up counseling	1
Not involved in decision making	1		
Not able to remember instructions	1	Simplified regimen	2
Not willing to accept chronic illness	1		

To sum up, the variety of determinants shows that various determinants can exist in a patient and that they may even vary over time. Also, many of the identified causes are specific to either a patient group (e.g., stigma in HIV/AIDS) or to areas (e.g., medication cost in developing countries). It is of utmost importance to investigate which determinants exist in which patients and to provide individualized adherence support tailored to both the patient and the existing barrier(s).

The articles not focusing on adherence determinants studied patients' experiences with, or vision of, adherence, as well as different types of adherers and the process of adherence. The study by Axelsson et al. (2011) described how patients perceive adherence. The findings show that patients with asthma perceive it as a way to achieve a functional day (see Fig. 22.2) (Axelsson et al. 2011). In order to do so, they had various foci:

- A promotive focus (trying to control the illness by promotive medication and, hence, promotive adherence reasoning).
- A preventive focus (trying to avoid uncontrolled illness through preventive medicine overuse and, hence, preventive adherence reasoning).
- A permissive focus (trying to act on the spur of symptoms through unstructured medication use and, hence, permissive adherence reasoning).

Although the findings and scheme are condition-specific (specifically for the case of asthma patients), this study makes clear what adherence really is and what drives intake behavior

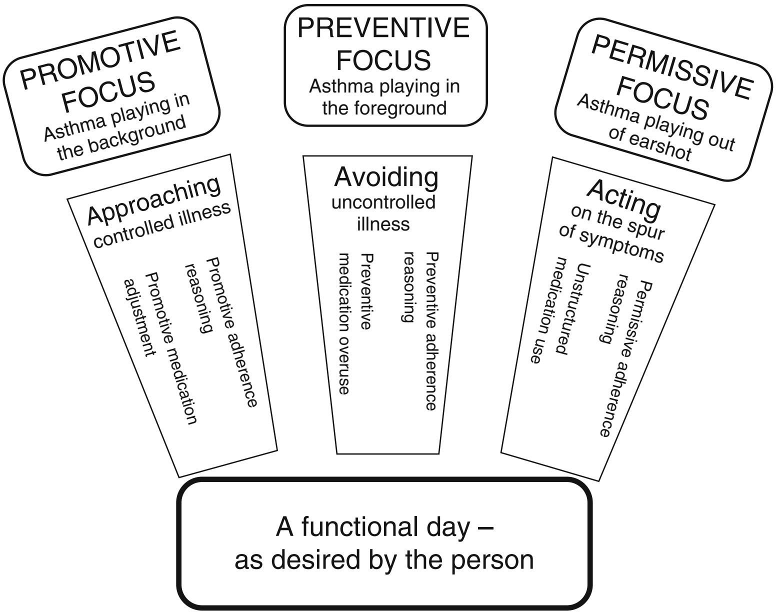

Fig. 22.2 Perception of adherence according to asthma patients (Axelsson et al. 2011)

from the patient perspective: a thorough model that only qualitative research can unravel.

Tong et al. succeed in providing similar insights in kidney transplant patients (Tong et al. 2011). Their review presents a summary scheme elucidating the attitudes, experiences and perspectives underpinning medicine-taking behavior following kidney transplant (see Fig. 22.3).

Marx defined adherence determinants to be fear, knowledge deficit, and fear of asking for information from a doctor (Marx et al. 2011). Therefrom, three types of "adherers" were identified:

1. The assertive actor (asking the doctor questions, wanting more information).
2. The unconscious avoider (not really interested in learning more about the condition).
3. The inconsistent actor (wanting more information but looking this up himself).

He concluded that all patients are different and require a tailored approach, which is in fact what many authors conclude after being confronted with various determinants of nonadherence, also insights that only qualitative research can provide.

Perhaps one of the most interesting publications is that of Mohammadpour et al. (2010). They prescribe adherence as a process including four steps:

1. Choosing to live and actively deciding to take the medication (which is influenced by information, knowledge and patient involvement).
2. Developing strategies to be adherent (such as aids, reminders, social support, or routine).
3. The relationship with health-care workers.
4. Being confronted with the advantages of the medication as a motivator for sustained adherence.

With these simple steps the authors are able to capture the most important determinants of medication adherence and link them in a logical way, elucidating the complex process of adherence. The description of this process is owing to the contribution of qualitative research and so much more meaningful than trying to quantitatively correlate a set of factors with nonadherence.

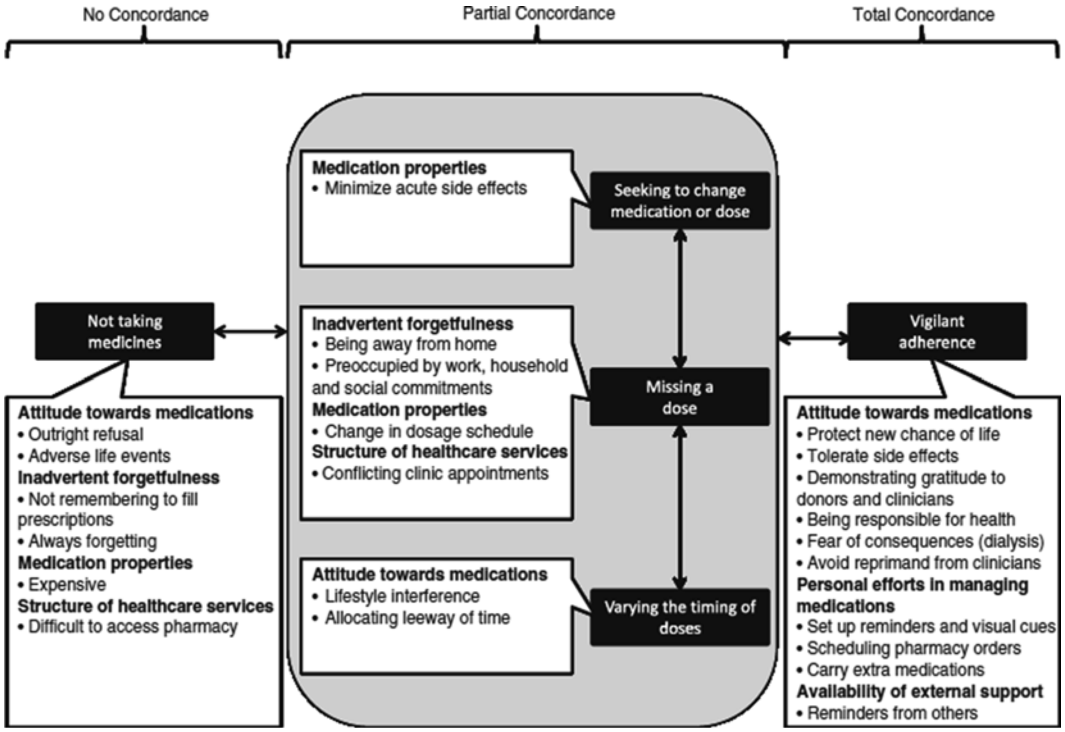

Fig. 22.3 Perception of medication adherence according to kidney transplant patients (Tong et al. 2011)

22.6.4 Adherence to Treatment in General

This section started by narrowing down the focus to medication adherence in order to give concrete examples of the value of qualitative research. However, similar findings apply to patient treatment adherence in general and in various disciplines. Of course, every profession has a (slightly) different view on adherence—e.g., for physiotherapists the main aim might be to support patients in executing physical exercises, whereas for a GP the focus might be medication intake. In this section, we want to give some examples of research on treatment adherence in general from the viewpoint of different professionals. The aim is to offer some interesting references that readers might employ as a starting point in their search for more qualitative adherence studies in the domain of their interest and to illustrate that the principles that apply to medication adherence apply to treatment adherence in general.

In the domain of *social medicine*, Donovan—a social medicine professor—had a major contribution, describing adherence as a patient decision, rather than a deviance (Donovan and Blake 1992). In the 1990s she published on the need to focus on the patient perspective (Donovan 1995). Sociomedical research in adherence is published in various journals and the conclusions are quite similar to those found in medication adherence research. Shelton, to give an example, concluded that adherence to diagnostic follow-up visits after a positive mammography was related to beliefs, finances, social support/obligations and distrust of health-care providers (Shelton et al. 2011). Inflexible work policies were identified as a barrier specific to follow-up visit adherence.

Examples of qualitative research conducted specifically by *social workers* can, among others, be found in the journal *Social Work*. For instance, Ka'opula and Westerfelt focus on qualitative adherence research and implications for social workers (Ka'opua and Mueller 2004; Westerfelt 2004).

Tijerina describes a social constructivist approach to understand how dialysis patients experience their disease and treatment (Tijerina 2009). Many of the findings are similar to those in medication adherence research. Kovacs concludes that patients could benefit from greater involvement with professionals and peers both to manage their condition and to increase emotional support (Kovacs et al. 2012). The author also points to financial pressure as a barrier—all determinants that were also found in medication adherence research.

Physiotherapists usually have psychology as a major in their education and they are trained to have a coaching attitude towards patients, rather than a paternalistic one. In journals such as *Physiotherapy* or *Manual Therapy* several articles on adherence research can be found. Recently, a systematic review on treatment adherence in physiotherapy appeared (Jack et al. 2010). Similar to medication adherence, the barriers to physiotherapy adherence were low self-efficacy, depression, anxiety, helplessness and poor social support. Specific to physiotherapy was the barrier of increased pain levels during exercise.

Similar conclusions are drawn in the domain of *occupational health*. Hambach et al. (2011) published on workers' perceptions of chemical risks. They point to communication problems and lack of trust in prevention advisers and hierarchy as barriers to following advice. Workers also did not feel their specific knowledge and proposals were taken into account, hinting at low involvement.

22.7 Implications for Research, Practice and Health Policy: Towards a Multifactorial Approach

22.7.1 Implications for Research

Four decades have passed since adherence research started. Despite continuing efforts, no substantial new insights have arisen from quantitative studies. Qualitative research, on the contrary, has in the past decade identified important issues such as the quality of the health professional–patient relationship and patient health beliefs. There is an immense need for sociological and psychological research models to study patients' attitudes and subjective perceptions such as the perceived efficacy of medicine, the balancing of risks and benefits, managing everyday life, and the discrepancies between doctors' and patients' risk perceptions.

Although patient factors have been examined extensively, this has rarely been done longitudinally (Vermeire 2010; Vermeire et al. 2001). Much research has been cross-sectional, whereas adherence is a dynamic process that may change over time and needs to be followed up on (Bastiaens 2010; Griffiths et al. 2007). If we want to explore how to deliver more tailored, person-centered care in which the uniqueness of each patient is addressed, then longitudinal research is needed.

Secondly, researchers need to pay attention to the all-important conversion of the findings of these high quality research studies into practice (translational research). Findings should not end on a bookshelf but sink into the minds of readers and health-care providers through gaining knowledge (transformational learning), changing attitudes (self-location) and, finally, taking action towards a multifactorial approach of nonadherence.

22.7.2 Implications for Practice and Health Policy

22.7.2.1 Enhancing Adherence

Enhancing adherence is a major concern. Indeed by enhancing adherence better patient outcomes may be obtained. Haynes and colleagues (2008) conclude that it is not clear which interventions improve adherence and clinical outcomes. For short-term treatments especially, counseling about the importance of adherence reinforced by written instructions showed an effect. For long-term treatments, it is clear that even the most effective interventions do not lead to large improvements in adherence and treatment outcomes.

22.7.2.2 Adherence in Medical Encounters: A Transformational Approach

The UK NHS report emphasizes the importance of the patient–prescriber relationship and the roles of patient and prescriber during medicine taking (Horne et al. 2005). The conclusion of DiMatteo's (2003) review, is that patient adherence to chronic disease regimens can best be achieved by improving patient–health professional communication, and by insuring that patients believe in the necessity and efficacy of treatment and have adequate support. Health-care professionals—all of them—should explore these cornerstones during their encounters and should try to deal with them in a longitudinal way, as sustained efforts. They should be trained in order to use these strategies effectively (Vermeire 2010).

Informed decision-making is an important first step in the process of being adherent. Because health-care professionals are often unaware of how patients take their medicines, assessing adherence is an important second step. The third step is that of supporting adherence (Vermeire 2010). In other words, one could speak about "adherence-centeredness" as a part of patient-centeredness. Addressing nonadherence starts with an understanding of patients' perspectives of medicines and the reasons why they may not want or are unable to use them (Horne 2001).

In medical encounters the goal is never to measure adherence but to explore those factors that may influence adherence. A number of questions may be helpful to do so, creating space to talk about adherence with patients (Vermeire 2010): What does the diagnosis mean to you? What do you expect from your health-care professional? How do you feel about your treatment? What are your treatment goals? Do you believe this treatment will help you? Asking questions and about patients' narratives/stories are helpful in illuminating patients' values (Bastiaens 2010; Peyrot and Rubin 2007). Addressing people with a non-judgmental, holistic and empathic attitude and engaging in a collaborative and individual-centered approach seems to be the most important action point for health-care providers.

Finally, as for other domains (research and practice), future health policies should strive toward the all-important multifactorial approach. Health policies should be oriented towards three major issues: (1) to encourage and to commission research concerning the key issues in adherence; (2) to encourage knowledge about adherence and skills to deal with informed choice and supported adherence in the medical education of all those confronted with any form of adherence and; (3) to ensure awakening in all parties concerned, including the community. The same applies to all contexts in which persons are encouraged to adapt their behavior in order to reach new goals.

Qualitative research has not only broadened insights into the complex phenomenon of nonadherence but has led to a whole new and more complete vision, thus implying that an important mission for health-care providers will involve sharing power in the encounter.

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Disability as a Dimension of Diversity

23

Rhoda Olkin

23.1 Introduction

In this chapter I review the qualitative evidence related to therapy with people with disabilities. I begin with a brief discussion of the conceptual factors that affect the conduct of research with, and about, people with disabilities. Additionally I review over 50 articles describing qualitative research related to people with disabilities as the articles pertain to therapy.

The call for more qualitative research should never be framed as either/or, i.e., qualitative or quantitative. Neither is better nor worse, but they are two very different approaches to topics. Herein, I explore three main concerns: (a) conceptual issues, (b) methodological issues, and (c) clinical issues. Additionally, I conducted a literature search for disability and qualitative designs and disability and quantitative designs and drew some tentative conclusions from the approximately 100 articles reviewed.

What is "evidence"? The APA Presidential Task Force on Evidence-Based Practice (2006) defines evidence-based practice as "the integration of the best available research with clinical expertise in the context of patient characteristics, culture, and preferences" (p. 273). The integration of research results with clinical expertise is a common aspect of many definitions of evidence in both psychology and medicine (Sackett et al. 2000). Notice that in these definitions the data that inform practice come from research (i.e., researchers) and clinical expertise (i.e., clinicians), but not from users (i.e., clients). These definitions thus seem inadequate as they privilege the professional to the exclusion of the consumer. To paraphrase and amend the APA Task Force definition (2006), I would assert that evidence is the integration of research that includes maximal input from those being researched, clinical expertise with diverse clients, and the lived experiences of the population in question. Qualitative research is more likely to include the lived experiences of people with disabilities than is quantitative research and thus adds an important component to evidence.

Ideally, the results of quantitative and qualitative studies would be well integrated. Unfortunately, they are often separated by ideology and publication. For example, *Rehabilitation Psychology* (the journal of Division 22 of the APA) is almost exclusively quantitative—none of the 16 articles in 2 issues from 2012 were qualitative. In contrast, *Disability and Society* (published in England) receives contributions from disability studies, which is an interdisciplinary field spanning history, sociology, language arts,

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and psychology. Of 59 articles in 6 issues from 2012, 22 (37 %) used qualitative methodologies. (The remaining articles were not necessarily quantitative studies; e.g., several articles were analyses.) These two journals are counterpoints in what is considered to be evidence—studies *about* people with disabilities versus studies *with* people with disabilities.

23.2 Conceptual Issues

23.2.1 Defining Disability

There are several conceptual issues that plague the research on disability. Chief among these is the problem of defining disability and parsing the overlap and differences between illness and disability, which are related but not completely overlapping concepts. For example, myocardial infarction and stroke can be considered illnesses, but can create impairments that require an alteration in functioning, thus becoming disabilities. Much of the research in health psychology includes conditions that fall into the overlap between illness and disability. This can create a problem because health psychology focuses in part on the behavior-to-health relationship. Lifestyle habits such as exercise, eating, or smoking play a fairly direct role in several illnesses. It becomes easy, then, to extend this model to disability and see causal relationships where none might exist and to blame persons for their disabilities.

Another problem is how best to categorize and group disabilities. Quantitative literature tends to group disabilities by medical diagnosis (e.g., spinal cord injury, rheumatoid arthritis). In contrast, qualitative literature tends to group disabilities by function (e.g., wheelchair users; cognitive processing problems) and relies on self-definition and identity as a person with a disability. Although medical diagnosis might be a part of this definition (e.g., adolescent boys with muscular dystrophy), screening is not about whether the disability has been certified by a medical professional but rather whether the potential participant has had certain experiences (e.g., attended a camp for adolescents with muscular dystrophy).

In too many articles authors aggregate diverse disabilities and pose research questions examining differences between those with and without disabilities. We should have moved well beyond such between-group comparisons, as the rationale for them is to examine deviance from an able-bodied norm. Conversely, many studies focus on a single population of persons with disabilities, sometimes in a specific setting (e.g., men with spinal cord injuries in a rehabilitation hospital; a single mother with an intellectual disability), and erroneously generalize results beyond the specifics of the study.

23.2.2 The Politics of Research

In 1992 (Volume 17(2)) a special issue of *Disability and Society* focused on paradigms of research on disability. The impetus for the special issue was the work of Mike Oliver and Len Barton, two British researchers, who had spent a year holding conversations with disability researchers and people with disabilities. This led to the development of the “emancipatory paradigm in […] disability research” (Oliver 1997, p. #), which is a rejection of the positivist view of truth and instead is “about the facilitating of a politics of the possible by confronting social oppression at whatever levels it occurs” (Oliver 1992, p. 110).

A key part of Oliver’s argument was that it was not possible to research oppression objectively. What is critical to our understanding here is the idea that research about disability is research about oppression. Emancipatory research is designed to facilitate actions of a disempowered group as it realizes its own empowerment (power is not bestowed, but taken). The questions and data gathering are very much in the hands of the researched. Thus, unstructured or semi-structured interviews are preferred over structured, so as not to constrict the focus a priori. Emancipatory disability research is associated with qualitative designs: “this is almost certainly due to the argument that up to now large scale surveys and detailed quantitative analyses have never captured fully the extent and complexity of the oppression encountered by disabled people" (Barnes 2003, p. 10). A key goal is to promote meaningful outcomes for people with disabilities; these outcomes should directly benefit participants, rather than indirectly through augmentation of the professional knowledge base.

The means to undertake research (i.e., funding) should also be within the power of the researched; without this financial control, research might be participatory, but it is not emancipatory (Zarb, 1992). However, disability organizations are generally shoestring operations that focus on services, and obtaining funding for research is generally a lower priority (Barnes 2003). Additionally, major granting organizations rarely ask, much less award points towards funding, whether any of the researchers are themselves members of the researched group. In the USA, an exception is the National Institute on Disability Rehabilitation and Research, housed within the US Department of Education.

Gains from emancipatory research might occur at three levels: the participants themselves; their immediate community; and persons with disabilities at large. But a critical counter question is whether the research could *dis*empower or further *dis*advantage any of those three levels. Whether the research was emancipatory or not can only be judged ex post facto. For a rubric to evaluate emancipatory research, see six mandates posed by Oliver (1997).

As we can see from the above discussion, there are those who view any research with and about people with disabilities as a political act. Much of the extant literature on disability would not qualify as emancipatory. And although the division may not be along the line between quantitative versus qualitative research, it is more likely that qualitative research, with its quest for inquiry and generation of ideas, is more likely to be considered emancipatory. If emancipatory research is evidence and emancipatory research can only be judged by its results, then it would seem that evidence can be bestowed on a study only by assessing its effects on those studied, rather than on the qualities of the study itself.

23.2.3 Inappropriate Comparison Groups

In many quantitative studies, disability is seen as a defining characteristic and results are interpreted as related to the disability status. Other factors may not be controlled, even when they are expected to contribute to outcomes. For example, although we know that there are higher rates of sexual abuse of children with disabilities than those without, the question of an abuse history often is not included. Thus, if a study were to examine quality of life in persons with or without a disability, even if matched on SES but without data on abuse factors, the two groups might not be comparable. There are many such examples in the published literature. Each study is likely to show differences between the groups of participants with and without disabilities. Such findings do not appreciably advance our understanding of the phenomenology of disability. Furthermore, they perpetuate the view of disability as other.

23.2.4 Terminology

The term *caregiver* is ubiquitous in the research literature and fairly often paired with *burden* (e.g., caregiving burden on family members of children with autism spectrum disorders). *Burden* research focuses on the impact of a person's disability on others, the idea that disability creates financial, social, psychological, and interpersonal stress on family members. Even more unfortunate is that this term is frequently used about children with disabilities, reinforcing the view of professionals that such children are burdens to their families. The term caregiver is used in thousands of titles of research articles. It is necessary to look in the methods section regarding participants, to decipher whether the caregivers were parents, partners, adult children, minor children, paid employees, or some combination. It is as if disability has come to define not only the proband but the relationship as well.

23.2.5 Models of Research

Previously I formulated five models of research that fall into two paradigms (Olkin 1997, 1999). The models one, two, and three were in Paradigm One and models four and five in Paradigm Two, a paradigm that is in line with disability studies. In brief, the first three models, in Paradigm One, were (a) who are people with disabilities?; (b) why do some people with disabilities fare better than others?; and (c) what are the family, financial, and psychosocial supports available to and used by the family and persons with disabilities? The fourth and fifth models, in Paradigm Two, were (d) how, from an interdisciplinary perspective, do we understand the greater systemic issues affecting people with disabilities? and (e) what is needed with regard to laws, policies, and regulations that will improve the lives of, and be more equitable for, persons with disabilities? When I first wrote about these models, my concern was that the prevailing types of research on persons with disabilities had not appreciably advanced the field—"research findings, per se, seem not to have contributed appreciably to improving the living conditions of people with physical disabilities. Such a conclusion is not new" (Kerr and Bodman 1994, p. 100). It is now over two decades later, and a similar conclusion is warranted. Although there have been tremendous advances in medicine regarding some disabilities (e.g., spinal cord injury), these advances are realized in survival rates, longevity, and initial rehabilitation. They are not realized in social acceptance, employment rates, economic security and viability, or political clout. Thus, it would seem that the research is not ameliorating the oppression experienced by people with disabilities, and new approaches are warranted.

A content analysis of five counseling psychology journals, over 20 years, regarding disability research (Foley-Nicpon and Lee 2012) examined methodologies and disability categories. The five journals were *Cultural Diversity and Ethnic Minority Psychology* (from its inception in 1995), *Journal of Counseling and Development*, *Journal of Counseling Psychology*, *Journal of Multicultural Counseling and Development*, and *The Counseling Psychologist*. The overall rate of disability research was small (1–2.7 % of all articles). The *Journal of Counseling and Development* (the journal of the American Counseling Association) had 69 % of the total number of articles on disability. Across all five journals there were never more than six articles related to disability in any one year. Out of 55 articles on disability, 14 were quantitative and only 4 were qualitative. The 55 articles on disability compares to 710 on social class, 134 on acculturation, and 75 on multicultural counseling competency. The authors noted that a common theme of the studies was adjustment and success among people with various types of disabilities. Although they considered this a strength-based model, I view it as a throwback to the type of question that gets asked early in the history of investigation of an outgroup (model two)—why do some members of the outgroup fare better than other members?

A previous analysis of journal articles (Olkin and Pledger 2003) indicated that most (81 %) of the articles in *Rehabilitation Psychology* reflected Paradigm One, and most of those in *Disability and Society* (68 %) reflected Paradigm Two. An examination of articles in those same two journals in 2012 yielded similar results: in *Rehabilitation Psychology*, 69 % of the articles were in Paradigm One (and 25 % could not be classified), and in *Disability and Society*, 71 % of the articles were in Paradigm Two. However, I was forced to refine the models of research in Paradigm One. While the analysis still held for Paradigm Two, in Paradigm One there were considerations I had not previously taken into account—the development of participatory action research and emancipatory research was clearly in evidence within Paradigm One in *Disability and Society.* Thus, although some of the research questions seemed on the surface to focus on Paradigm One models (e.g., who are people with disabilities, why do some people with disabilities do better than other people with disabilities), the express goals were to elicit voices of insiders and to use direct data from people with disabilities to influence policies and systems.

23.3 Methodological Issues

Rehabilitation psychology and mental health journals that focus on disability emphasize quantitative research. In contrast, the journals that are interdisciplinary or stem from disability studies generally include more qualitative research. This contrast in approach goes to the root of the philosophical and paradigmatic differences in approaches to disability in mental health versus disability studies. Qualitative research "refers to a tradition of enquiry concerned primarily with meaning and interpretation" (Barnes 1992, p. 115). Barnes posits several rationales for qualitative research: (a) the lack of objectivity possible and the benefits of explicit subjectivity; (b) the focus on meanings and understanding; and (c) the need for a direct link from end users to policy makers, unmediated by so-called objective experts. In qualitative research there is an iterative process of data collection and data analysis. Several authors have acknowledged interactionist qualitative methods as most appropriate for studying the experience of disability (Barnes 1992; Oliver 1986). The interactionist part implies that the researcher is an insider, i.e., a person with a disability. Unfortunately, data resulting from qualitative research often is not considered hard data, objective, or replicable and thus is less likely to directly influence policy.

Unless researchers are cognizant of the barriers to participation in research for people with disabilities (Olkin 2004), their research design is likely to exclude people with many types of disabilities. Focus groups are one methodology that allows for easier participation by people with disabilities (Keller and Galway 2010). Inclusion as participants, however, is insufficient; there also must be inclusion of people with disabilities in all phases of the research from inception to analysis to dissemination. Remarkably, disability research is dominated by outsiders—people not in the disability community – and is a state of affairs that is rarely questioned.

Qualitative research contains the possibility of challenging existing institutions and notions of appropriate science (Barnes 1992). Let me give an example. The gold standard for trials of a new pain medication would be masked, random assignment of participants to a drug or placebo group. Participants might be asked to keep a daily pain and activity journal, rating pain on a scale of one to ten. The desired outcome would be that pain rated as above level five has dropped to four or below in the drug group and has stayed above level five in the control group. But suppose both groups rate their pain about the same on average—does this mean the drug is a failure? Examining the daily activity levels reveals that the drug group was more active on more days compared to the control group, despite similar ratings of pain. How is this possible? A qualitative study reveals at least part of the answer, which is that the pain scale used in virtually all quantitative studies of pain is not the way people think about their pain (Zelman et al. 2001). People tend to think of their pain as "manageable" or "tolerable" (or not). Sometimes pain might be rated a six, but still manageable, i.e., the person could accomplish some desired activities, and other times a six was unmanageable and the person ceased most activities. Furthermore, manageability implied a change in mood, reducing dysphoria and irritability, which in turn allowed for greater sociability. The qualitative study yielded more information about the relationship of pain to mood and activity and highlighted how people think about their pain. In so doing, it challenged the institutions that treat pain, as well as the accepted gold standard for evaluating impact of medications on pain. If medicine is "a mechanism of social control" (Barnes 2003, p. 4), then one effect of qualitative research could be to loosen the control.

23.4 What Do We Talk About When We Talk About Disability?

A review of research projects in Sweden showed that most of the research was medical or health science focused (Ronnberg et al. 2011, as cited in Erdtman et al. 2012). Only 7 % of the research had groundings in user perspectives (i.e., those of people with disabilities) and could be classified as falling under the rubric of disability studies.

Despite the upsurge in studies on microaggressions in the past decade, there are only two studies on microaggressions experienced by people with disabilities. The first study was about the development of a Disability-Specific Hassles Scale (Timm 2002). The second study used focus groups (total $N = 12$) to inquire about experiences of microaggressions for people with various types of disabilities (Keller and Galway 2010). This latter study yielded eight domains of microaggressions: denial of identity, denial of privacy, helplessness, secondary gain (to the nondisabled person for helping or being nice to a person with a disability), spread effect, patronization, second-class citizenship, and desexualization. Given the importance of microaggressions in the everyday lives of people with disabilities, it is curious that more research is not being done in this area.

The models of research and the two paradigms (Olkin 1999) do not clearly align with either qualitative or quantitative approaches. But reading through the abstracts of approximately 100 articles, about 50 each in quantitative and qualitative studies, yields interesting results (see Table 23.1). The search terms applied were *disability and qualitative* and *disability and quantitative* using EBSCO and ProQuest. The themes and key words evidenced by each search indicate that qualitative research is more closely aligned with disability studies, with its emphasis on the researched as researchers, lived experiences, and distributive justice. Quantitative research is more likely to reflect the medical model of disability, Paradigm One (Olkin 1999), and negative aspects accruing to the individual with the disability (e.g., depression) or family (e.g., burden). The terms for similar concepts differ slightly, with the term *carer* used in qualitative research and *caregiver* in quantitative research, though this may be confounded by country (US journals use *caregiver* almost exclusively, while those in the UK or Australia favor *carers*). One term that appears on both lists is *resilience*.

Research in psychology and medicine has focused on quality of life (QOL) over the past decade. What is curious is that QOL appears frequently in the quantitative literature and very infrequently in the qualitative literature. It might seem that this is an area ripe for qualitative literature: that is, hearing directly from various groups of people with disabilities as to what they consider most important about their lives and how they evaluate its quality. But in pondering the absence of QOL studies in qualitative research, I came to realize that the question is more irrelevant for those of us with disabilities—it's an outsider question, this worry that people with disabilities have impaired or negligible quality of life or that our quality of life depends on factors other than those that account for QOL in those without disabilities. The QOL of people with disabilities is impinged on by stigma, prejudice, discrimination, and microaggressions, so let us research those phenomena.

Table 23.1 Terms associated with qualitative and quantitative articles

Qualitative	Quantitative
Agency	Assessment
Carers	Burden
Collective identity	Caregivers
Contextual understanding	Cognitions
Education	Coping
Empowerment	Cost
Integration/inclusion	Depression
Lived experiences/testimonies	Efficacy
Multiple identities	Functioning
Policies	Mediating effects
Resilience	Outcomes
Stigma	Pain (beliefs, cognitions, behaviors)
Supports	Prediction
Training	Quality of life
Voices of people with disabilities	Randomized
	Resilience
	Risk

23.5 Practice Issues

What do practitioners want from research on disability? What can guide our clinical work, teaching, research, assessment, training, and supervision? And how can research ameliorate the oppression experienced by people with disabilities? Next I examine what qualitative studies contribute.

23.5.1 What Can We Learn from Qualitative Research Studies?

To address the contribution of qualitative research to therapy with persons with disabilities, I conducted first a hand search through three journals from 2012 to 2013 to examine search terms (*Rehabilitation Psychology*, *Journal of Counseling and Development*, and *Disability Studies*) and then an online literature search in summer 2013 (using terms [*disab** or *handicap**] and [*therap** or *intervention* or *clinical* or *counseling* or *social work* or *community* or *outcomes*]). The search was difficult because there was not much to find, so I kept going back to be sure—one does not want to assert an absence of literature only to be proven wrong. I ended up with about 50 articles that seemed even tangentially relevant to clinical issues. Before discussing the implications of those articles, some overall observations are relevant. First was the array of journals necessary to search to find articles (see Table 23.2). Some journals, such as *Rehabilitation Psychology*, rarely publish qualitative research—I had to go back to 1994 to find one applicable to the topic. Journals were in a variety of disciplines, making it unlikely that a clinician, even one who often works with clients with disabilities, will come across relevant articles unless conducting a deliberate and difficult search. The second observation was that almost three-quarters of the articles came from countries other than the USA. One of the benefits of qualitative research is that it gives direct voice to the lived experiences of people with disabilities. When the frequency of qualitative studies declines, those voices are less heard. And if we are to learn about therapy with such persons, it would seem that this would be the first group to ask. Many studies asked professionals rather than end users. In this review I gave preference to studies that directly asked people with disabilities about their experiences. Starting with the most relevant, the first set of studies reviewed was about experiences of people with specific disabilities who had participated in a treatment. The second set pertained to the experiences of people with disabilities living with chronic conditions, in which there are implications for clinicians. The third set focused on providers' perspectives. The fourth set comprises evaluations of, or recommendations for, program protocols. And lastly is a series of three studies by the same authors regard-

Table 23.2 Journals containing articles on qualitative studies related to disability and therapy[a]

Biomedical Central (BMC Psychiatry) (4 articles)
British Journal of Guidance and Counseling
British Journal of Learning Disabilities[b]
Child: Care, Health, and Development
Clinical Rehabilitation
Contemporary Nursing
Counseling and Psychotherapy Research (2 articles)
Counseling and Values
Diabetic Medicine
Disability and Rehabilitation (12 articles)
Education
Exceptional Children
International Journal of Disability, Development and Education
Journal of the American Geriatrics Society
Journal of Applied Research in Intellectual Disabilities
Journal of Clinical Nursing
Journal of Developmental and Physical Disability
Journal of Intellectual Disability Research
Journal of Intellectual and Developmental Disabilities
Journal of Psychiatry and Mental Health Nursing
Journal of Rehabilitation
Journal of Rehabilitation Research and Development
Journal of Social Work Education
Journal of Visual Impairment and Blindness
Pediatric Rehabilitation
Perspectives in Psychiatric Care
Physical and Occupational Therapy in Pediatrics (2 articles)
Physical Therapy
Psychiatric Rehabilitation Journal
Psychology and Psychotherapy
Rehabilitation Psychology
Scandinavian Journal of Occupational Therapy
Sexuality and Disability

[a] Except as noted, only one article was found in each journal

[b] Note that "learning disability" in the UK refers to what is called "intellectual disabilities" in the USA and "intellectual developmental disabilities" in the *DSM 5*

Table 23.3 Countries providing relevant qualitative articles

Country	# of articles	% of total articles
USA	14	26
UK	12	23
Australia; New Zealand	12	23
Sweden, Norway, Denmark	7	13
Canada	4	7
China, Taiwan, Thailand	3	6
Spain	1	2
Total	53	100

ing exercise and fatigue in persons with MS. Although these three studies could have been separated into the sets just described, they are grouped together to show how multiple perspectives on one issue can converge into a more meaningful whole (Table 23.3).

However, there is one study directly on therapy with people with disabilities, which was an analysis of four videotapes from family sessions with people with intellectual disabilities (Pote et al. 2011). This study from the UK found that vulnerability and protection were key themes of the therapy. Protection was from the disability itself and its consequences, from peers and abuse by others, and from sensitive topics, unfairness, and inequality. But it was not just the person with the intellectual disability who was protected; each person took the role of protector and protected, spread across the family members in fluctuating waves. The themes of vulnerability and protection were the focus of therapy 25 % of the time. One method of protection was to reframe statements. When family members did this, they took a positive statement and reframed it as negative, whereas therapists did the opposite, going from negative to positive. The authors recommend that protection should be normalized for families with a member with an intellectual disability, so that there can be open discussion of protection—who does it, how it works, the types of protection, and whom it protects. This level of detailed analysis of sessions would be invaluable with individuals and families with other types of disabilities.

23.5.1.1 Perspectives of People with Disabilities in Treatment or Receiving Services

There were 20 articles in this area, six from the USA. It is hard to draw overall conclusions from the studies because they included such a range of disabilities: stroke, diabetes, traumatic brain injury or other neurological impairments, intellectual disabilities, hand osteoarthritis, multiple sclerosis, spinal cord injury, chronic pain, cerebral palsy, lower amputation, psychiatric disabilities, and unnamed disabilities in children. But two themes did stand out. The first theme was the isolation experienced by families when a member received a diagnosis, and the second related theme was the benefit of meeting with other similar families. Thus, group treatments, whether focusing on creating art (Beeseley et al. 2011), receiving education on diabetes (Due-Christensen et al. 2011), or learning new skills after an acquired brain injury (Nilsson et al. 2011), addressed the isolation and made clients feel less alone. Additionally, families frequently mentioned the value of learning concrete information from similar families (e.g., Carlson et al. 2010; Knis-Matthew et al. 2011; Schreiber et al. 2011).

The nonspecific factors of therapy would be expected to be as important for therapy with people with disabilities as it would be for people without disabilities. But there were nuances to the relationship aspects that were more unique to disability. For example, persons with intellectual disabilities mentioned the value of being able to talk about their problems and highlighted the relationship as the key aspect of therapy (Pert et al. 2013). Because persons with intellectual disabilities might not receive patient listening in many places in their lives, therapy provides a significant alternate experience. Similarly, adults with psychiatric disorders emphasized the importance of going from a *diagnosis* to a *person* with a psychiatric disorder (Ridgeway 2001). And the parents of children with disabilities valued commitment from the professionals that indicated that their children were more than *cases* and the work was more than a job (Blue-Banning et al. 2004). It would seem that the common experience of being reduced to a disability in daily life means that the relationship with the practitioner takes on extra resonance.

Communication with practitioners was a major theme throughout the studies. In focus groups with 70 family members of children with disabilities, specific practitioner behaviors were suggested (Blue-Banning et al. 2004). Parents did not want professionals to candy-coat or hide information or use jargon, and they valued privacy and tact. They were sensitive to blame and appreciated positive comments, as well as indications of valuing the child as a person rather than a diagnosis. Behaviors important to all consumers were important here as well, such as being on time, using last names, and being courteous, but these behaviors may be extra important given the amount of time families of children with disabilities spend with professionals. Conversely, being handed information or dismissed because there was no cure available left consumers dissatisfied and with unanswered questions (Hill et al. 2011).

There were some important considerations for therapy that emerged from other studies, though each study was on a different topic. Interviews with nine adults with neurological impairments on a rehabilitation ward in Taiwan indicated that there were institutional barriers to independence (Chang and Wang 2012). For example, the patients thought that nursing staff preferred to push them in wheelchairs than to wait while they walked slowly with a walker. The authors concluded that "the primacy of biomedical-oriented rehabilitation ideology, insurance reimbursement policies, and cultural values associated with family caregiving" countered moves towards independence in activities of daily living (p. 538). In a study conducted in Australia on persons with neurological impairments (traumatic brain injury), preferences for home versus day-hospital settings for rehabilitation with an occupational therapist were assessed in interviews with 14 adults who had received treatment in both settings (Doig et al. 2011). Both the adults with TBI and the occupational therapists preferred the home setting and felt it was more beneficial to rehabilitation outcomes.

There were two studies related to people with intellectual disabilities, both using short-term cognitive behavioral therapy (CBT) for anxiety and/or depression. The first study was in the UK (Douglass et al. 2007) in which researchers conducted two interviews with six adults with intellectual disabilities and anxiety and the person who attended therapy with them (one person did not have a significant other to bring). All clients felt they had better coping skills, and significant others felt they had a better understanding of the individual's difficulties. Results of the *Glasgow Anxiety Scale* showed a decrease in anxiety for three clients, but a slight increase for three clients. However, for those showing an increase on the scale, this was contradicted in the interviews. This discrepancy is important; there should always be multiple outcome measures used with people with intellectual disabilities, looking for convergence of data. The second study was on also in the UK, using interviews to assess responses to CBT for anxiety and/or depression, between the fourth and ninth sessions. Participants valued the opportunity to talk about problems and were able to identify areas of positive change, but interestingly thought these changes would not be sustainable.

A helpful study illustrated some of the difficulties people with disabilities might encounter in received psychological treatment in the USA (Hampton et al. 2011). Access to health services for women with multiple sclerosis (MS), spina bifida, or spinal cord injury (SCI) were addressed in six open-ended interview questions. Most (91 %) of the 23 women (ten were women of color) expressed a need for services (and 64 % had a psychological diagnosis of depression or anxiety). Although 48 % of the women had HMO insurance and 27 % drove (i.e., eliminating two major barriers), results indicated numerous perceived barriers. The women affirmed the need for psychological services, but identified three main barriers: (a) lack of expertise about disability among mental health service providers (and some mentioned "bad attitudes" on the part of therapists), (b) lack of choices for selecting psychological services, and (c) inaccessible environments in which services were available. Their major strategy to cope with problems was informal support, but socialization had decreased since disability onset, due to losing friends who backed away, inaccessible houses and other environments, and lack of accessible transportation. This study highlights the need and desire for services, but also the lack of training in mental health related to disability.

The reliance on others who were not service providers was echoed in a study in Canada with 22 adults with stroke, MS, or SCI in a six-session self-management group (Hirsche et al. 2011). Interviews with participants indicated multiple factors that accounted for program outcomes. But one factor was common experiences among the group and learning from peers.

Three studies on pain indicated mostly positive outcomes. Cognitions and beliefs about pain are key variables in outcome (Van Huet et al. 2009), and biopsychosocial approaches in a primary care setting can effect gains in adults with pain (Martensson 2001). This echoes much of the quantitative literature, but the Van Huet et al. study also showed that a variety of strategies are used by persons with chronic pain. This idea of variability is echoed in a very different study, in Ireland, on responses to phantom limb-movement therapy to address phantom limb pain. Although the number of participants was only four, there were individual differences in ability to use motor imagery to reduce pain, and outcomes were quite different across the four. The authors concluded that phantom limb pain is a multidimensional disorder. This idea of multidimensionality is critical in going beyond the diagnosis or disability, to the person with the disability, and in not taking treatments off the shelf, but matching them to the individuals, and viewing progress as a process that is neither straightforward nor quick (Van der Riet et al. 2011).

The last study I review here has results that seem so obvious once stated, yet are bolstered by having evidence. Ten Korean-American parents of children with disabilities were interviewed (in Korean) about their experiences with White therapists working with them on child management issues (Park 2012). The core result was that parents were not likely to follow the therapists' suggestions, and six of the ten felt they did not have a good relationship with the therapist. The problems were linguistically and culturally related. For example, therapists suggested withholding enough food and drink at meal time, to reserve these for primary reinforcers for behaviors. This seems so culturally obtuse on the part of the therapists that I cannot help but wonder if the presence of disability in the children overshadowed cultural variables. And again, as was culturally normative, most of the mothers did not discuss their disagreements with the therapists in therapy. Interestingly, the mothers referred to the therapist as a "teacher" when the therapist was effective and as "the person" when it was not effective.

23.5.1.2 Lived Experiences of People with Disabilities That Can Inform Therapy

There were 15 articles reviewed for this section, five from the USA. As in the previous section, there was a wide variety of disabilities and issues covered.

Several studies focused on the experiences of people with disabilities in social and leisure activities (Berger 2012; Hjelle and Vik 2011; Kramer and Hammel 2011; Lawlor et al. 2006; Liddle et al. 2011). An interesting study from Norway examined wheelchair users' experiences with participation in society (Hjelle and Vik 2011). The six participants in a focus group asserted the importance of being engaged in others' lives, work, leisure activities, and public or disability rights service. However, being out in public subjected them to others' comments and stares. The authors describe the variability of experiences from positive to negative as "climbing up and sliding down the participation ladder" (p. 2479). Two studies on children with cerebral palsy (one in the USA and the other in England) suggest that, for these children, competence was about the ability to actively engage in an activity, not about the skill level or how independently they could perform the activity (Kramer and Hammel 2011). And according to 13 parents of children with cerebral palsy, there were numerous barriers to full participation, related to mobility equipment, transportation, lack of information, and negative attitudes and staring by others (Lawlor et al. 2006). Finally, a study in Norway focused on driving after traumatic brain injury and identified distinct phases (learning about driving restrictions and application to oneself, being on hold, and returning to driving), each with its own issues relevant to therapy (Liddle et al. 2011). The 15 participants in that study felt strongly that they wanted the opportunity to show what they could do in simulated driving, rather than having a medical team make the decision for and without them about a return to driving. For older adults in the USA with later vision loss who were in otherwise good health, there were personal, environmental, and emotional barriers to participation in leisure activities (Berger 2012). Thus, the author recommends advocating for increased access, discussing ways to conserve energy, and helping clients practice assertiveness.

Five studies show how differently the person with the disability versus parents or professionals might view the same situation. Six children with cerebral palsy and their parents were interviewed in a study in Canada that focused on the value of walking (Gibson et al. 2011). Parents thought that being a good parent meant trying everything and maintaining hope and thus they wanted their children to walk. The children, on the other hand, equated walking with exercise and found it less functional than alternate means of transportation. And 12 persons with psychosis in the UK thought that the side effects of medications and symptoms of psychosis were equal, that is, they equally affected their quality of life (Hon 2012). Thus, going off medications did not seem like a bad decision, but merely trading one set of symptoms for another set. In the third study, for 16 Chinese-Australian women with breast cancer who had a mastectomy, concerns focused on still being able to be a good mother and wife, not sexuality or attraction (Kwok and White 2011). This article also discussed the misinformation held by some of the 23 women (e.g., that stress can cause cancer, that it is a White woman's disease), the cultural insensitivity of many resources, and thus the primacy of friends in giving information.

Assistive technology can be an important aspect of disability. For 24 lower-limb prosthetic users, functional independence was emphasized as a key goal by service providers, but psychological benefits were endorsed by the prosthetic users (Schaffalitzky et al. 2011). Quality of life was how service providers thought about changes in functioning after prosthetic use, but users gave specific examples (e.g., "I can still live at home"; "a wheelchair would be more stigmatizing"). Services providers thought about safety, but users thought that falling was embarrassing. These differences in language can guide therapists on how to frame ideas in therapy. For example, rather than saying, "being able to visit more friends would improve your quality of life," one could say "if you could go up three steps with a railing, you could visit your best friend at his house."

Two studies focused on those in either the hospital (So and Pierluissi 2011) or long-term care (Wang et al. 2011). For 28 English- or Spanish-speaking hospitalized older adults in the USA, the patients perceived discouragement from staff for them to exercise, in that the doctor did not suggest exercise and the staff was not keen on patients traipsing up and down the hallway (So and Pierluissi 2011). And a key to independence in care facilities was the ability to be independently mobile. However, staff may be reluctant for residents, especially those with dementia, to use power chairs. A study of using smart wheelchairs that provide collision feedback with five older adults with cognitive impairments showed that 5 hours of training yielded positive outcomes (Wang et al. 2011). That article has a good list of seven principles for assistive technology to be useable by people with cognitive impairments (p. 802), and these suggestions could help therapists make their materials more user-friendly.

A perennial issue is the underemployment of persons with disabilities, so understanding what makes it more or less possible for people with specific disabilities is important. A study in Sweden of people with fibromyalgia who were working found that "adjustment of the work tasks and work environment were the main factors influencing whether the women with fibromyalgia could work or not" (Mannerkorpi and Gard 2012, p. 1). Interestingly, cutting down from 8 to 4 h per day did not achieve an appreciable difference in stress or fatigue. Work demands, especially unclear roles, were still as prominent a problem. Therapists may need to be creative in helping clients with disabilities maintain employment, going beyond standard reasonable accommodations to individualized solutions.

An important study on partner violence in physically disabled women augmented previous data from quantitative research (e.g., Nosek et al. 2001). Those data had shown similarities in the incidence of abuse of women with and without disabilities, but differences in the length of abuse and the relationship to the abuser. A qualitative study was able to focus on the pattern of abuse and its relationship to disability onset (Copel 2006). In interviews with 25 women (ages 36–55), the pattern that emerged was different from Walker's cycle of violence in that there was no honeymoon phase post violence. Instead, there was a period of avoidance, followed by a return to superficial normality. Disturbingly, for 21 of the 25 women, the first episodes of abuse coincided with the onset of the disability and the changes in role functioning resulting from the disability. Furthermore, some of the abusive behaviors were unique to disability, such as hiding or destroying medications or insurance cards or disabling assistive technology. Barriers to leaving included lack of accessible shelters and reliance on others for activities of daily living. In all cases the abuse stopped only with the dissolution of the relationship. Copel makes several excellent recommendations for therapists, key among them being the need to inquire specifically about abuse. But she notes that, "there is a lack of research and clinical information about the type of counseling that the women with disabilities received and how a particular counseling approach contributed to the women leaving the abuser" (p. 127).

Several authors had recommendations for clinicians that emanated from specific studies. These included ensuring that the ability to engage in leisure activities did not get overlooked (Berger 2012; Kramer and Hammel 2011), asking about positive sequelae of disability (Karlen 2002; Kwok and White 2011), and being both comfortable and skilled in discussing spirituality in therapy (Specht et al. 2005).

Providers' Perspectives on Treatment for People with Disabilities

There were eight articles reviewed for this section (two from the USA). There were two most relevant to therapy by Pattison (2005, 2010) from the UK. She focused on how counseling can be inclusive for people with intellectual disabilities. She conducted a survey of 396 counselors (2005), most of whom were in private practice, and did semi-structured interviews with 15 of them. The interviews yielded six indicators of inclusive counseling, i.e., counseling appropriate for people with intellectual disabilities. The six indicators were that counselors took a proactive approach (e.g., increasing awareness that counseling for people with disabilities is appropriate, having accessible materials), focused on the relationship with the client (being warm, friendly, patient, and nonjudgmental), had policies that were inclusive, made initial assessments inclusive, were flexible and creative in their approach, and went outside the office to raise awareness among others and to get further training. Pattison notes that too often medications or therapy is used to address the goals of other people who are bothered by behaviors of the person with the intellectual disability, rather than for the person's own goals. In a follow-up article, Pattison (2010) gives strategies to reach out to adolescents with intellectual disabilities. These include simplifying language on all materials, checking for understanding more frequently, repetition, emphasis on main points, awareness of nonverbal communication, and more mirroring of clients.

There were two articles on training professionals to work with people with developmental disabilities. In the first study, in the USA (Russo-Gleicher 2008), master's level social workers (MSWs) who work with this population were asked about the rewards of the work, what other MSWs should know, what the opportunities were in the field, and what coursework and field work would have been useful. The 24 MSWs (21 White; 18 working in nonprofit organizations), many of whom felt they had fallen into this work through happenstance, stated that developmental disabilities were often overlooked and that they really had no specific preparation for this population: students have little exposure, and there was little connection between the classroom and the field work. Their message about working with people with developmental disabilities was that such people are appropriate for therapy, the work is very rewarding, but to focus on small achievements, and keep people living in the least restrictive environment. They also caution MSWs to see the person, not the diagnosis, a theme that echoes the studies reviewed in a previous section. A study in Australia (Iacono et al. 2011) used DVDs of children with cerebral palsy to train students in health care. They had 241 students complete a 5-question attitude scale (*Interaction with Disabled People Scale*) and conducted focus groups with ten students and ten tutors. The scale showed no differences before and after, but the authors posited that the scale focuses mostly on comfort level with people with disabilities, which may not be affected without direct contact. But the qualitative analysis showed that students had paid rapt attention to the DVDs, thought they were better than paper vignettes, and helped decrease the focus on the disability and increase focus on the person.

Authors from Sweden examined published articles on physiotherapy (PT) interventions for children with cerebral palsy (Larsson et al. 2012). From the 21 articles reviewed, they identified three paradigms: (a) making it possible, i.e., function based, PT as collaborative, based on a biopsychosocial model; (b) making it work, i.e., impairment based, PT as coach leading the goals, intervention, evaluation, and one who instructs the family, based on the biomedical and biopsychosocial model; and (c) making it normal, i.e., impairment based, PT as the authoritative expert, based on the biomedical model. They concluded that the paradigm of disability drove the intervention approaches, thereby influencing the entire process, including the relationships with the children. This has clear implications for therapy in that the paradigm of disability also would be expected to drive the therapy process. In a related article from Australia, 24 PTs were interviewed by phone about fall prevention in persons with disabilities. There was tension between what the PTs felt was the correct program, versus what they thought the consumer would adhere to. The paradigm of disability might influence the expectations therapists have for the capabilities and outcomes for clients. And in another study from Australia, 23 professionals in health and disability services at four agencies were asked about their definitions of wellness for children with disabilities (Breen et al. 2011). There was no consensus, but importantly it was the organizational culture of the agency that determined the definition. Again, paradigms drive everything.

The last study reviewed here focused on over-involved parents of children with developmental disabilities (van Ingen et al. 2008). Before turning to the results, I believe it is important to examine the premise of this study. It was conducted in the USA, in which a high value is placed on independence of children. Second, the concept of over-involvement usually gets applied to parents of children with disabilities, not to parents of children without disabilities, and we should question why this is the case. And third, in this study over-involvement and making things difficult for the professionals were conflated. Interviews with professionals about the parents they viewed as over-involved yielded three domains of behaviors: cognitive, emotional, and relational domains. Some of the behaviors identified included parents thinking they needed to be involved in every decision and distrust of providers, both of which may have some bases in reality for parents of young children with disabilities. Other behaviors were ones that would be troublesome in any parent, such as exhibiting anger and frustration, being inconsistent and demanding, and rarely being satisfied. These behaviors do not imply over-involvement but difficulty; I suspect that if the children did not have developmental disabilities the parents would simply be labeled difficult. There is something about the paradigm in which disability is viewed that allows for professionals to connect parents' behaviors with the disability of the child, in a way that may be quite inaccurate.

23.5.1.3 Program Evaluations and Protocols

There were four studies reviewed here, one from the USA. Two studies described online treatments for depression (Bendelin et al. 2011; Montero-Marin et al. 2013) and both would be very helpful for practitioners thinking of designing or using an online intervention. A third study, from the UK, describes the gap between training (in this case in solution-focused therapy) and learning (Smith 2011). The MSWs, who were working with adults with intellectual disabilities, found that they easily slipped back to old patterns of behavior and perceived conflicts between what they learned in the 2-day workshop and the organizational culture in which they worked, which seemed to encourage a more directive and task-focused stance. As in the previous section, we see that paradigms of thinking about people with intellectual disabilities directly affect the work.

The fourth study was the sole one to be published in *Rehabilitation Psychology* (Schwartz and Rogers 1994). The purpose of the study was to teach coping flexibility to people with MS, who participated in an 8-week course on coping with chronic illness. The description of the course would be useful to other practitioners. It covered dealing with feelings about the illness, teaching new methods of setting goals, developing strategies to compensate for cognitive impairments, and improving communication with so-called caregivers. Interestingly the authors note the difficulty of getting primary care physicians to refer clients with disabilities for therapies that have not been proven effective, but there are few proven therapies for clients with disabilities, as most randomized-controlled trials omit people with disabilities (Olkin and Taliaferro 2005). But one implication of this study for therapy is that coping flexibility, not just the number of coping strategies used, seems to be better for coping with long-term problems such as chronic illness or disability.

23.5.1.4 Three Interrelated Studies

Three studies from New Zealand examined the relationship between MS-related fatigue and exercise (Smith et al. 2009, 2011, 2013). The first study (Smith et al. 2009) focused on how exercise influenced fatigue in ten persons with MS (eight female). Results came from analysis of interviews with the participants in an 8-week exercise program. Five themes were identified: listening to your body, perceived control over fatigue, reaching the edge (of limits), the nature of tiredness (good tired or too much), and exercise outcomes. The authors stressed *listening to your body* as critical for persons with MS. The second study then asked nine women with MS how fatigue affected exercise participation (Smith et al. 2011). Interviews with the participants showed that perceived control over fatigue was influenced by seven factors. They recommended asking exercise participants about their *perceived control over fatigue*. In the third study, health-care providers who provided exercise programs for people with MS were asked about their beliefs related to this exercise (Smith et al. 2013). They described their beliefs about *the nature of fatigue* and barriers to exercise, including interdisciplinary conflicts. The authors stressed more *active listening* to clients with MS.

These three studies taken together underscore the complexity of the relationship among MS-related fatigue, beliefs (by the person with MS and by health-care providers), and exercise. MS-related fatigue suggests that listening to your body is critical. Both clients' and providers' beliefs about perceived control over fatigue levels influenced behaviors. And differences across treatment providers in different disciplines need to be addressed to remove barriers. The three related studies provide a composite picture to the understanding of an important question for people with MS. A quantitative study might have used multiple regressions to assess factors influencing exercise in people with MS, but beta values would be less informative than the qualitative results from these studies. The evidence shows that variables are related, but more importantly *how* they are related.

23.6 What Do We Know?

How is our profession doing with regard to these issues of how disability influences clients, awareness of our own attitudes and reactions, creation of barrier free environments, and integration of disability into the case conceptualization? As I look over mainstream rehabilitation journals, I do not find words like social justice, discrimination, and oppression, but rather words like compliance, correlation, and utilization. When I do see an article about stigma, it is most often the stigma experienced by family members of the person with the disability; again, the focus is on the deleterious effects of the person with the disability on the family. Nor do I see much attention to the universality of disability and the disproportionate effects of disadvantaged sociopolitical and economic environments on people with disabilities. There is little knowledge base about the types of microaggressions experienced by people with disabilities, about how they perceive and cope with these microaggressions, or about interventions to reduce the microaggressions. We do not know about the experiences of people with disabilities in therapy—what makes a therapeutic encounter between a client with a disability and an able-bodied therapist either positive or negative?

But let us start small. How many practitioners in private practice work in environments that are wheelchair accessible? How many practicing clinicians could conduct a session in sign language? How might neuropsychological assessments be modified for someone who is blind, how would these modifications be appropriate, and to what norms should they be compared? Are there ways that psychotherapy should be altered or augmented that would make the therapeutic encounter more disability affirmative? What should we be teaching the next generation of therapists?

Let us think a little bigger. Why do so few APA-accredited programs have courses on disability and even fewer on psychosocial aspects of disability (Olkin and Pledger 2003)? Why has disability been relegated to rehabilitation, when most potential clients with disabilities are seen outside rehabilitation settings? Why is disability not part of diversity training? Why do I still hear from students with disabilities that supervisors keep focusing on their disabilities? Why do students with disabilities have more trouble obtaining clinical placements?

And bigger still. How are psychology and disability studies still so far apart (Olkin and Pledger 2003)? Where is the policy advocacy for disability funding and issues on Capitol Hill? In accreditation visits, are programs evaluated on disability accessibility and inclusion, and their diversity classes examined for disability content?

Why is qualitative research so important to all of the questions posed above? It is not that quantitative research could not begin to address some of the issues. For example, a random sampling of private practice offices across the country would yield information about general physical accessibility of such offices. But quantitative studies could not provide insight into why so many therapists work in inaccessible offices, whether they think about it, if they have tried to make changes, and what the barriers are to change. Knowing this information would be more helpful in targeting change behaviors. Regarding therapists with disabilities, the studies on therapy with an able-bodied client and a therapist with a disability have used vignettes or confederates (who are in fact able-bodied and thus do not mimic the micro-movements of people with physical disabilities). Thus, we know very little about client perceptions of therapists with disabilities (Taube and Olkin 2011). Furthermore, we need more information about how therapists conceptualize their clients with disabilities and about the skills required to be culturally competent with this population (Artman and Daniels 2010; Balcazar et al. 2009). As seen in numerous studies cited, the paradigm in which disability is viewed very directly affects case conceptualization and treatment.

What can we learn from studies on evidence-based approaches about working with clients with disabilities? Unfortunately, most studies on therapy outcomes and evidence-based practice rarely include people with disabilities and certainly do not have analyses separately for clients with disabilities (Olkin and Taliaferro 2005). We need to focus less on evidence-based practice and more on practice-based evidence. Although large outcome studies are still considered the best evidence for evaluation of treatments, we are a long way from being ready for such studies regarding

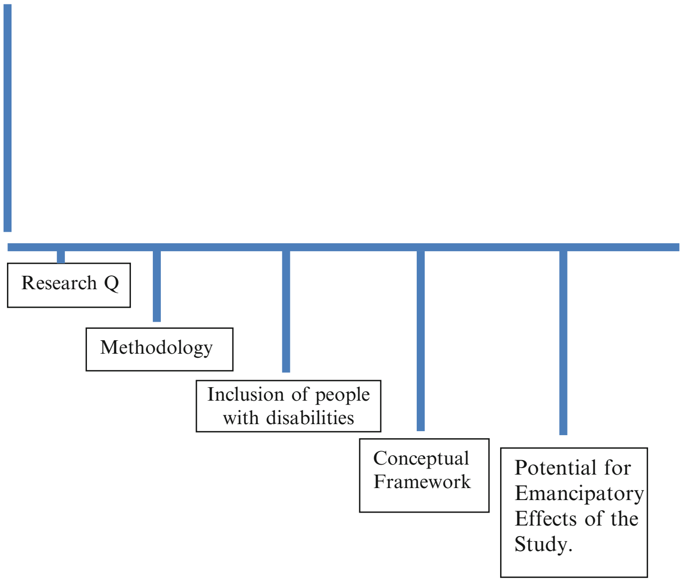

Fig. 23.1 A multidimensional model of disability research

clients with disabilities. There are many aspects to therapy with individuals and families with disabilities that are unknown. A logical study would be to collect the best and worst experiences of clients with disabilities and start to develop themes and categories that might be used to develop theory and practice. On a small scale this was the basis for disability-affirmative therapy (D-AT, Olkin 2008)—observations of my interactions and conceptualizations of multiple clients with various disabilities, with each iteration informed by previous experiences and feedback from clients.

How do the studies reviewed here fit into the five models of disability in two paradigms? I developed those models from an examination of articles in American rehabilitation journals, virtually all of which were quantitative. The models were based on the research questions posed by authors. Thus, the models are unidimensional and categorical. After conducting the review herein, I would modify the models to be multidimensional, thereby considering the research question, but also the methodology, the inclusion of people with disabilities in all aspects of the research, the conceptual framework, and the emancipatory effects of the study (see Fig. 23.1).

23.7 Towards Future Research

There is much we still do not know about the lived experiences of people with disabilities: how are relationships/partnerships formed between persons with and without disabilities; what are the experiences of lesbians and gay men with disabilities; as the population ages and longevity is increased for persons with various disabilities, what is the experience of aging with a preexisting disability; to what extent is abuse a cause or exacerbation of disability; what are the types of and experiences of microaggressions and how are these conceptualized and managed, what are their cumulative effects, and how can we use the knowledge gained to best educate and influence society to alter behaviors towards people with disabilities; how can we support parents with disabilities both as parents and as workers; does D-AT improve therapy outcomes; does D-AT enhance therapy regardless of the clinician's theoretical orientation; how can we improve the interactions across theory, practice, and disability? And importantly, who will fund such studies? Funding is but one obstacle to qualitative research.

Borrowing from earlier work by Asch (1984), I previously (1999) outlined nine factors that continue to constrain research on disability. That updated list would include (a) failure to include more disciplines; (b) underrepresentation of persons with disabilities and an acceptance of outsider research; (c) underrepresentation of ethnic minorities and those with multiple minority statuses; (d) a primary focus on the effects of persons with disabilities on others; (e) funding that privileges traditional rehabilitation- and hospital-based studies; (f) absence of disability studies in psychology; (g) problems in tests, measures, and norms regarding specific populations of persons with specific types of disabilities; (h) an abundance of research on some disabilities and some topics and a paucity on other disabilities and topics; (i) prevalence of research in Paradigm One, with too little research in Paradigm Two; and (j) the general privileging of quantitative studies over qualitative studies.

A key factor in determining the future of disability research is to have people with disabilities set the agendas and control the funding, neither of which occurs currently. An important question is whether people with disabilities would come up with different priorities than professionals. A study in Sweden examined this very question (Erdtman et al. 2012) and found a group of 60 people with disabilities (meeting in smaller idea groups) arrived at priorities that were in fact different from those that had been previously derived by a professional group. The disability groups prioritized *attitudes and beliefs in society, labor and employment, health insurance,* and *outcomes of political decisions*. In contrast, the professional group prioritized *neurology, habilitation, psychiatry, health, care,* and *social medicine*, *labor and employment* were low on the list. Generally, for the disability groups, the "issues tend to pull towards key advocacy areas and less towards research questions" (p. 882). Understanding the fact that the lists and priorities differ is crucial to the process by which the research agenda is set.

An APA Task Force on Enhancing Diversity (2005) made several recommendations for immediate implementation, which included development of ways to train researchers to design, conduct, and evaluate research with diverse populations. This recommendation lends itself to qualitative studies. I would invite researchers not to wait for APA to take the lead, but to work towards undertaking these endeavors themselves. The data are sorely needed.

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24

Qualitative Evidence in Chronic, Disabling Conditions (Childhood- or Early-Onset Physical Impairment)

Laura R. Moll, Cheryl A. Cott, and Stephanie Nixon

24.1 Overview of Aging with Lifelong or Early-Onset Physical Impairment

Advances in health care and technology have extended the longevity of individuals with lifelong (childhood) neurophysiological conditions. Many individuals have benefited from receiving comprehensive pediatric rehabilitation that has contributed to the achievement of functional independence and participation in activities they value (Jahnsen et al. 2002, 2003; Harrison and Stuifbergen 2005; Sandström 2007). However, an expanding number of individuals with traumatic brain injuries, spinal cord injuries, and polio have encountered declines in physical functioning and secondary health issues 10–20 years after finishing rehabilitation (Dean et al. 2000; Bauman and Waters 2004; Colantonio et al. 2004; Harrison 2006). Many individuals with relatively stable lifelong conditions like cerebral palsy and spina bifida have also experienced declines in physical functioning during young and middle adulthood which impinge on their quality of life, maintaining independence, and participating in activities that are important to them (Neri and Kroll 2003; Lutz and Brown 2005; Liptak 2008; Moll and Cott 2013).

The purpose of this chapter is to present a review of the issues that individuals with lifelong and early-onset physical impairments encounter as they grow older. The chapter begins with a description of the literature. The next section differentiates aging and disability from aging with disability. Distinguishing between aging *with* disability and aging *and* disability will be described in order to highlight how our current health-care and rehabilitation policies and practices disadvantage individuals aging with a disability. The next section describes the experience of *impairment and disability as complex and multifaceted*. This section is followed by, one, identifying and describing how *changes in physical functioning* impact aging with a lifelong physical impairment. Gaining an understanding of why social-psychological adjustment is not limited to functional adaptation to one's condition is the focus of the next section. The embodiment of

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physical impairment is the focus of the next section. Access barriers to health-care and allied health services are then discussed, followed by learning about the role of health promotion in the prevention of secondary health problems. The chapter closes with a recap of the findings including implications and recommendations for health-care and rehabilitation policies and practices. Specific attention is given to discussing how the competing needs and issues of seniors and individuals with lifelong physical impairments can be addressed in a climate of increasing health-care costs and scarce resources.

24.1.1 Method of Data Collection

Research on aging with a disability was identified by completing a comprehensive search of ten databases that included CINAHL, PubMed, AgeLine, PsycINFO, Social Work and Sociological Abstracts, Google Scholar, and ProQuest. The search centered on publications from 1995 to 2014. Peer-reviewed studies from gerontology and disability research and transitioning to adulthood are included. The key terms that were used included: functional and health-related changes associated with aging (biological, physiological, medical), engaging in meaningful occupations including ADL and IADL, school and work, identity, adaptation/adjustment, and independent living. The search terms employed were aging and disability, aging combined with each condition, adaptation OR adjustment AND disability, identity AND disability, childhood-onset chronic disability AND aging, and growing older AND early-onset physical disability. All studies that focused on this topic were read and then summarized in a chart to highlight the attributes of each study in order to identify similarities and differences in the use of theoretical frameworks, data collection, analysis, and findings. Central themes were also identified. The references from every study were reviewed to identify other research that did not come up in the database search. Two bibliographies on aging with a long-term disability were searched for relevant studies (Carrothers 2005; Tremblay et al. 1995).

The findings from this literature review were derived from research undertaken in multiple disciplines as well as at different phases of the life course. Peer-reviewed journal articles from rehabilitation, physiotherapy, and gerontology are represented, as well as studies on childhood disability, transitioning from adolescence to young adulthood, and aging with a childhood disability. While it may seem unusual to review pediatric research on disability, many studies provide valuable information to enhance our understanding of the issues they grapple with (Bottos et al. 2001). This body of research is relevant because research has found that some adolescents with childhood disability begin to experience difficulties with physical functioning during late adolescence and upon transition to adulthood (Lankasky 2004; Gall et al. 2006; Young et al. 2006). Consequently, the aging process begins much earlier for these individuals. Case studies were also included as individual accounts of aging with childhood disability increases the credibility of the research that has taken place.

The qualitative studies were assessed for their richness of accountability of the research process, from the conceptualization of the research question (including the theoretical framework) through the boundaries of data collection and analysis (including sample size and its attributes and strategies used for collecting and analyzing the data) to the strategies used to ensure rigor. The articles were read multiple times using a template (developed by the first and second authors) to identify the distinct attributes of each study. The attributes of each study were then transformed into a table for the purpose of comparative analysis in order to identify similarities and differences, shared and/or unique themes and concepts, and implications. Four themes emerged from this process.

24.1.2 A Description of the Literature

To date, the vast majority of research being undertaken has used quantitative methods which typically involve having research participants complete a series of questionnaires that assess their cognitive or psychological well-being including quality of life, as well as the completion of a physical examination by health-care professionals (Andrén and Grimby 1999; Bottos et al. 2001; Charlifue et al. 2004; Colantonio et al. 2004; Zaffuto-Sforza 2005).

Although much smaller, there is an expanding number of qualitative studies that explore the experience of aging with disability, the lived experience of impairment, and psychological adjustment to impairment and disability. These studies tend to reveal the complexities and temporal nature associated with this experience. That is, the experience of impairment changes over time and is influenced by multiple forces that permeate the lives of individuals at micro-, meso-, and macro-levels of organization.

Micro-forces include a person's age at the time of injury/illness, pre-injury/illness coping patterns, and reactions to the consequences of the illness/injury. Meso-forces include the interactions of individuals with impairments with significant others and their social environment. Macro-forces include the social, political, institutional, cultural, and historical contexts that mediate between the other forces (Giele and Elder Jr 1998; Heinz and Marshall 2003; Priestley 2003). As a person with impairment progresses through life, these forces collectively affect self-esteem, identity formation, and construction and reconstruction of biography. The role of these forces provides an in-depth understanding of the broad range of issues, other than physiological changes, that stand alone and interact with one another to disrupt the former patterns of physical and social-psychological adjustment that these individuals achieved earlier in their lives. This body of research provides a more in-depth understanding of the complexities associated with the experience of impairment and disability. The social-psychological impact of aging with disability is captured within the context of the lived experience of disability. The lived experience of disability describes the embodiment of impairment and disability, identity formation and reconstruction, and psychosocial adjustment that is mediated by the interactions that take place between individuals and their external environment including significant others, as well as access to supports and resources needed. The patterns of adaptation that individuals adhere to change over time depending on the social, historical, and cultural contexts they are situated in.

This review is grounded in the comparative analysis of 20 qualitative studies, which included three research papers on consumers' accounts of aging with disability (Lo Surdo 1997; Lankasky 2004; Jones 2009).

The approaches that were used to research these experiences were grounded theory, phenomenology, narrative inquiry, life history/life course research, and participatory action research. The purpose of these studies is to capture the everyday lives of individuals living and aging with physical impairment and the biopsychosocial forces that impede and/or support the long-term independence and participation in valued activities (Neri and Kroll 2003; Smith and Sparkes 2004; Harrison and Stuifbergen 2005; Lutz and Brown 2005). Social-psychological adjustment to physical impairment is a dynamic process that is not limited to the achievement of functional adaptation (Galvin 2005; Lutz and Brown 2005). Six studies focus on how the experience of impairment and disability impacts identity construction and reconstruction as well as achieving and maintaining social-psychological adjustment (Nochi 2000; Galvin 2005). The embodiment of physical impairment was captured by five studies (Tighe 2001; Goodwin and Comptom 2004; Harrison and Stuifbergen 2005; Harrison 2006; Sandström 2007). Forces that impede and/or support aging with a physical impairment were the focus of five studies (Darrah et al. 2002; Neri and Kroll 2003; Harrison 2006; Horsman et al. 2010; Moll and Cott 2013).

All the studies had an adequate number of participants to achieve an in-depth understanding of the topic(s) being explored. They ranged in size from 6 to 92. There was diversity in the types of conditions participants had, as well as the age and gender of participants. For instance, three studies focused on the experience of women (Tighe 2001; Goodwin and Comptom 2004; Harrison 2006) living and aging with polio, spinal cord injury, and cerebral palsy. Three studies explored the experience of disability in adolescents and young adults including both males and females (King et al. 2000; Darrah et al. 2002; Kinavey 2006), while three other studies explored the experiences of adult men and women with acquired physical impairments (spinal cord injury and traumatic brain injury), congenital conditions (spina bifida and cerebral palsy), and chronic disabling medical conditions (lupus and arthritis) (Neri and Kroll 2003; Smith and Sparkes 2004; Lutz and Brown 2005). Only three of the studies were conceptualized using theoretical frameworks (Lutz and Brown 2005; Harrison 2006; Moll and Cott 2013). Nonetheless, the absence of a theoretical framework did not diminish the quality of the findings that emerged from the analysis of the data.

Many of the studies used a variety of strategies for data collection and analysis that gave credibility to the findings and increased the trustworthiness of the information that was collected and how it was analyzed. For instance, data collection in four studies involved multiple interviews (ranging from two to five) with each participant (Harrison and Stuifbergen 2005; Harrison 2006; Horsman et al. 2010; Moll and Cott 2013). Most of the studies used a variety of strategies to increase the trustworthiness of the analysis of the data and ensure rigor (Harrison 2006; Horsman et al. 2010; Moll and Cott 2013). For example, the study on social support (Gall et al. 2006) had the research team review all transcripts and generate a coding scheme which was revised several times through ongoing discussion. The researchers invited participants to a group session to provide feedback on the findings. In the study on perceptions of health-care service delivery (Darrah et al. 2002), participants were invited to a town hall meeting to give feedback on emerging themes, and transcripts were read by all authors and an undergraduate rehabilitation student to verify the issues that were raised in the town hall meeting. Participants were also mailed a copy to give feedback. These strategies were also used by two studies that were derived from larger quantitative studies (Darrah et al. 2002; Neri and Kroll 2003). The methods used by a few of the studies were not explicitly defined; however, the authors provided detailed accounts of the strategies that were used in data collection and analysis (King et al. 2000; Tighe 2001; Darrah et al. 2002).

24.2 Differentiating Aging and Disability from Aging with Disability

The issues that individuals with lifelong and early-onset physical impairment encounter are a relatively new phenomena that are challenging the resources and practices of the disability and gerontology fields. Disability is a term that describes the challenges faced by individuals with physical or cognitive impairments that may affect their ability to perform multiple activities of daily living, which in turn may have an impact on their ability to participate in mainstream society (World Health Organization 2002). Until very recently, our understanding of disability and aging was limited to the onset of disability in old age, or *aging and disability* (Gilson and Netting 1997; Tremblay et al. 1997; Putnam 2002). However, in the presence of advanced medical technology and increased life expectancy, many individuals with a lifelong or acquired physical disability are now reaching middle and old age, or *aging with disability* (Priestley 2003; Kemp and Mosquida 2004). We have limited knowledge about the supports and resources that are needed to maintain the functional independence, psychosocial well-being, and quality of life of people with lifelong disability as they transition into adulthood and old age (Lankasky 2004; Zaffuto-Sforza 2005; Hilberink et al. 2007).

Over the past 30 years, there has been a growing awareness of the issues of aging for individuals living with physical impairments acquired in late adolescence and young adulthood as a consequence of conditions such as polio, spinal cord injury (SCI), and traumatic brain injury (TBI). Ten and twenty years after completing rehabilitation, in midlife, many are encountering declines in function and secondary health problems that are usually associated with aging. The functional declines associated with aging coincide with limitations in activity (activities of daily living [ADL] and instrumental activities of daily living [IADL]) and threaten these individuals' ability to participate in daily life and to continue to fulfill the roles and responsibilities associated with work, social, family, and leisure activities (Colantonio et al. 2004).

Even less attention has been paid to issues of aging for those individuals aging with lifelong physical impairments such as spina bifida and cerebral palsy (CP) (Bottos et al. 2001; Hilberink et al. 2007). The experience of growing up and growing older with lifelong physical impairment (aging *with* disability) is different from that of aging and acquiring physical impairment in adulthood (aging *and* disability). Individuals with lifelong physical impairments may not have had the same opportunities as others without impairment to achieve traditional social milestones (such as graduating from high school, embarking on a career, marrying, and having a family), establish strong social support networks (through work, family, and friends), and accumulate the financial resources needed to support themselves in old age (Wilkins and Cott 1993; Bigby 2002). Furthermore, the patterns of physical and psychosocial adaptation individuals with lifelong physical impairments achieve in early life may not be suitable for maintaining long-term independence due to changing abilities with age, changing life circumstances, and changing access to support and resources such as health care and rehabilitation.

The narrow scope of the current research on aging with disability presupposes that the foundation of the quality of life and well-being of an individual living with lifelong physical impairment rests on the achievement of functional independence while paying much less attention to a multitude of factors that contribute to overall well-being, such as developing social, psychological, and intellectual capacities (Wiart and Darrah 2002; Priestley 2003). Further, by placing the emphasis on functional independence, the focus of research on aging with disability locates the source of difficulties encountered within the individual, ignoring the important role of the social environment in shaping the experiences of growing up and growing older with physical impairment.

Individuals who are aging with a physical disability may include people (including the first author) who have/are living with spina bifida, polio, spinal cord injury, cerebral palsy, or traumatic brain injury. Each condition presents a specific set of residual consequences or impairments that can impact a person's ability to negotiate and participate in mainstream society. Even though there are physical impairments associated specifically with each condition, the complexity of the phenomenon of disability means that individuals living with the same physical impairment may not experience the same disability. To put it another way, two individuals living with the same physical impairment will have different life experiences (Lezak 1988; Crawford 1996) and therefore may experience different levels of disability. The complexity of this experience is depicted by the interaction between an individual and his/her environment. An understanding and awareness of the issues that many of these individuals confront was first identified in research on persons with intellectual disabilities (Ansello and Eustis 1992; Tremblay et al. 1997; Gill 2001). The changes experienced by these individuals facilitated research on the secondary and health-related issues confronted by individuals living with other conditions (Tremblay et al. 1997; Neysmith 1999).

Of the literature that has looked at aging with a physical impairment and disability, most has been limited to identifying the functional limitations that are associated with the aging process (Kemp and Mosquida 2004; Liem et al. 2004; Hitzig et al. 2008). Studies have found that many individuals living with a physical impairment and disability have experienced premature aging that impinges on their overall well-being (Pentland et al. 1995; Dean et al. 2000; Kemp and Mosquida 2004). For example, recent studies have found that individuals who are living with spinal cord injury, traumatic brain injury, cerebral palsy, spina bifida, or poliomyelitis are confronting secondary conditions concurrently with age-related declines characteristic of the final stage of development, in midlife. These changes can compromise both their well-being and quality of life by disrupting former patterns of adaptation and participation in activities related to work, family, daily living, and leisure (Pentland et al. 1995; Gilson and Netting 1997; Kemp and Mosquida 2004). Individuals living with polio have received a great deal of attention as many of them have experienced what has been diagnosed as post-polio syndrome, 10–40 years after the recovery from polio (Schanke 1997; Perry 2004; National Institute of Neurological Disorders and Stroke 2004). Symptoms include fatigue, slowly progressive muscle weakness, muscle and joint pain, and muscular atrophy. Individuals living with spinal cord injury are confronting similar disruptions in living as they age, as many of these individuals are susceptible to experiencing one or multiple health-related problems. These include infections due to pressure sores and changes in bowel, bladder, and respiratory capacities, as well as the development of arthritis—often in the shoulders—due to the repetitive strain required to operate a manual chair and perform transfers. These individuals are also more susceptible to bone fractures in their lower extremities due to inactivity and decreased bone density (Pentland et al. 1995; Bauman and Waters 2004). Some secondary and/or health-related changes have also been identified in individuals living with TBI (Dean et al. 2000; Colantonio et al. 2004), yet less is known about those aging with spina bifida. Despite these findings, there is no certainty that every person living with a physical impairment will develop secondary problems as they age.

24.3 The Experience of Impairment and Disability Is Multifaceted

This theme captures both the complexities and temporality associated with the experience of impairment and disability. That is, the experience of an individual is mediated by multiple social and environmental forces that interact with one another at micro-, meso-, and macro-levels of organization.

This dynamic process is embedded in a symbolic interactionist perspective (Blumer 1998). Symbolic interactionism describes how individuals assign meaning to objects and situations that are important to them and the actions that are associated with those meanings. That is to say, the meaning they ascribe is an outcome of their interactions with others, as well as how they interpret the situations with which they are confronted. These interpretations also serve to guide their behavior, which also impacts how they see themselves through the eyes of significant others (Blumer 1998; Galvin 2005). Therefore, the meanings people assign when confronted with impairment and disability impact their adjustment to their experience. Consequently, the self-orientations that people adhere to are shaped by how they experience the world around them and how they perceive themselves through their interactions with others. At the microlevel, for instance, the attitudes that individuals possess toward having impairment can negatively or positively impact how they negotiate life with impairment. Therefore, individuals who have a positive outlook on their lives will be more successful in achieving physical and emotional adjustment to their circumstances as well as pursuing new opportunities than individuals that have a negative outlook on life (Livneh and Antonak 1998; Smith and Sparkes 2004).

Many studies found that individuals' ability to adjust to their circumstances, lead meaningful and productive lives, as well as reconstruct their self-identity is mediated by forces at all three levels of organization. Collectively, they impact the patterns of adaptation individuals adhere to which supports diverse outcomes that parallel the outcomes associated with individual forces. These experiences were captured by a number of studies (Smith and Sparkes 2004; Galvin 2005; Harrison and Stuifbergen 2005; Lutz and Brown 2005).

Kinavey (2006) found that young adults with spina bifida adhere to one or multiple self-understandings which involve diverse patterns of adaption that are adaptive or maladaptive, while Smith and Sparkes (2004) found that the participants in their study used one or multiple narratives—as conceptualized by Frank (1996)—that parallel those identified by Kinavey (2006) and which are used to make sense of their experience. These self-orientations change over time in response to how they experience the world around them. The circumstances and contexts in which a person finds himself/herself will influence the self-orientation(s) that he/she favors. Consequently, living with a physical impairment is not as difficult as negotiating the physical, social, and attitudinal barriers that individuals encounter in their external environments (Galvin 2005; Lutz and Brown 2005; King et al. 2006a).

24.4 Changes in Physical Functioning

The studies on aging with disability found that research participants encountered unexpected and gradual declines in physical functioning usually characterized by chronic pain, increased fatigue, and difficulties with walking. These changes typically occurred during late adolescence and midlife (between 40 and 50 years old) (Neri and Kroll 2003; Harrison 2006; Horsman et al. 2010; Moll and Cott 2013). Many individuals with CP tended to notice changes in their abilities during late adolescence and young adulthood, at a time in their lives when comprehensive rehabilitation and health care was no longer available to them. At the same time, many individuals with early-onset physical impairment from polio, spinal cord, or traumatic brain injuries found that they began to encounter difficulties with physical functioning 10, 20, or 30 years after rehabilitation (Neri and Kroll 2003; Harrison 2006; Young et al. 2006). Many research participants found that activities they could once do with ease were taking much longer to complete and in some instances required assistance as they could no longer be performed independently in a timely manner (Sandström 2007; Moll and Cott 2013).

Individuals who encountered difficulties walking often made the decision to use mobility aides such as a cane, walker, and/or wheelchair in order to reduce fatigue and minimize the pain associated with secondary health problems and changes in musculoskeletal structure. Overall, the early onset of these physical changes resulted in finding it more difficult to manage and regulate their bodies. Many individuals found that the changes to their bodies disrupted their daily personal, professional, and social routines (Tighe 2001; Neri and Kroll 2003; Lankasky 2004; Harrison 2006; Horsman et al. 2010; Moll and Cott 2013). It was not uncommon for individuals to alter their work schedule or retire from their career as well as disengage from other roles and responsibilities they performed (Lankasky 2004; Lutz and Brown 2005; Harrison 2006; Sandström 2007). Some individuals found themselves unable to achieve specific social milestones, while others had to withdraw from activities they valued (Lankasky 2004; Harrison 2006; Moll and Cott 2013).

24.5 Social-Psychological Adjustment Is Not Limited to Functional Adaptation to One's Condition

This theme captures the idea that achieving functional adaptation to the limitations associated with one's condition is but one piece of the larger puzzle. All individuals have certain needs throughout their lives that are essential to their overall well-being (Maslow 1987). These needs constitute achieving a sense of belongingness that includes: the formation of meaningful interpersonal relationships through the development of intellectual, cognitive, and emotional attributes; engaging in activities that bring meaning to their lives; access to supports and resources, such as attendant care, adaptive technology, and mobility aides; and having access to health-care and rehabilitation services that enable them to manage life with impairment. Therefore, developing and maintaining adaptive patterns of social-psychological functioning do not rest on rehabilitation alone.

Most studies emphasized the importance attached to being engaged in meaningful roles and activities and the importance of staying physically active to maintain functional abilities and health. Having a variety of supports available was also highlighted as contributing to physical and emotional well-being.

In two studies, King et al. (2000) and King (2006) found that receiving three kinds of social support was essential for achieving these outcomes. Emotional support is extremely important because it provides a sense of belonging and intimacy that impacts one's self-esteem through interaction with others. Instrumental support—advice and practical assistance—can enhance a person's self-confidence and support feelings of self-efficacy. Cognitive support can also improve a person's self-concept and perceptions of the world around him/her. It is through interactions with others that individuals make sense of the world by the meanings that they attach to how they interpret the way that people react to them. The meanings they assign affect the development of self-concept and feelings of competency. A lack of support, or receipt of negative support, can lead to positive outcomes in life as well; some participants approached these experiences by becoming motivated and determined to achieving meaningful and productive lives.

Goodwin (2004) found that remaining physically active and engaged in living was regarded as being important to the overall well-being of her research participants. Staying physically active (including ADL and IADL) was considered important because it served as a mechanism that would prevent and/or prolong the onset of secondary health problems and declines in function and therefore support the physical and social-psychological well-being of an individual.

Even though Goodwin's (2006) research participants were relatively healthy at the time they were interviewed, Harrison's study (2006) reveals that the positive outcomes associated with rehabilitation have short-term benefits given that individuals with impairments are reaching old age. That is to say that once individuals complete rehabilitation, they return to their communities without knowing what to expect as they grow older or are unequipped with the information or resources they need to maintain their achievements long term. This creates a problem because medical and rehabilitation practices that were provided to facilitate the recovery from polio, for instance, emphasize the achievement of normative functional adaptation.

Unfortunately, striving for normalcy places an enormous amount of pressure on individuals to conform to societal standards and gender-specific roles in order to maintain their independence and full participation in daily life. This hinders individuals with impairments in being able to strive for their potential while simultaneously being able to look after themselves through modified work environments and flexible schedules, access to healthcare and rehabilitation, and rest to rejuvenate their physical abilities. Being successful in the face of adversity tends to provide a person with the incentive to pursue new opportunities and establish higher expectations of themselves without being able to receive programs and services to support them in these endeavors (Galvin 2005; Harrison and Stuifbergen 2005).

24.6 The Embodiment of Physical Impairment

The embodiment of disability recognizes the subjective and lived experience of impairments as an outcome of the connection between the body and the social world in which a person is situated (Wendell 1996; Barnes and Mercer 2003). This means that the experience of a person is influenced by how he/she experiences his/her body with respect to supporting and/or interfering with participating in daily living, due to the limitations or restrictions related to changes in body structure and function that are a direct consequence of the impairment and any secondary conditions attached to it (Stewart 2002). Spasticity, pressure sores, fatigue, and pain often accompany the primary physical condition (Wendell 1996; Barnes and Mercer 2003; Harrison 2003; Lutz and Brown 2005).

Living with a physical impairment coincides with developing strategies to manage these secondary issues so they can engage in meaningful activities (Lo Surdo 1997; Tighe 2001; Lankasky 2004). Many individuals have spent many years doing that successfully; however, living with an altered body tends to regulate the level of independence and participation a person achieves and maintains. The presence of pain and fatigue, for example, takes away a person's ability to exercise control over his/her body, which interferes with daily living. It is important to note that the altered body's ability to support an individual in daily living changes from day to day and week to week is mediated by the number of responsibilities and activities in which he/she is engaged. A heavy work schedule 1 week can place more stress on the body than weeks characterized by a lighter agenda. Also, the trajectory of living with a physical impairment can be unpredictable and unfolds differently for individuals living with the same or different conditions (Tighe 2001; Harrison 2003; Goodwin and Compton 2004; Lankasky 2004; Lutz and Brown 2005). This experience can be exacerbated when secondary health problems unrelated to the primary condition develop.

This experience was captured by many of the studies and was considered to have an impact on self-perceptions and self-identity. For instance, Harrison (2006) found that the achievement of functional adaptation to the consequences of polio provided her participants with the incentive to pursue personal and professional goals and aspirations by "willing the body to achieve potential," while conflicts between self and body were confronted when the women began to experience declines in function due to post-polio in later adulthood. These changes coincided with not being able to engage in personal and professional activities in the same way they did when they were younger. These changes also threatened their self-identity and earlier success as they were losing control of their bodies (Harrison and Stuifbergen 2005).

Perceptions of a dys-appearing body and perceptions of a not-appearing body distinguish between having a body that is plagued with symptoms that impose restrictions on participation as opposed to a body that supports it as reflected by the second theme (Sandström 2007). Therefore, the subjective experience of impairment impacts participation and restrictions, as well as the construction and reconstruction of self-identity. It is important to note that the reconstruction of self-identity is not limited to the experience of impairment as it is simultaneously nurtured through interactions with others in everyday life. How individuals feel about themselves is a product of how their physical and social attributes are perceived, validated, accepted, and/or rejected by people in their social environment (Seymour 1998).

Living with a physical impairment not only changes the physical appearance of an individual but also disrupts their ability to maintain their body on a daily basis (i.e., personal hygiene). It is therefore difficult to separate the two. Consequently, the social-psychological issues with which individuals with impairment grapple are influenced by their experiences with impairment and disability and the interaction between the two.

24.7 Barriers to Health-Care, Rehabilitation, and Allied Health Services

During childhood and adolescence many individuals with lifelong physical impairment have benefited from comprehensive rehabilitation as it contributed to achieving functional independence which, in turn, supported participation in meaningful activities and the pursuit of personal and professional goals (Harrison and Stuifbergen 2005; Harrison 2006; Moll and Cott 2013). Transitioning to adulthood presents a new set of issues with which individuals with childhood-onset physical impairment and their families grapple. Not having access to information and resources that will support these individuals in maintaining meaningful lives is just one of the issues they have (Tighe 2001; Darrah et al. 2002; Neri and Kroll 2003; Lutz and Brown 2005). Participants in Darrah's (2002) study felt that physicians did not respond to their inquiries or provide them with information they could benefit from, such as community programs (health care), funding for assistive devices, and mobility aides. Others felt that they were not prepared to know what to expect in adulthood especially when it came to navigating the adult health-care system (Tighe 2001; Young et al. 2006; Horsman et al. 2010).

Preparing adolescents to transition into adulthood and the adult health-care system are becoming more common practices among pediatric rehabilitation centers both in Canada and the United States (Kingsnorth et al. 2007, 2010). Even with these programs in place, there are significant issues and barriers that individuals with childhood-onset physical impairment continue to encounter that negatively impinge on their social-psychological well-being and participation in daily living. Many individuals have found that, upon transition to adulthood, they were discharged from pediatric care without having a physician and were unable to navigate the adult care system (Darrah et al. 2002; Horsman et al. 2010; Moll and Cott 2013). Another issue that participants struggled with was that, when a physician was approached due to health concerns, they found that doctors didn't have the knowledge, training, or experience in treating adults with childhood-onset disability nor were their issues taken seriously. Sometimes their concerns are perceived as disability-related issues. For example, Horsman et al. (2010) found that:

> Participants expressed fear and frustration, stating that information about what to expect when growing older with CP would be helpful: 'And the doctors don't have a clue so I guess as far as aging with CP, it would help if somebody could say this is aging with CP and this is what's not . . .' (Barbara). (Horsman et al. 2010, p. 299)

While many individuals with childhood-onset physical impairment may have the knowledge and skills to access the resources and supports they need, the adult health-care system is not structured to respond to their long-term needs. Aging with a physical impairment is a relatively new phenomenon, as 30 years ago many individuals with lifelong and early-onset physical impairment had a shorter life span than they do today. Traditionally, health-care policies, programs, and rehabilitation were developed to respond to specific developmental phases according to age. Today there are individuals with disabilities who have benefited from disability funding and services but now find themselves experiencing secondary health problems that have disrupted their lives. They may benefit from senior services due to the problems they are having, but they do not qualify because they have not reached retirement age (Priestley 2000; Tighe 2001; Bigby 2002; Priestley and Rabiee 2002; Naidoo et al. 2012). The challenges that these individuals encounter make it very difficult for them to achieve and maintain both their physical health and their social-psychological well-being when the appearance of secondary health problems impose specific activity limitations that negatively impact the completion of basic activities of daily living and participating in activities they value. These changes also contribute to increased health-care costs and a client group that will be a burden to society, which could be reduced with appropriate supports and resources (Neri and Kroll 2003; Lutz and Brown 2005; Moll and Cott 2013).

Many individuals encounter environmental barriers at different times in their lives that challenge these achievements and negatively impact their social-psychological and physical well-being. All the studies found that participants encountered one and/or multiple environmental barriers at different times in their lives that made living and aging with impairment difficult (Tighe 2001; Galvin 2005; Harrison and Stuifbergen 2005; Harrison 2006). For instance, difficulties accessing information, knowledgeable and caring professionals, health-care and educational support programs on a consistent basis made it difficult for adolescents and young adults with cerebral palsy to achieve their potential through developmental and social milestones (Darrah et al. 2002). This challenges them in developing the skills they need to successfully transition to adulthood and being able to negotiate the world around them.

Neri (2003) found that access barriers to health care have a ripple effect on living and aging with a physical impairment. Barriers to health care affected five areas/domains of their lives: physical, psychological, economic (additional health-care costs and loss of income due to illness), social, and independent living (declines in abilities to engage in activities of daily living and/or work and increased dependence on others). That is to say that the consequences associated with access barriers to health care were very complex, overlapping, and impacting one another. For instance, not having access to physiotherapy for acute conditions, the maintenance of functional abilities, and prevention of secondary problems would often coincide with physical deterioration which impacted a person's ability to care for themselves, complete ADL and household activities, as well as taking time off work. Some individuals also experienced secondary health problems that could not be improved when treatment was available. In other instances, many individuals experienced declines when repairs to durable medical equipment (DME) could not be done in a timely manner. Failure to access what they needed had a significant impact on their psychosocial well-being, as the circumstances created unnecessary physical and financial consequences that could not be regained once lost.

24.8 Health Promotion and Prevention of Secondary Health Problems

Exercise and physical activity are considered important for maintaining independence and reducing the risk of secondary health problems (Goodwin and Comptom 2004; Harrison et al. 2010). The experience of fatigue and pain that many of these individuals experience impacts the kind and frequency of physical activity and exercises in which they can engage. Researchers have found that women injured in late adolescence or young adulthood are more likely to engage in health-promoting activities than individuals with childhood-onset physical impairment. The differences are attributed to being provided with health education. Many individuals with childhood-onset physical impairment haven't received health education or been taught about the conditions that would threaten their long-term physical well-being and independence (Harrison et al. 2010; Moll and Cott 2013). Another barrier to maintaining long-term health and well-being is not having access to fitness centers that are physically accessible, equipment they can use, and fitness trainers who are knowledgeable about the physical activity needs of people with disabilities.

24.9 Conclusion

The review of qualitative research on individuals aging with a childhood- or early-onset physical impairment reveals that living and growing older with a physical impairment can lead to achieving a meaningful life. However, the unfolding lives of these individuals were impacted by the interaction with their embodied experience of impairment with their external social environment and significant others. Therefore, the patterns of social-psychological adaptation they adhered to (adaptive or maladaptive) were a consequence of the supports, resources, and opportunities available to them as they grew up and grew older (Moll and Cott 2013). Many of these individuals grew up to have families of their own, have careers, and participate in valued activities.

Despite these achievements, many individuals encountered unexpected declines in functioning, as well as secondary health problems that disrupted these endeavors while in their prime or impeded others from achieving these outcomes upon transition to adulthood. Loss of income associated with early retirement, and declines in functioning placed great demands on social services, health care, and rehabilitation. Since it is more likely that individuals with preexisting physical impairments will reach old age, it is paramount that health and rehabilitation policies and practices be adjusted to meet the needs of individuals with childhood- and early-onset physical impairment across the life span. Adopting this approach is important as it could be more cost effective for health care and rehabilitation, because having access to necessary services and resources could prevent and/or slow down the early onset of secondary health problems (King et al. 2006b).

What is also distinct about all the studies is that the experience of impairment overlapped with the experience of aging and disability. That is to say, how the body was experienced by an individual influenced restrictions as well as capacity to participate in daily living. Capacity was mediated by the degree to which secondary conditions associated with impairment interfered with and/or supported participation. These conditions were an outcome of living with a body that was asymmetrical and was managing the pain, stiffness, and spasticity that usually accompanies neurological conditions such as cerebral palsy. When secondary health problems are added to the primary condition, former patterns of physical and psychological well-being are threatened. The external environment impacts this experience in two ways: it creates and sustains barriers to participation in one or multiple areas of one's life that are structural and attitudinal in nature.

The ways in which individuals experience interactions with others can either impinge and/or support the development of a positive self-concept which also impacts social-psychological well-being and engaging in meaningful occupations. It is also important to consider that the issues that individuals grapple with when growing older with a physical impairment are an outcome of not being able to continue to conform to the normative standards associated with being male and female. It seems apparent that the successful achievement of normative patterns of functioning that enable the participation in gender-specific roles associated with adulthood, accompanied by a premature loss of these abilities, seems to be at the heart of social-psychological attributes associated with aging and impairment (Tighe 2001; Goodwin and Comptom 2004; Harrison and Stuifbergen 2005; Sandström 2007).

The growing number of challenges and health issues that these individuals are encountering has facilitated discussions, research, and forums among policymakers, health professionals, individuals with childhood- and early-onset physical impairment, as well as other stakeholders, to develop initiatives to address the needs and concerns of these individuals as well as reduce the gaps between services for seniors and disability services for those aging with a physical impairment (Bigby 2002; King et al. 2006b; Naidoo et al. 2012). While eradication of our current policies and practices for both these client groups is not feasible, other initiatives have been explored to meet the long-term needs of individuals with childhood- or early-onset physical impairment. Any changes that are made to improve their circumstances can be beneficial to other client groups, such as individuals growing older with complex chronic illnesses like diabetes, asthma, or cardiovascular disease. Policymakers, researchers, and health professionals have been advocating for establishing partnerships between disability services and organizations and seniors services. Some changes that have taken place in Ontario are that Community Care Access Centres (CCACS), which oversee in-home health-care services, are now providing services to children and young adults for as long as they need it. Also, pediatric rehabilitation centers make it possible for former patients to come back to be fitted for ankle-foot orthotics (AFO) if they don't have access to the service in their community. Collaboration between all stakeholders and between pediatric and adult care systems is being encouraged. Several researchers and health-care and rehabilitation professionals are encouraging a shift in policy formation and services and programs to constitute a continuum of care rather than using the traditional phases of development to organize and deliver services, programs, and resources. Looking beyond childhood has become very important. Some community organizations have life care planning programs. Improving the long-term well-being of these individuals is not just about making these changes. Professional education and training needs to be available to individuals considering a career in health-care, rehabilitation, or research. Finally, reducing the dependency of these individuals rests on making education and information available to them.

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Part III

Using Qualitative Health Research to Improve Health

What Use Is It Anyway? Considering Modes of Application and Contributions of Qualitative Inquiry

25

Janice M. Morse

25.1 Introduction

Last week I sat in a conference listening to several presentations back to back about implementing qualitative research in the clinical setting. Each of the presentations reported a failure. I moved to the microphone. "*When are we going to listen to our evidence*?" *I asked*. "*All of the evidence points to our research as* not *being implemented*."

Something is wrong. For many years I have been concerned about the low funding rate for qualitative inquiry, as well as the meager dollar amount granted for the awards. It often seems that qualitative research is only funded if it is "tacked onto" a quantitative project, or couched within a mixed method study. This speaks volumes about the way the scientific community values qualitative inquiry. Perhaps that is the reason our research is not noticed or valued.

Several years ago, Sandelowski (1997) noted that qualitative inquiry must "be of use" if it is to be worth doing, and this is particularly true in applied fields in health, mainly medicine and nursing, which are often physiologically or epidemiologically oriented, and based in quantitative inquiry. Of greater concern—if the development of knowledge and theory building is considered the primary use of qualitative inquiry, and if we privilege the criterion of usefulness as *application*—is that qualitative inquiry may be devalued and overridden by other methods. Clearly, application to practice is something we are not doing very well. Why?

In this chapter, I do not argue that the basic contribution of qualitative inquiry to knowledge is unimportant, but rather argue that this basic contribution to knowledge does not preclude application of this knowledge to practice. I suggest that qualitative researchers ourselves are guilty of, and in part to blame for, this lack of appreciation for qualitative inquiry, for as researchers we undervalue and underestimate the strength of qualitative inquiry. We fail to generalize, to cite each other, and sometimes do not even use our own research incrementally, purposefully building research programs that target application.

I suggest here that with individual projects we do not extend our findings *far enough* for the practitioners to use or for quantitative researchers to take seriously and use as a foundation or their inquiry. By far enough, I mean that we cease our investigation before we have made concrete recommendations with practical instructions for the clinicians, and before we have provided enough data for applied researchers to set up a program to implement, test, and make a standardized part of practice. This leaves the clinicians who read our articles thinking, "Oh, how interesting, but so

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what?" It leaves our research in limbo, stuck in journals unread and waiting for the inevitable 5 or 10 year expiry date, only to find some time later that our studies have been replicated and our findings rediscovered (Morse 2003).

But I go further. I suggest a solution, an advocate—a new clinical role for a nurse to be responsible to oversee the implementation of changes from our research.

25.2 Types of Contributions for Qualitative Research

When we examine the research programs of qualitative researchers who have made important contributions, we find they may be categorized into three groups: (1) by individual projects; (2) a lateral research program (multiple projects) by scope; and (3) an incremental research program (multiple projects), addressing a particular problem.

The first type of qualitative research that may be applied is the most common unit of qualitative research—the single publication. As our "use" criterion demands that each article or book must have some level of relevance and application, and often these are unique and do not interface with the work of others, they often pass unnoticed in our growing number of journals.

The second group has conducted significant projects within a general area, developing knowledge piece by piece, laterally, and even developing a subfield. An example of such contribution is that of Arthur Kleinman (Collins 2011), who developed a field combining medical anthropology, psychiatry, culture, and health. His interests have ranged from the illness experience (Kleinman 1988), social suffering (Klienman et al. 1997), global health (Kleinman 2010a; Kleinman et al. 2008; Farmer et al. 2013), and caregiving (Kleinman 2010b). These are all important works complete in themselves, but they occur in different (but complementary) domains around a central area of inquiry.

The third type is *an incremental research program*, and this of equal importance. It consists of a targeted (and funded) research program, comprising a number of related projects in a particular substantive area. These projects focus on a particular problem, and work towards an intervention. These programs of research are therefore less broad in scope than the second type of program. For instance, Beck systematically studied postpartum depression for a number of years, beginning with phenomenological studies on postpartum depression (Beck 1992, 1993), and conducting a meta-analysis of predictors of postpartum depression (Beck 1996). Next, with a collaborator, Gable, they developed a screening scale for post partum depression (Beck and Gable 2000), compared its performance with other instruments (Beck and Gable 2001a), conducted further validation (Beck and Gable 2001b), and published a Spanish version of the scale (Beck and Gable 2003). From this it is clear the value of qualitative inquiry—indeed the validity of the subsequent quantitative studies rests on the foundation of the qualitative theory developed in the first projects. Both the second and third types of qualitative research programs consist of numerous articles and sometimes even books, all complete in themselves. They are most effective and have most impact as a group created by individual researcher. We do not always respect the work of a single researcher in qualitative inquiry, denigrating the research as one who "only cites themselves" (even if there is not other work to cite). Further, as Beck (2013) notes, such incremental work by a single investigator is quite uncommon.

25.3 The Single Qualitative Study

I began this chapter by suggesting that our primary task in qualitative inquiry is to develop knowledge that will contribute to practice. Yet, because a single qualitative study is limited in scope, application of findings may not be achieved in one study, as it may take several sequential studies to achieve this aim. However, our studies are often very descriptive, and therefore close to practice. There may be other problems that impede application. Some have blamed the practitioners for not using the research literature. However, I suggest an alternative view: that qualitative researchers are hesitant in trusting their own findings and therefore hesitant to recommend that others apply them or use them to change practice. In the final part of this article, I will suggest some strategies to facilitate integration of qualitative inquiry into practice.

25.4 How Bad Is the Problem?

As qualitative researchers, we have been carefully taught several criteria that have impeded our own perception of the worth of our studies, but these are criteria that are, in fact, not correct. The worst is "Qualitative research is not generalizable" (Morse 1999; Hall 2013). At no time do we expect qualitative research to be generalizable in the quantitative sense, but the findings and the theory produced from qualitative inquiry is generalizable by abstraction at the level of concepts and theory, and by linking these findings with the concepts and theories of others. In other words,

> the knowledge gained is not limited to demographic variables; it is the fit of the topic or the comparability of the problem that is of concern […] it is the knowledge that is generalized.
>
> (Morse 1999, p. 6)

This is an exceedingly powerful form of generalizability, for once we develop, for instance, a concept that others can recognize, it becomes evident everywhere; once we develop an applied theory, it becomes essential. We have seen this with much qualitative inquiry—consider, for instance Goffman's work on stigma (1963/2009) and the subsequent impact that it has had on health care in the past two decades.

But I must agree that there is a difference in the years of work Goffman put into his work on stigma (a type three research program) and the monographs he published, and the scope of some of the single 15+ page articles we see published in as qualitative research. Some of these published studies often have little cognitive/theoretical development, have small samples, descriptive findings that are obvious, and therefore contribute little. I agree that it is hard to produce *enough* qualitative articles to make tenure, when there is little appreciation for the amount of unseen cognitive work that goes into micro-analytical description or good interpretative qualitative inquiry. The system, in part, does work against us.

But even if we have a solid theory, with innovative findings, those findings often remain at the theoretical level. We tend to consider theory as the outcome—we do not attempt to move the findings back into the practice arena and provide the detail necessary for practitioners to actually use our work. We are researchers, after all. So we describe our theories in an interesting form and as generalizable knowledge—*but not in a useable theory or form* that may actually be applied in a program or policy.

Thus, it seems that qualitative researchers truncate inquiry before they have actually finished or pushed the conceptual results as far as possible, back to application.

I asked: How bad is this problem? I surveyed practice-oriented journals looking for qualitative articles published in a 1 month period, and reviewed these articles for detailed recommendations for implementation.[1] Because of this method of sampling, the articles addressed a variety of topics and many issues. Some of the journals spotlighted the implications in a bordered callout (for instance, the *Journal of Advanced Nursing* inserts them as a bulleted list in a callout box titled "Implications for practice and/or policy"). But mostly the implications for caregivers are hidden in the Discussion section or in the Conclusions of the article. For example, in the callout of an article describing diabetic immigrants self-care with cardiac rehabilitation (Nielsen et al. 2012), the callout for "Implications for Practice or Policy" reads:

> - Understanding the interplay of multiple identities held by immigrant participants will allow clinicians to better understand how to support adoption of cardiac rehabilitation recommendations to mitigate cardiovascular risk.
> - Nurses should probe beyond standardized assessment forms to identify and reinforce immigrants' creative and effective approaches to diabetes self-care and cardiac rehabilitation.
> - Nurses should advocate for health services that address immigrants' needs better, such as offering cardiac rehabilitation programmes and materials in other languages and targeting cardiac rehabilitation referrals to immigrants.
>
> (Nielsen et al. 2012, p. 2726)

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[1] This is an excellent exercise for a class to do, when exploring application.

These implications are at best, principles for the provision of care, and are too far removed from everyday practice to actually provide guidance for practitioners. These recommendations must be pragmatic, precise and clear.

25.4.1 The "Shoulds," the "Oughts," and Our "Need to Realize" the "Suggestions"

When we examine qualitative articles for recommendations for practice, the most striking characteristic of such articles is that the findings are written in a soft and non-directive way. Authors *suggest* in generalities what nurses *ought* to do as general principles, and the recommendations for patients' needs are not specifically identified. Many suggestions are in the realm of common sense, are not new, and do not seem to be linked directly from the data presented to the project to the clinical setting or patient care. Some of the findings are so obvious that it is unclear why a study had been conducted at all, or else the findings fail to inform the reader. For example, the primary recommendation for Marshall et al.'s (2012) study on patient's views about patient-centered care, was the obvious recommendation that "Patients must be included in the discussion around patient-centered care." (p. 2671). The next two recommendations were that: "Common attributes around staff behaviours require further exploration" and "Additional exploration of the impact of health system elements on patients' view of patient-centered care is recommended" (Marshall et al. 2012, p. 2671). These are vague recommendations for which a research study was not necessarily required to develop. Thus qualitative findings may appear weak, obvious, and lacking specificity. Without innovation, direction, and just plain "oomph," it is not surprising that qualitative findings are ignored. The ideal research program could be carried on to the point where an intervention program is developed, implemented, and evaluated.

Some qualitative articles have made a fine contribution to developing theory, but the findings have been left at the theoretical level without informing the reader what it means, or most of all, what to *do*. It is only expected that the reader will recognize "what is going on" and therefore experience enlightened understanding of the patient's situation. But again actual guidelines for care are omitted. The questions remains: why?

25.4.2 Why Do Qualitative Researchers Not Trust Qualitative Research?

Qualitative researchers, on the whole, are cautious in the presentation of their findings. It is as if they tend to adhere to *quantitative* principles when planning their research, designing their study, and submitting it for publication. Qualitative researchers are reluctant to predict, or to claim causality (Hall 2013). Not understanding that qualitative research is generalizable, by developing internal rigor (Meadows and Morse 1991), as well as through its theoretical outcome, authors may inappropriately delimit their work. They apologize for its small size, for the lack of randomization and representation of the general population. Similar problems occur with the overzealous administrations of interrater reliability with interpretative research (Morse 1997), by preliminarily truncating data collection, working with meager data sets, and cherry picking data for presentation in the results (Morse 2010). Researchers confuse analytic procedures for categorizing and theming (Morse 2008) and have an overt fear of theorizing. Although we have moved a long way in the past two decades, there is still a considerable distance to go in communicating the principles of qualitative inquiry to both quantitative and qualitative researchers.

The result is a crisis of confidence in qualitative researchers. If they themselves do not rust their findings, then the result is that their recommendations for practice are made lightly, cautiously, and tentatively.

25.5 Making a Contribution: Requirements of Qualitative Inquiry

How are the results of qualitative inquiry used in practice? Presently, this is not very clear, with the clinician reading or hearing about a theory with relevance to practice, and somehow remembering it in his or her mind. But the theory usually contains very few specific recommendations for practice. Yet *developing a theory* is the most frequent outcome from qualitative inquiry. Because of their loose application to clinical action, somehow the theory is virtually ignored by others, even researchers themselves. Generally, theory is supposed to assist the nurse to "make sense" of whatever is going on with a particular client, but lacks specific directions.

25.5.1 The Theory Fails on Its Lack of Pragmatic Application

Some theories are supposed to provide a foundation for practice. But how such theories fit into ongoing practice and what they offer the clinician is not stated. One could ask: *Does learning a caring theory make a caring nurse*? That is, does the theory teach *how to care* by providing directions for caring, or *how to recognize a caring nurse*? Or, perhaps, *does a caring theory explain what a caring nurse does, compared with a non-caring nurse*? And the most tricky: *Does caring make a difference to patient outcomes*?

This begs the question: if theory is actually used clinically, how? And is it important in solving clinical problems? Or is it simply window dressing for a hospital: adopted, distributed in brochures and philosophy, but not consulted again, nor demonstrated at the bedside. These questions are of utmost importance given the theory requirement of the Magnet program for improving standards of care in hospitals (ANCC, http://nursecredentialing.org/Magnet/ProgramOverview).

Theory is supposed to be used for informing practice. We rarely read a qualitative study that reveals to the reader "what is going on," and combines the general with the particular, that also contains with a particular client, in a convincing and compelling way. Theory that informs must be logical, have grab and fit (Glaser 1978), and provide a clear direction for practice, yet often we fail with this dictum. This is an obvious statement and criteria for the evaluation of grounded theory (Glaser 1978) that may be applied to all qualitative research with the goal of theory development. Minimally, the theory must provide a detailed description of the participants' behavior as it moves through the theoretical description; it must link the behavior to the context, when where and why the behaviors occur, and what the clinician must do to modify these behaviors. These interventions must be clear enough to be followed and implemented, the outcomes observed and preferably measured.

Of course, if such a qualitatively derived theory could be readily tested, the final project in the research program could be such a study (see, for example, Wuest et al. 2013). However, this is easier written than done. Recall the reason that a researcher used qualitative inquiry was because there were no identified concepts to measure or to use within the topic, in order to conduct a quantitative study. At the end of the qualitative study, even though new concepts are now identified, the problem remains for quantitative measurement—the only pertinent concepts are those just developed—and of course, it would be a tautology to use the just-developed concepts to measure itself. Again, qualitative researchers must trust their own procedures to establishing internal rigor (Meadows and Morse 2001), so that qualitative findings are rigorous, solid and tested within the process of qualitative inquiry. Remember that testing is not necessary and often not possible.

25.6 Essential Project Requirements Necessary for Application

If a qualitative project (or series of projects) is to make a pragmatic contribution, certain characteristics must be in place:

1. *Rigor*: the project must be sound;
2. *Relevance*: the project must address a significant clinical problem;

3. *Comprehensiveness*: the findings must be comprehensive in scope, depth and time;
4. *Role*: the project must be explicit in its mode of utilization, thereby fitting into practice; and
5. *Forms of recommendations*: recommendations must be consistent with and used in practice.

While this list may appear simplistic, as I discuss each I will also discuss the inhibitors to achieving these criteria.

25.6.1 Rigor

The project must be conducted rigorously and transparently, so that the reader/user is convinced that the study is sound. There must be twofold criteria: methodological and substantive rigor. The researcher provides clear evidence that the criteria to rigor has been met. These are: sampling adequacy and appropriateness; methodological cohesion, description of theoretical construction, and so forth, as well as adequate substantive evidence of the nature of the data, and examples of the cognitive development of the theory as it is abstracted and linked with the literature.

Inhibitors: Qualitative researchers frequently do not understand the principles of qualitative inquiry, and use quantitative criteria. As previously mentioned, researchers themselves do not appreciate the generalizability of their own work. They write that, as study was conducted in one ____(nursing home, community, fill in here), it therefore cannot be generalized to other _____ (elderly, communities, fill in here). Researchers do not understand how qualitative research is generalized (Hall 2013; Morse 1999). Thus it is the author's own erroneous recommendation, that his or her findings not be generalized which intercepts the application of these findings.

25.6.2 Relevance

The project must address a significant clinical problem. This is the most difficult criterion to meet, for it is often not possible to conduct basic research that has direct application. Alternatively as the study progress, a problem that may initially appear to have clinical application, may become more complex and lose its direct link to application. The most unfortunate scenario is that in the conduct of an apparently basic study, relevance for application emerges, but the researcher himself is not aware of this aspect of the study.

Inhibitors: The most common inhibitor to relevance is revealed in the case above. We are so ingrained "not to go beyond our data" that we forget in qualitative inquiry that it is the concepts and theory that is transferred, and that our findings in this study have relevance for similar problems in other areas, if similar characteristics are present. An example is a study on privacy in a nursing home, has relevance for other groups with problems of privacy-maintenance when residing in another total institution (See Applegate and Morse 1994).

25.6.3 Comprehensiveness

The findings must be comprehensive in three dimensions: in scope, in depth and over time. The trick in qualitative inquiry is to keep sampling and collecting data and analyzing until you are finished, i.e., until your theory is completed, rich, convincing and significant, so that you "know it all."

Inhibitors: Too many qualitative researchers terminate data collection before they have adequate data. Others may have delineated their problems so tightly that the findings become obvious and the variation and the complexity in context is not appreciated. Or, they use an inappropriate method: for instance, semi-structured interviews delimit data, forcing participants to focus unnecessarily, and when administered to a small sample, results in data inadequacy (Morse 2012), which is a common problem with some methods, such as interpretative phenomenological analysis (IPA) (Smith et al. 2009). And, as previous mentioned, the problem is in analysis, with the researcher not trusting (nor defending) their own interpretive analysis, and conducting interrater reliability that further restricts the development of interpretative theory (Morse 1997).

25.6.4 Role

The project must be explicit in its mode of utilization. Any recommendation for practice that emerges from the study should be more than simply admonishment or principles. If you tell practitioners what to do, you must also tell them specifically *why* and, most importantly of all, *how*.

Inhibitors: We cannot tell practitioners of what they *should* do without telling the *how* and *why*. For example, once I identified "talking through"—that is, the way nurses talk to conscious and extremely distressed trauma patients. Talking through assists these patients to maintain control and not to fight caregivers (Proctor et al. 1996; Morse and Proctor 1998). Talking through needs no instruction—nurses are already doing this in trauma rooms, but without documentation, learning from each other. They realize it is important, but it is not a part of nursing tests or instruction or incorporated into their work role. Our research identified and documented the practice. We disseminated, presented, and published. But talking through remains an informal strategy for care.

Importantly, we have demonstrated the qualitative adequacy of the procedure, but not demonstrated concrete efficacy, such as, how talking through makes a difference to morbidity and mortality in trauma care. Doing so would require a randomized control trial, and we could not determine how such as study could be designed, given the complexity of trauma patients. Our only evidence for efficacy was that the patients did not fight off the caregiver, and remained in control until the anesthetist took over. Those who were partially aware told us that they "just heard the nurse's voice and held on." Secondly, nurses themselves do not have control over their workload, so that talking through was only done if there was a nurse available and who "had time." Administrators were not prepared to provide an extra staff member in the trauma room to be there for the patient. So, the practice was not formalized and is now being lost in the literature as its 10 year publication anniversary nears.

25.6.5 Form of Recommendations

The research must be developed and disseminated in a form that is accessible to the clinicians, or to the nurse educators and students.

Inhibitors: The main problem is that researchers publish in research journals; clinicians read clinical journals. Attempts to remedy this disconnect have been tried, but with limited success. For instance, *Evidence-Based Nursing* summarizes research articles to their essential details needed for application for speed-reading clinicians, who are supposedly not concerned with the technical details.

Occasionally, qualitative researchers will take their research to the level of practice, developing their research into assessment tools and so forth. But this is a several step process: we must decide what a "contribution" actually is, and then, must a program be developed, and subsequently tested.

25.6.6 What Is "a Contribution to Practice"?

When we examine the work of qualitative researchers who have made a difference, we find definite patterns of research programs: those who have worked in different substantive areas, and those who have worked on a single problem or phenomenon intensively throughout their career, in a cohesive research program. But can a single qualitative project impact on a discipline?

Obviously, whether or not a single article can have important implications for practice depends on the topic, and the researcher's agenda. Some projects may be implemented as *basic* research, research to find out *what is*, but the majority of research in health has practical application. Next, the level of abstraction, and the *form* of the findings, must be considered. If the researcher was addressing a practice issue, and moved the inquiry into areas that enabled recommendations to be made, then the recommendation should be in the form that the practitioner can use. For whom is the intervention suited? Recipients of the program should be identified. Researchers need to present clear goals, with the steps for achieving these goals, a program of implementation outlined, and outcomes specified and plans for evaluation. Such detail may be presented in a second article, and even in a different journal. If the research is conducted by a team, then it is possible that one of the team members is an expert in translational research.

25.7 Strategies for Moving Qualitative Research into Practice: Forms of Recommendations

25.7.1 From Descriptive Studies

The most straightforward interventions are from descriptive studies—developed from observations in the clinical area. Often these studies are conducted by videotaping care, and explicating the interventions used—of which the caregivers may or may not be aware.

An example of such an intervention was previously mentioned as "talking through," or the *comfort talk register* (Proctor et al. 1996) that enabled patients in extreme distress to maintain control. An adaptation of this was then developed for patients in second stage labor (Bergstrom et al. 2009).

Mary Beth Happ (2013) conducted microanalytic studies of patients on ventilators in the ICU, examining ways that nurses could best communicate with patients on ventilators. She developed a very basic training program, iSPEAK, to facilitative nurse-patient communication, consisting of the necessary equipment and teaching nurses how to read patient cues (Happ et al. 2010).

25.7.2 For Assessment Using Theory

Moving theory from grounded theory back into clinical practice is remarkably straightforward. The format of grounded theory in stages, phases and behavioral descriptions lends itself to recognizing the behaviors that lead to the theory, and each behavior—and description of how the behaviors appear in each stage or phase of the process—is clearly delineated. These descriptions may then be converted into an assessment guide (Morse et al. 1998). Each behavioral description becomes an item, and converted into a question asking the clinician if it is present or absent. If the behavior is absent, then strategies are identified for the clinician to assist the person to work towards attaining those goals.

25.7.3 Assessment Guidelines

The Hope Assessment Guide (Penrod and Morse 1997) used a stepwise theory of the attainment of hope (Morse and Doberneck 1995), to develop criteria to assess a patient's stage of hope and the ways staff may help them attain hope. For instance, the first step, before one commences the process of hoping, is to identify what you are hoping for and hoping against, *recognizing the threat*. Next, identify the steps necessary to achieve the hoped-for goal, *making a plan*, *envisioning alternatives*, *setting goals and bracing for negative outcomes*. As the person moves through the process, they must periodically *take stock*, *by realistically assessing personal and external resources and conditions*. They *reach out*, *soliciting mutually supportive relationships*; *continuously evaluating signs of reinforcement*; *holding on—determine to persevere* (p. 1062). In this way the caregiver may identify the person's level and needs in attaining their hoped-for goal, and support them in this process.

25.7.4 Use by Clinicians: Developing Assessment Guides

Clinicians who observe clinical problems do not necessarily have to start as researchers. They may find a reasonable amount of qualitative literature in their topic of interest—even grounded theories, and even a model or theory that already addresses their concern. Such was the case of Vennie Ying, a DNP student, who wanted to identify a way to intervene with others who had experienced traumatic birth. She was aware of Beck's (2004a, b) model of causation and interventions for traumatic birth, and recognized the need to develop an assessment guide. The methods of converting a theory to assessment questions (above) provided a straightforward and valid method for the development of an assessment guide (Ying in review). Such a guide enables the collection of complete and systematic information and allows the application of appropriate interventions.

25.7.5 Research Programs

Research programs beginning qualitatively may extend in several directions. They may, using the initial qualitative studie(s) as a theoretical base, move into quantification—to the development of a questionnaire. They may extend even further, developing into intervention programs or become a foundation for policy.

25.7.5.1 Developing Quantitative Questionnaires

Quantitative surveys and questionnaires are frequently constructed from qualitative data. Most often they are developed from focus group data that determines the theoretical structure of the questionnaire and provides the wording for the items that are derived directly from the group. The use of focus group data to develop the questionnaire is considered to be more valid than developing the question from the researcher's own perspective. One warning about this approach: the researcher has a lot of weight for the validity of the questionnaire (and ultimately the entire study), resting on the focus group data; it is therefore essential that these data (usually themes) be adequate and appropriate for their purpose.

A more satisfactory way to develop the theoretical basis of a programmatic study is to conduct qualitative study first, then use the resulting theoretical development as the foundation of the questionnaire. An example of such a research program was an inquiry into adolescents' response to menstruation. This research program consisted of the following projects:

1. Developing a qualitative base and theoretical structure: This was acquired by administering a semi-structured (written) questionnaire to 7–9th grade girls. Content analysis provided the theoretical structure (Morse and Doan 1987).
2. From this a trade book was written for girls, using their words and their questions, explaining menarche (Doan and Morse 1985).
3. Using the theoretical structure as hypothesized factors, we developed a Likert scale (Morse et al. 1993), and administered to all 7–9th grade girls in 48 randomly selected schools. From this we validated the scale and obtained normative scores and symptoms for girls (Morse and Kieren 1993).
4. Two other quantitative studies followed: Studying preparation factors for menarche (Kieren and Morse 1992), and developmental factors and post-menarcheal factors (Kieren and Morse 1995).

Most important is the way that all of the quantitative studies including the questionnaire, "sit" on the foundation of the qualitative study.

25.7.6 Developing Intervention Programs

Wuest and her collaborators (Wuest et al. 2013) conducted a series of studies on the health of women after leaving an abusive partner. These studies used grounded theory, and the core variable was "Strengthening Capacity to Limit Intrusion." This process consisted of six components: Managing basics; managing symptoms; regenerating family; renewing self; cautious connecting; and safeguarding.

The investigators then translated the theory, by developing a program, iHEAL, for women across Canada. As they launch the program, all instructors are taught the theory, and all activities and practices are cohesively linked. The next step that they are embarking on is evaluation of these programs across communities.

Note that these researchers are extraordinary in that they: (a) converted their research into a useable program that may be clinically applied, and (b) moved across Canada training instructors in the use of their research.

25.7.7 Using an Advocate

Researchers are the scarcest resource in this equation. We cannot all take time to travel across country to "sell" our interventions. It seem that our present model of publishing and waiting for our findings to be noticed and used is simply not working. Placing our findings out there is not realistic and does not give our studies enough "dose," or "hard sell" to be adopted into the clinical arena. Perhaps it is time to introduce a new clinical partner, the advocate. This person will work between the emerging research findings and the clinicians with problem. This person will evaluate the suitability of the evidence for the clinical area, set policy, educational programs and oversee change.

25.7.8 Developing Policy Recommendations

Some have used policy recommendations to make change. Kayser Jones' research program has remained focused on the care of the elderly in nursing homes for almost three decades. But within the context of nursing homes she has systematically studied critical aspects of care for the elderly, primarily using ethnographic methods. Her ethnographic dissertation compared the care of the institutionalized elderly in the USA and Scotland. In *Old alone and neglected* (Kayser-Jones 1989/91) she focuses on the use of restraints in the USA comparing it with fieldwork in restraint-free care in Scotland. Since then, Kasyer-Jones has systematically explored acute illness on nursing homes (Kayser-Jones 1995), dehydration (Kayser-Jones et al. 1999); malnutrition (Kayser-Jones 2002); pain management (Kayser-Jones et al. 2006); pressure ulcers (Kayser-Jones et al. 2008; Kayser-Jones et al. 2009), drawing national attention to conditions in nursing homes. Finally she raised the important questions, do "nursing homes promote health or dependency in the elderly?" (Kayser-Jones et al. 2009).

Using ethnography, it is relatively easy to translate the findings into a language that policy makers, governmental agencies politicians and the lay public can relate to and understand. Dr. Kayser-Jones wrote lay publications, on radio and television, and in 1997, she appeared before the US Senate, Special Committee on Aging, thereby moving her research into policy at the highest level.

25.8 Conclusion

In this Chapter, I suggest that the reason for the lack of appreciation of qualitative findings is because even qualitative researchers themselves are not confident of their own results. Evidence of this hesitancy may be found in the forms of the recommendations themselves—they are tentative suggestions, rather than specific strategies for active practice. There is an urgent need for qualitative researchers to gain confidence in their work, and to present it in a way that is meaningful for clinicians.

I recommend five criteria considered necessary for implementation: rigor, relevance, comprehensiveness, role of the recommendations and the form of the recommendations that will greatly facilitate the fit of the findings in practice, hence adoption, by clinicians. The final step, examination of the strategies for moving qualitative research into practice, using assessment guides, and developing intervention programs will provide clinicians with the concrete tools to assist them with patient care.

But placing our results in a form that they may be used is still not enough. I am recommending a new clinical role for an advocate: someone assigned to evaluating the research and evaluating the practice. That person will be responsible for the implementation: for the education of staff and the changing of policy. We can no longer put the onus on busy staff to scan the literature, identify solutions and each, one by one, put them into practice. It is a professional and institutional responsibility, as well as an individual quality of care issue.

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26

Beyond Dissemination: Generating and Applying Qualitative Evidence Through Community-Based Participatory Research

Maria J. Mayan and Christine Daum

26.1 Introduction

Why all the fuss about "evidence"? Why is everyone talking about it, debating it, and deciding what counts as evidence? We have evidence-based research, evidence-based practice, evidence-based policy, and evidence associated with disciplines including evidence-based medicine, evidence-based nursing, evidence-based pharmacy, evidence-based social work, and so on. "Evidence informed" was introduced to acknowledge two things. First, we do not all agree on what evidence *is*, and, second, decisions cannot be based on evidence alone; in reality, other contextual factors weigh in, including politics, resources, and patient preferences. Ultimately, regardless of what we call it and what we believe counts, we all aim to create a foundation on which we can confidently make decisions—decisions about improving healthcare practice, health outcomes, and the social and environmental conditions that underlie negative health outcomes. In other words, we want and need evidence to make things better.

This chapter outlines an approach called community-based participatory research (CBPR). CBPR is a strategy for "generating and applying" rather than "generating and disseminating" qualitative evidence. We first situate CBPR in relation to qualitative methods and show how it builds on the concept of dissemination. We then include how we think about evidence from a CBPR approach and, through a conventional research design, demonstrate how using a CBPR approach can generate qualitative evidence. We also argue that CBPR can create a foundation on which to confidently make decisions about pressing health and social problems and can build mechanisms to ensure that the evidence generated can and will be applied toward effective practice, program, and policy change. We conclude with trends in healthcare research and delivery that complement a CBPR approach for generating and applying qualitative evidence.

26.2 Situating Community-Based Participatory Research

Qualitative research is an approach to making sense of the meaning people attach to their experiences or underlying a particular phenomenon.

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It is concerned with life as it unfolds. Qualitative researchers invite the context in which people live and work and have numerous and distinct qualitative methods (e.g., phenomenology, grounded theory, ethnography, discourse analysis) that tap into experience in unique ways. As such, qualitative researchers have argued that our methods can generate evidence in particular ways to improve the lives of patients and people.

In the 1980s and 1990s, however, scholars recognized that creating and disseminating qualitative evidence did not necessarily lead to changes in practice, programs, or policies. They argued that qualitative research approaches with more applied rather than theoretical foci were required in health disciplines. For example, interpretive description, introduced by Thorne and colleagues (Thorne et al. 1997; Thorne 2008), is intended to answer questions about problems encountered in everyday clinical practice. Knowledge generated is discipline specific, and findings "make sense" to clinicians to facilitate application to clinical practice. Yet even with this applied approach, the onus remains on clinicians to take up the evidence disseminated by researchers. Dissemination is where the problem lies.

Dissemination is the process of circulating information to as many people as possible. Scholars, both quantitative and qualitative, have disseminated their research in refereed journals or government reports for years and have complained that their research has rarely or never been used. What makes dissemination problematic is that it typically happens at the end of a project and is a one-way, "pipeline" (researcher to end user) or "push" process that has little influence on practice (Davis et al. 2003). But if dissemination is the problem, then what is the solution?

In the late 1990s, Israel et al. (1998) identified CBPR as a way to go beyond dissemination of research. CBPR is strongly influenced by action research (Lewin 1997) with its utilization of a problem-solving focus, as well as participatory research (Fals-Borda and Anishur Rahman 1991) and the work of Freire (1970) (Wallerstein and Duran 2003) with their commitment to community participation and social change. As such, CBPR is characterized by partnerships between academics and communities for the purpose of generating knowledge to creating change for communities. CBPR thus directly troubles the way in which we have traditionally disseminated research. In CBPR, "action" is part of the research design, and the research is considered complete only when some type of change in practice, program, or policy has occurred. In this chapter, we argue that CBPR is a way to bridge the gap between qualitatively generated evidence and policy, program, and practice changes.

26.3 Community-Based Participatory Research

CBPR is essentially about academics working *with* communities to conduct research on a pressing and relevant issue of importance to a community. Community partners and researchers equitably design the research; collect, analyze, and interpret the data; and implement plans for change. CBPR is based on the premise that each partner, regardless of title, position, or past experience, brings strengths and knowledge needed to address a community's problem. In health research, CBPR is often oriented to the study of unequal access to healthcare and negative patient and population health outcomes. Those who use a CBPR approach believe that individuals' access to healthcare and their health outcomes should not be dependent on such things as their income, gender, education, where they live, and their ethnicity. They use a CBPR approach to reveal and ameliorate these types of injustices. Thus, CBPR has the dual purpose of knowledge generation *and* action to make a difference to a community's situation.

While CBPR was borne out of a community health setting, the principles that guide CBPR are now being utilized in other health disciplines. For example, it has been used with patient groups (Latin American, Chinese, Iranian, and Punjabi) to develop patient-related educational material to enhance the self-management of asthma (Poureslami et al. 2011) and to evaluate an education and support program for Aboriginal people with diabetes and their families (Mendenhall et al. 2012). Healthcare providers have also used it to improve how patient information is communicated between daytime and out-of-hours primary care staff (Asprey et al. 2013) and to evaluate a protocol to screen and manage intimate partner violence in primary care (Joyner and Mash 2012). Ironically, many health researchers employ CBPR to examine the lack of evidence use in clinical practice (Abad-Corpa et al. 2013; Tolson et al. 2006) with the aim to improving uptake. Additionally, a literature on teaching CBPR principles to healthcare providers is emerging (Rosenthal et al. 2009).

Regardless of who is engaged in the research (e.g., patients, healthcare providers, ethnic communities), *community, community partners, core research team,* and *stakeholders* are present in all CBPR partnerships. *Community* is defined as a group of people that are associated with each other regardless if it is through geography or if members come together through a shared experience. Accordingly, a community could be a First Nations reserve, an inner city, and a hospital, or it could be a particular group of people such as a homeless population, a refugee group, a patient group, or healthcare providers (e.g., physicians and nurses in a primary care practice group).

While it is important for the problem to be considered urgent and relevant by community members, it is unrealistic and impractical to work with all people in a community. Thus, in CBPR, a partnership among particular members of the community is established. These members become community partners. There is no one way of partnering with communities or choosing community partners that is consistent across CBPR projects. It really depends on the nature of the problem and the nuances within the community. However, it is plausible that people living with the problem *and* their natural supports *and* their formal service or healthcare providers *and* decision-makers *and* community leaders may all become involved. Once community partners have been identified, they join with the researchers to become the core research team. Sometimes, other stakeholders are involved in the research to help with such activities as recruitment and interviewing. Although they contribute to the research project in some way, they are not community partners or members of the core research team.

26.4 Evidence from a CBPR Approach

Evidence is needed to make things better, yet what should be the nature of this evidence? Evidence must be good, relevant, and applicable. Good evidence is based on rich data, often described in qualitative research as “thick and dense” (Richards and Morse 2007, p. 109). Rich data are focused on the problem but are broad enough to include context (Richards and Morse 2007). Rich data are generated by enabling participants, from varied perspectives, to “have their say” (p. 110). Rich data are not simplistic; they are comprehensive, yet detailed, and as complete as possible. We need rich qualitative data to create good qualitative evidence.

But good evidence is not enough to make things better; evidence must be relevant. In other words, you can have good but irrelevant evidence. Evidence that is relevant is so because it is meaningful to the people who are affected by the problem. The evidence is beneficial and valuable to them in their work and everyday lives: it is constructive, practical, helpful, and timely.

If evidence is good and relevant, how do we ensure that knowledge users can and will take this evidence to make change within and across their systems? The ability to use evidence or ensure its uptake has developed into the science of knowledge translation. Evidence must be applicable or implementable in order to improve healthcare practice, health outcomes, and the social and environmental conditions that affect health outcomes. Evidence that is applicable can be moved from its typical place “on a shelf” to real practice, program, and policy change. A CBPR approach can build qualitative evidence that is good and relevant and applicable through each phase of the research design.

26.5 How a CBPR Approach Generates Qualitative Evidence

26.5.1 Identifying the Problem and Research Question

CBPR creates good, relevant, and applicable evidence because it centers on a problem of importance to the community and is aligned with its priorities. In other words, what constitutes a problem is that which the community confirms as worth pursuing. A research question is generated once the problem is defined, substantiated, and vetted by the community. This increases community buy-in and involvement and elicits multiple perspectives on the problem. As mentioned, it can involve people living with a particular health problem and their natural supports, as well as healthcare providers, community leaders, and policy makers. Because they are invested in the problem, they make sure they "have their say." With a shared concern, the community is more likely to problem-solve when difficulties arise in the research project and ultimately resolve to generate and apply evidence through the research process. Complete and relevant evidence is created and may be applied because it is significant to the community itself.

One way to think about identifying the research problem and question is to ask "why create evidence for a problem that does not exist?" This is almost what we did in Brazil. Our academic partner from Brazil identified a possible problem of teenage pregnancy in *favelas* (huge megalopolises where the poorest poor live). To explore this possible problem and whether it truly existed for the community (that is, residents of the favela), we worked with a specific favela with whom our Brazilian researcher had worked in the past. Community partners were recruited, and a core research team was established to define the problem and corresponding research question. Community partners were comprised of the following groups: (1) healthcare providers (e.g., physicians, nurses, lay personnel) who worked in the community, the nearby community clinic, and the hospital bordering the favela and (2) community health workers (residents of the favela who had paid positions to support the residents to access health and social care).

When we suggested teen pregnancy as a possible issue to explore, the community health workers—many of whom had had their children in their late teens—laughed and explained how the community *would* recognize this as a problem, but not as an urgent one. However, environmental conditions within the *favela* including contaminated water supplies and inadequate sewage disposal (high incidences of intestinal parasites and gastrointestinal diseases), air pollution (respiratory disease), and substandard housing (risks of collapse, electrocution, and fire) were identified as urgent community problems that required immediate attention. Without using CBPR to identify the problem, we would have been trying to create evidence around and make changes to a problem that existed for us, but not considered most pressing by those living their everyday lives in the community. Genuinely working *with* communities rather than only *in* communities to define the problem as demonstrated in this example requires researchers to relinquish control and share decision-making. While it is unrealistic to assume that power differentials between communities and researchers are always equalized when adopting a CBPR approach (Wallerstein and Duran 2003), constant discussion and negotiation between community partners and researchers means that power is at least partly shared.

26.5.2 Developing Research Protocols and Materials

CBPR generates good and relevant evidence because protocols (e.g., recruitment, incentives, and compensation) and materials (e.g., information letters, consent forms, interview and observation guides) are developed that are sensitive to the community context and culture (Diaz and Simmons 1999; Macaulay et al. 1998). As such, a CBPR approach is congruent with the community's ways of knowing and expressing and is often used to engage harder-to-reach groups (i.e., those who are vulnerable or hidden).

Because community partners are knowledgeable about the community and its members, partners can suggest who should be recruited for the research project as well as where best to locate and how best to recruit. Participation is limited when researchers rely solely on conventional recruitment strategies (e.g., posters, information sessions, email notices). Community partners may, for example, suggest recruiting participants through one-on-one conversations at a community barbeque mediated by a trusted community member over sending letters of introduction by mail.

Partners can suggest how best to obtain the support of key stakeholders and facilitate entry into the community. What hierarchies need to be navigated? Who are the formal and informal community gatekeepers? Who is likely to champion the research project? Who can formally and informally grant permission for the research project to be present in that particular community? How should a particular decision-maker or group of clinicians be approached and by whom? People may be more willing to participate if they are approached by someone who shares the same language, culture, or identity (Lee et al. 2003). From a healthcare perspective, the language could be medical or belong to a particular discipline (e.g., physiotherapy), the culture could be specific to a hospital or clinic, and the identity could be that of a healthcare provider or a particular subgroup, such as obstetricians or community health nurses.

Partners can also advise on how and who should give consent. Should consent be obtained verbally (audio-recorded or not), with a head nod, a handshake, or in written form according to conventional research practices? Does consent occur at the community level (e.g., as is necessary in many Aboriginal communities) or at the individual level, or are both needed? Partners can further advise on whether providing cash, gift cards, or something else is appropriate as an acknowledgement of participation. Or if nothing at all is considered respectful. What happens if tobacco giving is expected, but the research project is conducted by an oncology group and sponsored by the cancer board?

Without community partners' understanding of the community, protocols and materials may be insensitive or even detrimental. The chances of the community engaging in and caring about the research are lost, and with that so is the opportunity to generate good, relevant, and applicable qualitative evidence. Simply put, people will not participate.

The lack of participation in research is a growing concern (Dyas et al. 2009). Literature dedicated to outlining strategies for improving recruitment and retention of participants is now available (e.g., Schnirer and Stack-Cutler 2012; Sixsmith et al. 2003; Thompson and Phillips 2007). Those who still participate in research are generally those who find it easy to participate and have few barriers to participation: they have time, language skills, and confidence. Not surprisingly, research participants are often middle-class adults of European heritage, resulting in the underrepresentation of many, including children, teens, older adults, and especially those who are harder to reach (e.g., ethnic minorities, marginalized and/or stigmatized groups such as sex trade workers, injection drug users, or the socially isolated). They do not "appear" in samples, and their experiences are not captured. What is the quality of the data, and thus the evidence developed, when the experiences and perspectives of some people are not represented or are underrepresented?

CBPR is more likely to engage harder-to-reach populations not only because the research is relevant and matters to them and protocols and materials are tailored so that they are appropriate and respectful but also because trustworthy community partners are integral members of the core research team or are research collaborators. These partners—typically workers from local community organizations who are trusted by the harder-to-reach community—often *screen* and *approve* the academic researchers. Once screened and approved, the members of the harder-to-reach community, in turn, also *approve* the researchers and may be more willing to participate in the research project. This was particularly evident when working on a research project with children who had physical and cognitive disabilities as a newly graduated student. To reach this vulnerable group, a physician whom the parents of children with spina bifida trusted introduced academic researchers to the board of directors of a local community agency that provides support, education, and advocacy to people affected by spina bifida. The board, which consisted of adults with spina bifida and parents of children with the condition, *screened* the academic researchers and considered the community's involvement. Only once this screening occurred, and community approval was granted could academic researchers start working with the community. CBPR offers an approach that welcomes and respects the perspectives of harder-to-reach people and consequently can create more comprehensive or rich and relevant evidence that can be used to address a community's problem.

26.5.3 Collecting Data

Many of us have had the experience of conducting interviews that feel flat, monotonous, and off. It seems like we are just not asking the *right* questions. The problem is that our questions are built from the extant literature and our own experience, and as such we often only get slight variations from the norm, if any at all. And research findings become very repetitive and boring. In CBPR, community partners can guide what questions to ask—and to avoid—that will invite participants to tap into deeply embedded lay knowledge that truly generates the data we need for comprehending the experience and improving practice, programs, or policy.

Additionally, community partners can also guide researchers in how to collect qualitative data. What medium is best so that participants are more comfortable sharing their experiences, especially if literacy is an issue? We typically rely on one-on-one interviews, but what about the use of visual methods (photos, drawing, film, art), diaries, sharing circles, games, and storytelling?

When participants are able to share generations of lay or cultural knowledge, in the form that is comfortable for them, data are gathered that capture what is real and true for participants and their communities. And often outside of what western science defines as such. Consequently, the sharing and development of lay knowledge enable the generation of rich and relevant qualitative data. We then have a better and deeper understanding about, for example, traditional religious or folk beliefs regarding mental illness and its treatment.

A mistake is made when we take the lay knowledge that is true for communities and discount it because it does not match Western models of understanding. In other words, if we cannot prove it through dominant and quantitative methods of science, it does not exist for us. Yet Harding (2008) reminds us that we all have experience with "knowledge systems" (p. 216) that modern Western biomedical sciences have not yet "proven" or do not legitimate, such as acupuncture, chiropractic, and vitamin regimes. Thus, knowledge is not solely the product of dominant scientific inquiry (Harding 2008) but can exist in lay knowledge that we can tap into through a CBPR approach. Thus, rich and relevant qualitative data are created because lay knowledge and understanding are joined with dominant knowledge and understanding to get a fuller, more complete picture of the experience.

For instance, we are currently trying to understand the transmission of tuberculosis (TB) and HIV (work in progress), and, in doing so, it was important that we learned about hospital and community programming for the distribution of pharmaceuticals. In our context, monetary support becomes available upon diagnosis so that many community members choose to become infected with HIV to access these grants. Additionally, the pharmaceuticals have street value, so many of those who are infected sell their medication in order to provide for themselves and their families. We know that effective pharmaceuticals and adherence regimes developed through dominant science are important, yet lay knowledge reveals other explanations why TB and HIV are still being transmitted.

26.5.4 Analyzing and Interpreting Data

Qualitative data can be analyzed and interpreted in numerous ways. What one person sees as pivotal to an experience, another person may skim over. This is due to our own personal history, disciplinary training, and context. When two academic colleagues analyze and interpret the same data in different ways, lively discussions and deeper understandings result. This is intensified by the numerous and varied people that are included in a CBPR approach and the narrative or visual form of qualitative data. Questions are posed such as "what does this mean to you?" or "how does this fit with your context or your community?" When the data are opened up to partners for analysis and interpretation, they make sense of it and do not attempt to eliminate or simplify that which "cannot be." Thus, evidence is developed that reflects the meaning of the data as given and interpreted by both the researchers and the community partners.

For example, during the analysis and interpretation of another research project on TB transmission, the concept of Old Keyam was called upon (McMullin et al. 2012). Old Keyam is a fictional Aboriginal figure created by a Cree Anglican priest, Edward Ahenakew, to express the mood of his people. Our analysis of the stories about getting sick with TB revealed that participants were somewhat indifferent to acquiring and managing TB: "For some, this apathy was borne from a lack of support within the health care system or the idea that TB is a foretold disease destined to reappear as a continuing part of life. To some it is treated with the same normalcy as the common cold" (McMullin et al. 2012, p. 33).

Our analysis would have never been directed to Old Keyam if it stayed with a research team with dominant experiences. Our First Nations coinvestigator and community partners interpreted the data—TB as something expected and a part of life—in the context of Aboriginal health and history. If getting TB is considered "normal," this completely alters the way we need to design and deliver TB programs and treatment.

Yet qualitative evidence becomes even more complete and relevant through a CBPR approach because, in working with communities, contexts of the past and present are often considered in the analysis and interpretation. As learned through community archeology, engaging in the past is done to establish meaning in the present (Marshall 2002). CBPR examines the past to answer research questions in the present. If we follow the example above, transmission of tuberculosis and health-seeking behavior among Aboriginal peoples in the present day can only be understood by placing it in the context of their past experiences in TB sanatoriums and residential schools. For example, TB patients were isolated in the hospital and removed from their families for months and even years and, in many cases, died alone. This has negative consequences in the way individuals seek medical help today (see Moffatt et al. 2013).

Because CBPR relies on continual dialogue among all partners, the present context is naturally brought to bear on the problem. For example, a practice, program, or policy that is new or under review may occur during the course of a research project and affect data generation, analysis, and next steps. For example, during a study with low-income families, affordable housing became a political issue and was reported in the newspaper almost daily for over 3 months. A new program was put into place called the "Eviction Prevention Program," which should have changed the way participants reported their housing situation, yet the data was mixed. Having community partners who were knowledgeable about the program and its shortcomings provided the insight needed to analyze and interpret the data and understand why housing improved for some families but was made worse for others (see http://www.familiesfirstedmonton.ualberta.ca/resources for more information about this study).

Qualitative data generated through CBPR creates a space for lay knowledge to be developed, analyzed, and interpreted from both past and present perspectives. Data is weighed in context with other data on the issue and then integrated as evidence into decision-making about care, the improvement of health outcomes, and the community's future.

26.5.5 Making Recommendations

In most applied disciplines, our papers and reports typically conclude with recommendations for practice, programming, or policy. When evidence is good and relevant, it captures a community's reality upon which recommendations—that are applicable—can be generated. Yet again, this is done at the direction of community partners as they understand their systems' intricacies and know how, where, and when to leverage them. Partners know what is amenable to change now and in the near and distant future. They know what areas, if evidence is applied, will garner *quick wins* and where more incremental change is needed.

For example, during the study with low-income families mentioned above, if acting alone, the researchers would recommend raising income support (i.e., welfare) for low-income families. However, our community partners knew that this recommendation was unrealistic; it would take years to even have this recommendation considered at the provincial level. Instead, they advised attaching our research to the current attention being given to affordable housing and the initiatives the city and province started due to the housing crisis. Since our overall goal was to enable low-income families to have improved quality of life, our partners helped us draw attention to our issue and make recommendations for more affordable housing that would more likely be considered.

Additionally, because analyses in CBPR are embedded in the past and present, recommendations often take into account the long term to understand how trajectories extend from the past through the present and into the future. Given that CBPR projects tend to be long-term investments in a community, understanding possible future outcomes over a generation or more can be helpful in making good programming or patient care decisions in the present. Recommendations are made that balance how effective a course of action is in the short term with the effect of the decision in the long term. Aboriginal people call this "The Seventh Generation Principle," which means that decisions about how we live today should be based on how these decisions will impact the next seven generations. This principle is often enacted when making recommendations on environmental policy.

By making recommendations according to the way a community's systems are established and operate, and with the past, present, and the effects of decisions on the future in mind, we generate more relevant and applicable evidence.

26.5.6 Translating Knowledge

Making recommendations, however, is not where CBPR ends. Inherent in the definition of CBPR is action; research is not complete until some problem is solved or some situation is changed for the better. Ultimately, this is why researchers and community partners join together in the first place, not just to create evidence and disseminate it but also to use it to make change. Indeed, CBPR shares the same central premise with integrated KT: by having community partners (knowledge users) and researchers join together as equitable research partners, research will be more relevant and more likely to be applied (Canadian Institutes of Health Research 2012). KT plans are part of the research design, creating the foundation for action from the beginning. Messages are targeted, the messengers are carefully chosen, and the mediums are natural points of learning. Communities, regardless if they are geographic or they come together through a shared experience, have their own ways of representing knowledge and bringing about change that is embedded in their own patterns of interaction. Some communities may be motivated for change through plays or other performances. Storytelling is a natural medium in many communities, as is art, ritual performance, and the display of culturally significant objects. Oral histories can put flesh on the outline of a community's heritage. Governments too, as communities, have their own ways of representing knowledge and introducing change, even if it is a high-level meeting with a credible guest speaker and a glossy report.

In the research project with low-income families, a particularly compelling part of the project was the experience of mothers as they tried to access health and social support for themselves and their children (see Mayan et al. 2011). We presented these findings on numerous occasions until it became impossible for us (the mothers and researchers) to keep up with the demand. Our community partners (which included government decision-makers), along with the mothers, suggested we transform the findings into a film that could be shown anytime and anywhere as a free download. While the main purpose was to highlight the study's findings and provide decision-makers with the message they needed to create change, the film reached a wider audience and was ultimately used as a professional development tool for current service providers and a resource for professors of students in social work, nursing, medicine, and sociology. To view the film and discussion guide, visit http://www.familiesfirstedmonton.ualberta.ca/use-research-now/collaboration-partnership.

By designing and working through the research together, CBPR develops a connection among partners that creates a culture that is not only receptive to generating good, relevant, and applicable qualitative research evidence but is eager to do it effectively. And now is the time to incorporate CBPR to generate qualitative evidence for the advancement of healthcare research and its uptake.

26.6 Trends in Healthcare Research and Delivery

The context of healthcare research and delivery has changed in recent years. Governments that have funded research for decades, using public dollars, are asking how the research has improved healthcare delivery and the overall health outcomes of patients and the population. There is a great onus on researchers to demonstrate the impact of their research and how it has been incorporated into practice, programming, and policy. Research being done for the sake of research alone is increasingly questioned. In this section, we briefly describe several trends in healthcare research and practice and conclude that these trends mirror a CBPR approach to generating and applying qualitative evidence.

26.6.1 Research Trends: Translational and Patient-Oriented Research

For findings to have practical relevance, they must be taken up and applied. This is the premise of translational research. While variously defined, translational research involves integrating "basic research, patient-oriented research, and population-based research, with the long-term aim of improving the health of the public" (Rubio et al. 2010, p. 4). Findings generated through biomedical research at the benchside (basic research) are translated into approaches used to prevent, assess, and treat conditions at the bedside (patient-oriented research). Next, findings generated through patient-oriented research at the bedside are moved to curbside (population-based research) (Dankwa-Mullan et al. 2010; Rubio et al. 2010).

The patient-oriented research (bedside) component of the research continuum has particularly been emphasized in the Canadian context. It involves translating findings from the research setting (i.e., clinical trials in a controlled setting, existing knowledge) to the practice setting (i.e., patient care) and institutionalizing this knowledge into everyday practice (Canadian Institutes of Health Research 2011). As in CBPR, advocates of patient-oriented research also recognize that patients themselves must be included in the research process not only as data sources but also in setting research priorities.

26.6.2 Practice Trends: Primary Healthcare, Patient Engagement, Patient-Centered Care, and People-Centered Healthcare

While proposed some 30 years ago, primary healthcare is receiving renewed interest. Primary healthcare is both "an orienting philosophy and an overarching strategy for promoting and protecting people's health" through full patient and citizen participation (Aggarwal and Hutchison 2012, p. 7). Primary care is a component of primary healthcare and is “that level of the health service system that provides entry into the system for all new needs and problems, provid[ing] person-focused (not disease-oriented) care over time…” (Starfield 1998 cited in Aggarwal and Hutchison 2012, p. 7).

Patient engagement and patient-centered care are essential elements of primary healthcare and, by extension, primary care. Patient engagement is “[t]he capacity of patients to discuss issues with their care provider, to generate options for treatment and management, and to share in decision-making” (Health Council of Canada 2011, p. 5). Many patients want an active role in their own care (Coulter 2012), no longer relying exclusively on healthcare professionals to make decisions on their behalf. Engagement spans beyond the personal (i.e., patient and the healthcare provider) level and includes citizen and other stakeholders’ participation at program (i.e., a community planning service to address a specific problem) and system (i.e., the public setting priorities for program and policy) levels, especially by communities who are socially disadvantaged and have high needs (Aggarwal and Hutchison 2012).

Many health disciplines utilize practice models that advocate patient-centered (and similarly person-centered) care. While lacking a commonly accepted definition, patient-centered care includes treating patients as individuals and viewing them from a holistic perspective rather than from a disease perspective only (Barry and Edgman-Levitan 2012; McCance et al. 2009), delivering care specific to the needs of each patient (Titchen and Binnie 1993) and patient participation and involvement (Kitson et al. 2013).

Some critics argue that patient-centered care focuses too much on people who are already receiving care in the health system. Proponents of people-centered healthcare suggest that health professionals, policy makers, and researchers widen their scope to view health beyond the walls of the clinic, reaching people *before* they are patients so that they are empowered to promote and protect their own health (World Health Organization 2007). This involves taking into account the needs of individuals, families, and communities. A people-centered healthcare approach also recognizes that health professionals are more than service providers—they are people whose needs and rights must also be considered. Participation by all stakeholders is central to people-centered healthcare and is what drives CBPR and the generation of rich, relevant, and applicable evidence.

The principles of CBPR are evident in primary healthcare, patient engagement, and patient-centered and people-centered care trends. There is overlap in the notions of patient and citizen participation, active involvement in decision-making, and the acknowledgement of the need to include those who are disadvantaged.

26.7 The Time to Use CBPR to Generate Qualitative Evidence

The trends in healthcare research and practice are evident in conferences, workshops, webinars, reports, and scholarly literature dedicated to outlining why engaging with patients—as opposed to disseminating information to them in a pipeline fashion—and their families, health professionals, policy makers, and the general public for healthcare improvement and better health outcomes is necessary. Healthcare organizations are becoming serious about this significant shift in culture and the resultant draw on human, financial, and educational resources. Given that CBPR values lay knowledge (e.g., patient) and meaningful participation and is inherently people- and action-focused, its application is promising for health researchers, policy makers, and service providers. It not only provides the needed research approach for translational and patient-oriented research, but it can guide changes to health practice, programs, and policies that patients and their families, and many other stakeholders, are calling for. Indeed, using CBPR to generate and apply qualitative evidence is exactly what is needed in today’s complex healthcare milieu.

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Using Qualitative Evidence to Develop an Intervention for Enabling People with Chronic Disabling Conditions to be More Physically Active

27

Catherine M. Smith, Gareth J. Treharne, Hilda Mulligan, and Leigh A. Hale

27.1 Introduction

In this chapter we describe how we used qualitative evidence to plan, deliver and evaluate a novel intervention, Blue Prescription. We developed this intervention to help facilitate increased and sustained engagement in physical activity for people living with chronic, disabling conditions. We also describe several important considerations for novice and seasoned researchers, and clinical practitioners making use of qualitative evidence in rehabilitation.

As our work reflects the usefulness of qualitative research approaches in the field of rehabilitation for people with chronic, disabling conditions, the chapter begins with an overview of the current conceptualizations of *disability*, *rehabilitation*, the *patient*, *chronic disabling condition* and *self-management*. We define these terms and discuss how current understanding of these constructs has shaped our research direction.

We then use vignettes to introduce the four members of our research team. Cath Smith explores how the research question and her worldview drove her to select qualitative research methodology to explore exercise and its impact on fatigue among people with Multiple Sclerosis (MS) (Smith et al. 2009a, b). Gareth Treharne describes two qualitative rehabilitation research projects he has been involved in that reflect his position on qualitative research, and discusses the place of "cookbook" approaches to qualitative methods for novice researchers doing rehabilitation research. Leigh Hale outlines how she consulted with stakeholders, and argues how crucial this step is for the planning and design of interventions (Hale et al. 2012a, b). Hilda Mulligan illustrates the development of a model developed as part of her doctoral thesis to facilitate sustained engagement in physical activity by people with chronic, disabling conditions (Mulligan et al. 2012b). We then identify three overarching themes from our work that people with chronic, disabling conditions have told us: (1) control, (2) choice, and (3) support are important for physical activity participation. We then discuss how we used these themes to spur development of an innovative approach (named Blue Prescription) designed to engage people with chronic disabling conditions in higher physical activity levels. We describe the development of our first trial of Blue Prescription, with people with MS, and then discuss how we used qualitative methods to evaluate the acceptability of this intervention for our participants (Smith et al. 2013).

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We conclude with a reflection on qualitative methodologies that we used both in individual studies and in our collaborative Blue Prescription research and examine the conflicting opinions around qualitative research and ways forward for future qualitative research methodologies for rehabilitation health professionals. We also call for stakeholder involvement to be recognized as an essential and robust research method in its own right.

27.2 What Are Disability, Rehabilitation, Patients, and Self-Management?

27.2.1 Disability

Researchers' and clinicians' understandings of the term disability have evolved over the past 40 years. Until the 1990s, and even into the turn of this century, the accepted concept of disability was based on an individualistic pathological or medical model, in which disability was attributed to the inability of an individual to perform activities in an expected manner because of body impairments arising from, or related to, a disease process (Murray and Lopez 1996). Disability was seen as "inhering in the individual, and stemming from functional limitations or psychological losses" (Shakespeare 2006, p. 15). From this viewpoint, disability was equated to a state of poor health. The World Health Organization's (WHO) first framework for disability, the International Classification of Impairments, Disabilities, and Handicap (ICIDH), created in 1980, used an individualistic understanding of disability that did not go beyond the body of the individual (Gate and Niewenhuijsen 2000; World Health Organization 2001).

A social understanding of disability emerged during a time of political "affirmation" for disempowered groups, including the Black consciousness movement in the United States in the 1970s. The change in understanding of disability, from an individualistic model to a social model, enabled society to more readily acknowledge that disability arises not only from individual factors, but from sociopolitical factors within a largely able-bodied environment (Shakespeare 2006). Recognition that an individual's inability to carry out socially expected roles can be considered at least partly socially determined, led to revisions of the ICIDH and the creation of ICIDH-2 (Gate and Niewenhuijsen 2000; Jette 1994).

In 2001, the World Health Organization adopted the International Classification of Functioning, Disability and Health (ICF) as a framework for human functioning and disability (World Health Organization 2001; Stucki et al. 2007). In this framework, impaired body structure and function and activity limitations are recognized as part of the disabling process. Personal and environmental factors add to the process, and the process as a whole constrains an individual from participating in life activities, thus experiencing disability (World Health Organization 2001). Disability is currently conceptualized as interactions between bodily systems and functions, personal and social expectations, and environments that curtail participation in life situations. This conceptualization has important implications for rehabilitation practice and research.

27.2.2 Rehabilitation

As definitions of disability developed so too did the concept of rehabilitation. Within the scope of the biomedical model, rehabilitation was primarily aimed at the correction of physical impairment and the return as far as possible to the generally accepted state of "normality." More recently the Convention on the Rights of Persons with Disability (Article 26) extends the definition of rehabilitation to include "appropriate measures, including through peer support to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability and full inclusion and participation in all aspects of life […]" (Convention on the Rights of Persons with Disabilities 2006, p. 19 Article 26). This report also states that persons with disabilities have the right to "the enjoyment of the highest attainable standard of health without discrimination on the basis of disability" (Article 25). At its inception, the World Health Organization defined health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (World Health Organization 1946). Whilst some have argued that this definition is somewhat utopian (Üstün and Jakob 2005), it nevertheless demonstrates that health, in its complexity, is not limited only to physical or psychological factors. More recently, Rimmer (1999) described health as a dynamic continuum, fluctuating throughout a lifetime. It can be assumed this fluctuating state of health is experienced by a person living with disability regardless of the level of impairment. Rehabilitation for people with chronic, disabling conditions is thus currently conceptualized as a process in which health professionals direct and/or deliver care and support in the context of an individual's current life situation.

27.2.3 The Patient

Recent years have also seen a shift in the conceptualization and terminology used to refer to individuals seeking health care, including those engaging in rehabilitation. The issue of terminology is pertinent for people living with a chronic, disabling condition. Many will receive health-care services for a particular disease process. Thus it may be appropriate to use the term *patients* in relation to that scenario. However, use of the term patient implies an inherent power differential between health service provider (the health professional) and health service receiver (the patient). Should we label all people living with chronic, disabling conditions as patients? In other words, should we retain the term patient when referring to an individual who is engaging with health-care services? Alternative terms are *consumers, customers,* or *clients*. Using such terms implies reference to capitalist models of health care and the growing conceptualization of health care as a service industry to a range of people, including people with chronic, disabling conditions and the "worried well." Mol (2008) distinguished between a logic of choice (leading to the emphasis for health professionals on helping individuals make the "right" health choices) and a logic of care (leading to the emphasis for health professionals on helping individuals find the right health care and optimizing comfort). Rehabilitation health professionals may engage to a greater or less extent in both of these logics. Investigating experiences of a two-sided (or indeed multi-sided) interpersonal situation of health care lends itself to qualitative research approaches. In Aotearoa/New Zealand, the term *tangata whaiora* is being used in place of patient, consumer, or client (Moeke-Maxwell et al. 2008). This term comes from Te Reo Māori (the language of the first nation people of New Zealand). It literally means "individuals seeking well-being." It illustrates the importance of terminology choice when considering rehabilitative relationships and processes relating to chronic, disabling conditions such as MS.

27.2.4 Chronic, Disabling Condition

The Australian Institute of Health and Welfare (AIHW) defined chronic conditions as diseases which:

> Do not resolve spontaneously, and are generally not cured completely. Some can be immediately life-threatening, such as heart attack and stroke. Others can persist over time and can be intensive in terms of management (e.g., diabetes). Most chronic diseases persist in an individual through life, but are not always the cause of death (e.g., arthritis).
>
> (AIHW 2012)

In addition, the AIHW described characteristics of a chronic condition that include functional impairment or disability. Many conditions under this definition, for example diabetes and heart disease, may be preventable or modifiable with lifestyle changes; however, others, for example arthritis and MS, are unpredictable and unpreventable, but perhaps modifiable by pharmacological means.

If we apply the above conceptualization of health as a dynamic, fluctuating state through a lifetime, a person living with a chronic, disabling condition might experience health fluctuations regardless of their primary health condition. Persons living with such conditions have been found to be at greater risk for developing secondary health conditions than those without disability. For example, people living more sedentary lifestyles, as is often the case for those living with disabilities, are more at risk of developing type II diabetes than those who are physically active (Foster et al. 2009). The problems of sedentary lifestyles are compounded by the multiple barriers to physical activity encountered by people with disability (Mulligan et al. 2012a). We argue that rehabilitation should include promotion of physical activity to help people with chronic, disabling conditions minimize their risk of developing secondary health conditions. Current reports indicate that supply of rehabilitation health professionals is not meeting the demand of a growing worldwide number of people living with chronic, disabling conditions. Potential solutions to this issue include the expansion and testing of self-management strategies.

27.2.5 Self-Management

27.2.5.1 The Concept

Difficulty exists in assigning a simple definition to the complex idea of self-management, yet this term is currently dominating literature focused on chronic disabling conditions. Lorig and Holman (2003) described self-management as a life-long task via the Shifting Perspectives Model. In this model, Patterson (2001) proposed that people living with chronic, disabling conditions sometimes have their health condition in a foreground perspective and at other times have wellness in a foreground perspective. Lorig suggests that self-management is most useful when individuals have wellness in a foreground perspective. Lorig described three aspects to self-management: (1) dealing with management of the disease symptoms, (2) changing behaviors and life roles, and (3) dealing with emotional states triggered by living with a chronic condition (Lorig and Holman 2003). We regard self-management as pertaining to behavior change particularly in relation to physical activity. The concept of self-management indicates a move away from paternalistic models of health care (where care is provided for an individual) toward a more person-centered and holistic approach (where decisions about care are made with the individual). In theory, applied self-management should mean that an individual with a chronic, disabling condition can focus on the health issues that are most important to them; however, self-management behaviors and advice require critical consideration in order to minimize decisions which might disadvantage health for the individual (Gomersall et al. 2011; Kendall et al. 2011). Application of self-management principles in rehabilitation practice has implications for how communication occurs during consultations or treatment sessions, particularly as it pertains to who makes decisions and how decisions are made about factors such as treatments and dosage.

27.2.5.2 The Evidence

Whilst self-management has been promoted as a potentially useful strategy for the prevention of secondary health conditions by a person already living with a chronic disabling condition, little definitive statistical evidence exists to suggest the efficacy or cost-effectiveness of this approach. Possible explanations for this outcome, with an assertion of qualitative evidence as vital in developing new and innovative approaches such as self-management in health care and rehabilitation, are discussed.

Statistical analyses of large longitudinal studies have been invaluable in identifying crucial links between behaviors and health conditions: We know that increases in physical activity at the population level will improve long-term health outcomes for the general population (Ewing Garber et al. 2011). However, such studies do not provide the type of information required to successfully get people engaging in increased levels of physical activity on an individual level.

We recognize the need for both qualitative and quantitative evidence in the ongoing quest for optimal self-management of health. Qualitative research can be particularly useful when exploring unexpected results from controlled studies.

For example, qualitative studies of the Stanford self-management program revealed that feelings of control were pertinent in positive outcomes of the program (Lorig and Holman 2003). We argue, however, that research programs may be more cost effective if qualitative research precedes larger comparative trials, so that the results can be used to inform trial design and interventions.

The randomized controlled trial (RCT) is considered the gold standard of comparative intervention research with controlled experimental conditions being a key criterion for judging the validity of results. We argue that the very nature of this criterion reduces the likelihood of translation of results into "the wonderfully messy world of clinical practice" (Shepard et al. 1993). Complementary qualitative evaluation, as an integral component of intervention research programs, might help to redress this situation. Later in this chapter we use our own and other research to illustrate these arguments.

Definitions of health, disability, the patient, rehabilitation, and therapeutic interventions have undergone rapid change in recent decades. Meanings of disability and rehabilitation have evolved from definitions embedded in the medical model paradigm to new explanations that embrace a more biopsychosocial approach. The emerging concept of self-management has challenged health-care providers to consider new therapeutic interventions that promote health. Health clinicians and researchers have started to examine what health interventions are desired by people living with disability and chronic conditions. These developments indicate a change towards a health philosophy that encompasses health across a lifetime, in spite of disease or disability, and this philosophy reflects our worldview with regard to the use of qualitative research in rehabilitation. This served as a catalyst that triggered our focus in our research on chronic, disabling conditions. A second factor was the number of questions that remained unanswered to us through quantitative research. Examples of the questions we came up against are included in Table 27.1.

Table 27.1 Unanswered research questions

1.	What is self-reported fatigue?
2.	How does exercise influence pathology-based fatigue in chronic conditions such as multiple sclerosis and rheumatoid arthritis?
3.	What are the barriers and facilitators to people with disability engaging in physical activity?
4.	If physical activity is good for you why don't people do it? And can people be "made" to be physically active?
5.	What do people really want from health professionals in terms of assistance to engage in physical activity?

As a research team, we felt that qualitative methodologies and stakeholder consultation would help us answer these questions. More importantly, by answering these questions, we would be better able to facilitate increased physical activity in people living with disability and chronic conditions and contribute positively to their health by doing so.

Before discussing the development and evaluation of Blue Prescription—which we feel goes part way to achieving this goal—the four individual vignettes are presented. These incorporate aspects of our individual work with our worldviews and reflections and describe how our paths eventually crossed. Each vignette is accompanied by key references, providing further background.

27.3 Tell Me What You Want, What You Really Really Want

Leigh Hale

27.3.5.1 Key reference:

Hale, L. A., Smith, C., Mulligan, H., & Treharne, G. J. (2012). "Tell me what you want, what you really really want…": Asking people with multiple sclerosis about enhancing their participation in physical activity. *Disability and Rehabilitation*, *34*(22), 1887–1893.

As a research team, and as individual researchers, we have long recognized the role of the *expert patient* in developing and conducting our research; however, the catalyst for a wider scale stakeholder consultation process was the disheartening news of an unsuccessful grant application from New Zealand's largest external health funding body. Based on earlier studies that had shown promising signs that engagement in exercise could lead to health benefits (Hale et al. 2003), we developed an exercise intervention study with a randomized controlled trial design. For 3 years, we refined and further developed the study protocol based on feedback from the funding body's scientific panel; in the meantime, other research from around the world was demonstrating positive effects of exercise upon health in people with MS (Rietberg et al. 2005). We decided to pause for reflection, and then decided that undertaking a wider national consultation with people with MS, their family, supporters, and advocates, would be the next step. Armed with a small seed fund, we consulted face-to-face or via telephone over a 6 months period with people with MS, their families, MS society support workers, MS society administrators and executives, and physiotherapists with a special interest in MS. We asked over 20 individuals whether physical activity was high on their priorities list and how physiotherapists could best help people with MS engage in physical activity. We received a very strong message that physical activity was important to people with MS, but that individuals desired choice and control over the type of exercise activities they did. Our stakeholders also told us that they valued physiotherapy input, but that what they really needed was more ongoing support. Interestingly, this message strongly resonated with research emerging in the Ph.D. research by Cath Smith and Hilda Mulligan, which also identified the importance of choice, control and support as crucial for people with disabilities to be physically active (Smith et al. 2009a, b; Mulligan et al. 2012a, b). We have continued to actively involve our stakeholders in subsequent and current research projects. Often, this was through a Research Advisory Group, where people with MS or another chronic, disabling condition, advocacy/support workers, and other health professionals met on a regular basis throughout the project to advise the research team. As a research team we found this process invaluable in further developing our research.

There is increasing recognition that public involvement in research planning, implementation and dissemination influences the impact of study results on policy and practice (Staley 2009; Schnirer and Stack-Cutler 2011). Staley (2009) defined involvement as "an active partnership between the public and researchers" (p. 13) a process which involved, for example, members of the public advising on a research project or helping to develop the research design. The main themes identified in Staley's review were that involvement resulted in better recruitment, helped researchers to choose outcomes that were more meaningful to participants, and ensured the ethical acceptability of clinical trials. Most importantly, it also identified that public involvement was particularly valuable when designing research, and increased the likelihood that results and recommendations would have better translational outcomes. Schnirer and Stack-Cutler (2011) explored barriers to recruiting low income families as research participants. People with chronic, disabling conditions often have low income due to difficulty maintaining paid employment and costs associated with health care and treatment. Schnirer and Stack-Cutler (2011) made recommendations to overcome barriers to participation in research, which included strategies around time and incentives. They argue that more time is required in order to plan recruitment strategies, build trust, and make personal contact with potential participants and that incentives such as travel vouchers or grocery coupons give an indication that researchers understand financial burdens and value participant input. Research funding bodies in the United Kingdom now require that researchers have to describe involvement of the public in both the preliminary planning and the ongoing development of a research project (National Institute for Health Research 2012). One of Staley's recommendations, however, was for researchers to be more explicit regarding the proposed impact of stakeholder involvement on policy and practice uptake (Staley 2009). Whereas stakeholder consultation is often considered as a scoping activity, we found stakeholder involvement crucial and see now that it played a key role in shifting our research focus toward our intervention, Blue Prescription. We think that individuals may be more vocal regarding their desires when contributing to stakeholder consultation as advisors, compared to a more formal and sometimes daunting interview (Wickenden et al. 2012). We recommend the development of a process that provides clear guidelines about how to document and disseminate important insights that arise from consultation with expert patients and other stakeholders.

27.3.1 In Summary

Our expert patients told us that they wanted to participate in more physical activity but that they also wanted more choice and control over the types of activity they did. They valued the input of physiotherapists in this process, but expressed the desire for more long-term support. Such reoccurring themes in our research led to the development and testing of a novel approach which aimed to increase engagement in physical activity for people living with chronic conditions. These themes are listed in Table 27.2.

Table 27.2 Uniting themes from our previous research

1. Control
– Over symptoms (e.g., fatigue)
– Over type of exercise
2. Choice
– In exercise activity
– In exercise frequency and exercise context
3. Support
– Is ideally low key
– Is ideally ongoing

27.4 How Does Participation in an 8-Week Exercise Program Influence Fatigue in People with Multiple Sclerosis? An Interpretive Description

Catherine Smith

27.4.1.1 Key reference:

Smith, C., Hale, L., Olson, K., & Schneiders, A. G. (2009) How does exercise influence fatigue in people with multiple sclerosis? *Disability and Rehabilitation*, *31*(9), 685–692.

Self-reported fatigue is a frequently experienced symptom in people with MS and yet little is currently known about its physiological genesis (Giovannoni 2006). It is generally thought to be multidimensional (experienced in physical, mental, and psychosocial domains) and multifactorial (having pathophysiological, physical, psychological and pharmacological contributors) (Smith and Hale 2007). Traditional advice for this symptom was to exercise less and rest more; however, a growing number of studies have demonstrated health benefits associated with regular exercise engagement in this population. Despite this evidence, close scrutiny of these studies usually revealed participant withdrawal from studies due to excessive fatigue. On the one hand, it seemed that many people with MS and fatigue could exercise without significant worsening of fatigue whereas, for others, exercise was not desirable due to an increase in fatigue (Smith 2012).

I identified Interpretive Description as a methodology that resonated best not only with the research question for my Ph.D. study, but also because it was developed to acknowledge specific ways that health-care providers know what they know (Thorne 2008). Thorne acknowledged that scientific literature forms an integral part of knowledge attainment in the health-care arena and encourages researchers to use this as a valuable data source. Interpretive Description was proposed to acknowledge the world view of the health-care professional who, on the one hand, assimilates the best of experimental evidence into practice yet, on the other hand, recognizes how individual human complexities can render this evidence difficult to apply (Thorne 2010).

In this study, I interviewed people at three time points over an 8-week period. Thorne recommended this repeated form of interviewing to clarify and confirm meaning with the intention to increase rigor of the analysis (Thorne 2008). During this time, participants engaged in individualized exercise programs that included elements of muscle strengthening, cardiovascular endurance training, neuromuscular retraining (often balance activities) and flexibility. Interpretive Description is not formulaic with regard to analysis techniques; this may lead to difficulties for the novice researcher. I employed a four-step analysis process when using interpretive description in this study:

1. Coding early transcripts line by line for key words/phrases/sections that seemed related to the research question. Coded items were labeled and grouped into preliminary categories (groups of codes with similar meanings) (see Note 1).
2. Clean copies of the same transcripts were given to a second researcher who repeated the coding process noted above. The research team then met to compare and negotiate areas of disagreement.
3. Categories arising in step 2 were used to guide subsequent interviews, which were also analyzed as noted above. Identified categories were examined for links between them to inform meaning. These categories and linkages were presented for comment at the conclusion of data collection to an expert informant who had not been a participant or a researcher in the study.
4. A preliminary analysis was posted to all participants together with a short list of reflective questions/prompts. For example, "How well does this analysis reflect your experiences?" and "Is there any part of your experience that has not been represented here?" (see Note 2).

I identified five linked categories in this study: perceived control; listening to your body; reaching the edge; nature of tiredness; and exercise outcomes. Perceived control over the symptom of fatigue played a pivotal role in influencing positive or negative exercise outcomes. Participants who experienced little or no sense of control over their fatigue seemed less able to listen to their body during exercise. This resulted in over-exercising or being too afraid to exercise enough to achieve the physical and/or mental benefits of exercise. Both scenarios of lack of control resulted in a sense of unhealthy tiredness and negative experiences of exercise. Participants who felt that they had high control over their fatigue were able to listen to their body and therefore could choose how much exercise was sufficient. This choice resulted in a sense of healthy tiredness and consequent positive feelings about exercise.

Notes

1. It has been noted that the terms "categories" and "themes" are often used interchangeably and we would recommend that readers read an editorial by Janet Morse (2008), which was of great assistance in defining the role of these two constructs. We now refer to our preliminary groups of codes as categories, and our identified key meanings as themes.
2. Thorne advised caution regarding the use of "member checking" as a way of ensuring the trustworthiness of an analysis (that the analysis reflects the individual and shared experiences of participants). She suggested that repeated interviews might be a more useful way of clarifying participant experiences and key meaning and we agree with this; however, we felt an ethical obligation to involve our participants throughout the research process, and by sending a preliminary analysis and reflective questions, we minimized any incidences of participants changing their minds, withdrawing data or withdrawing from the study. In addition, whilst far from ideal, many of our projects are bounded by funding requirements. We made every endeavor to include participants from rural as well as urban areas in our projects and this can render repeated interviews problematic. As a minimum, good practice might involve researchers sending a final thank-you message after the analysis is completed and/or published.

27.4.1 In Summary

Using Interpretive Description, we learned about the influence of perceived control over fatigue on exercise experiences. Perceived control resulted in more self-informed choices as to how hard one exercised. The presence or absence of these choices strongly influenced whether an individual perceived positive or negative feelings after exercise. This led us to contemplate that perceived control and choice might be important factors for people with MS who are making decisions about exercise.

27.5 Is It Best to Follow a "Cookbook" Approach to Qualitative Research When Developing Interventions for People with Chronic Health Conditions? Thoughts on Qualitative Research Mentorship

Gareth Treharne

27.5.1.1 Key references:

John, H., Hale, E. D., Treharne, G. J., Carroll, D., & Kitas, G. D. (2009a). "All singing from the same hymn sheet": Healthcare professionals' perceptions of developing patient education material about the cardiovascular aspects of rheumatoid arthritis. *Musculoskeletal Care*, *7*(4), 256–271.

John, H., Hale, E. D., Treharne, G. J., Carroll, D., & Kitas, G. D. (2009b). "Extra information a bit further down the line": Rheumatoid arthritis patients' perceptions of developing educational material about the cardiovascular disease risk. *Musculoskeletal Care*, *7*(4), 272–287.

Hyland, G., Hay-Smith, J., & Treharne, G. (2014). Women's experiences of doing long-term pelvic floor muscle exercise for the treatment of pelvic organ prolapse symptoms. *International Urogynecology Journal,* 25(2), 265–271.

In order to further develop and promote the application of robust qualitative research in rehabilitation, it is vital to mentor novice researchers. I use cooking as a metaphor to unpack the practices of "cookbook" research that follows methodological guidelines. I review two rehabilitation research projects in which I was a co-supervisor. In one project, a qualitative approach was used to plan a preventive/rehabilitative intervention for people with rheumatoid arthritis. In the other project, a qualitative approach was used to unpack the results of a rehabilitation intervention for women with pelvic organ prolapse. The two projects reflect the development of the position that I brought to the Blue Prescription project, which is described in this chapter.

The metaphor of the "cookbook" can help novice rehabilitation researchers reflect on the goals of their research and the role of qualitative research in the development of rehabilitation evidence. The research "recipes" detailed within cookbook approaches can provide a structure to what can otherwise be uncharted waters for novice qualitative researchers, given the ongoing hegemony of positivism in many fields of research (Treharne 2011). If we want a workforce of rehabilitation researchers who can understand the epistemology of qualitative research, then teach them we must. Cookbook approaches provide a place to start understanding how qualitative rehabilitation research happens (e.g., what the data collection might involve, what the data will look like, and what the results might look like). But it is hard to communicate the gruntwork of these phases. I have yet to meet a researcher who has said doing qualitative research is easy after trying it, despite the rumors of a utopia of interviewing and never having to run statistics. Innovation is feasible within qualitative rehabilitation research but cannot take the form of corner cutting or cherry picking tasty looking but unsubstantiated data (Morse 2010). It is also possible to hybridize different qualitative approaches, an approach sometimes referred to as *bricolage* (Warne and McAndrew 2009).

Phenomenological methods have been formalized in various cookbooks that focus on analyzing participants' lived experiences. Interpretative Phenomenological Analysis (IPA; Smith 1996; Smith et al. 1999, 2009a, b) is one formalization of phenomenology (see also Hale et al. 2008 for discussion of its application in musculoskeletal settings). The two research projects that I describe were both based upon the IPA approach, but with some deviation and innovation, which I will use to show what is typical of IPA and to illustrate some examples of how researchers do not have to stick to the cookbook.

In the first example, I was an advisor for Holly John's Ph.D. studies of cardiovascular disease prevention/rehabilitation among people with rheumatoid arthritis in the UK in concert with Elizabeth Hale (Chartered Health Psychologist), George Kitas (Rheumatologist) and Douglas Carroll (Chartered Health Psychologist). In building up to a theory-based and consultation-based intervention, two preliminary studies made use of IPA with people with rheumatoid arthritis (John et al. 2009b) and a range of relevant health professionals (John et al. 2009b). The main thing that was typical about Holly's IPA studies is that she was investigating and interpreting her participants' experiences of the phenomena of rheumatoid arthritis (either as patients or health professionals). The interviews with patients were semi-structured and one-to-one, which is the most common method of data collection in IPA (see Hale et al. 2008; Smith et al. 2009a, b). The data collection with the health professionals involved focus groups. The aim in using focus groups was to allow simultaneous consideration of a range of professionals' views and engender discussion. Focus groups are not typical in IPA studies, but Palmer et al. (2010) have subsequently devised an IPA-based approach to analysis of focus group data that expands upon data collection and analysis. Something else less typical for an IPA study is that Holly is a rheumatologist, which permits an insider perspective with the participants who are health professionals. Holly has a professional, but not personal, perspective on what it is like to have rheumatoid arthritis. Holly's participants also had a range of experiences because she used a purposive sampling approach that included variation with respect to age, sex, and heart disease status (e.g., some had experienced a heart attack, others were at considerable risk for this, others had very little risk). A key feature of purposive sampling is heterogeneity with respect to experience (Treharne 2011), while meeting the crucial element of homogeneity with respect to the phenomenon under investigation—in this case having rheumatoid arthritis and thus greater risk of cardiovascular disease. In this example, Holly moved from qualitative exploration to delivery of a pilot rehabilitation intervention with the aim of reducing the risk or impact of cardiovascular disease (John et al. 2013). The broad goal of the IPA approach to qualitative research is to "give voice" to people who have experienced a specific phenomenon by asking them to look back over their experiences, thus making it ideal for use in retrospective rehabilitation research (Larkin et al. 2006; Smith et al. 2009a, b). The role of IPA researchers is to "make sense" of how the participants are making sense of their experience, drawing on the philosophies of phenomenology, hermeneutics, existentialism, and symbolic interactionism (Larkin et al. 2006; Smith et al. 2009a, b). Holly's specific aim of developing the intervention therefore made it appropriate to think outside the cookbook approach to doing IPA. Holly was careful to plan the interview questions so as to collect qualitative data covering possible intervention components and preferred delivery methods whilst also embracing the experiences and sense-making participants wished to share. As well as looking back over their experiences, the participants were asked to think forwards to help plan what could be done differently, and the themes that were developed answered questions about the pragmatics of the potential intervention by using past experiences in a way that stayed true to the broad goal of IPA (John et al. 2009a, b).

In the second example, I was a co-supervisor of Gail Hyland's Master of Health Sciences study of the experiences of pelvic floor muscle exercises (PFME) amongst women with pelvic organ prolapse in New Zealand. The other supervisor was Jean Hay-Smith (Physiotherapist and Associate Professor). Gail's study also involved the most common approach to data collection in an IPA study: semi-structured, one-on-one interviews, in this case with women who had a pelvic organ prolapse, all of whom had met Gail when she was their treating physiotherapist during the small local arm of the international trial called Pelvic Organ Prolapse Physiotherapy (POPPY). It is atypical for the researcher in an IPA study to have provided treatment to their participants, but in this instance the treatment was a very discrete and finalized experience within the timeframe of the trial. The study served as an opportunity for these women to have an additional follow-up to share both their trial experiences and ongoing adherence (or not) to the prescribed exercises. Jean and I used the metaphor of hats to help Gail (and the participants) differentiate the two main roles that Gail had with these women: (1) as their therapist and (2) as a researcher to hear their stories, interpret these stories and "give voice" to their experiences. This distinction helped Gail make a pragmatic and ethical distinction between her research role and her health professional role. It also raised questions about how best to respond to the tension between simply being a genuinely interested listener (researcher role) and a responder to questions or requests for sources of support or referral (health professional role). Gail handled the requests with considered professionalism, by both writing about the requests in her reflections whilst wearing her researcher "hat" and addressing them at the end of the research encounter and beyond, when switching back to her physiotherapist "hat." Gail also reflected on how the switching of hats may have influenced the data participants chose to share—her sense was that the participants were comfortable sharing information as they already had a strong rapport and that participants were comfortable talking about instances of non-adherence. Themes are not found nor do not emerge magically, they are crafted and argued and result from immersion with the data. When mentoring novice rehabilitation researchers doing qualitative research, the support with analysis is a careful balance. Supervisors/advisors should not do their students' analysis for them in qualitative research, but a good supervisor/advisor will be like a ranty celebrity chef on Valium: instructional but calm and supportive.

No research is ever done truly alone. Even when we reflect on our own research methods we do so in the context of our relationship with others, and I am grateful for my fruitful collaborations and enthusiastic students. Novice rehabilitation researchers using a qualitative approach need to be helped to learn why they might do the things that are typical of a cookbook approach, such as IPA, and how to rationalize any innovations they add. When joining the Blue Prescription research team I brought with me this attitude of the importance of cookbooks and innovation when applying qualitative methods to the development and evaluation of rehabilitation interventions.

27.6 The Nuances of Choice, Control and Support: How These Three Factors Play Out in Relation to Physical Activity

Hilda Mulligan

27.6.1.1 Key reference:

Mulligan, H. F., Whitehead, L. C., Hale, L. A., Baxter, G. D., & Thomas, D. R. (2012b). Promoting physical activity for individuals with neurological disability: Indications for practice. *Disability and Rehabilitation*, *34*(13), 1108–1113.

There are a large number of studies that have investigated barriers and constraints to physical activity for people with neurological disability. Although we identified and then summarized the barriers in a review study (Mulligan et al. 2012a), this in itself did not provide sufficient information from which to develop rehabilitation strategies for the promotion of physical activity. Instead, it seemed pertinent, useful and enlightening to discover factors and processes that assisted people with disabling conditions to overcome the barriers and therefore to become physically active. For my Ph.D. research, therefore, I aimed to discover what drives and shapes participation in

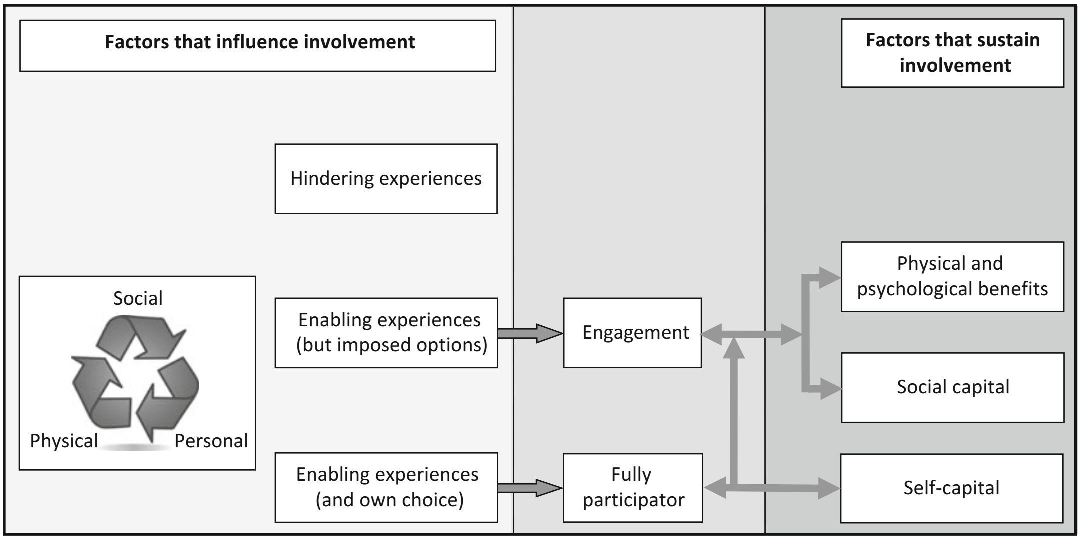

Fig. 27.1 Conceptual model of processes that influence physical activity for people with disabling conditions

recreational physical activity by people with long-term neurological conditions. Together with my thesis supervisors, I was interested in finding out not only what personal motivations people had for becoming physically active, but also the forces that drove their involvement, despite the barriers to doing so.

Guided by a General Inductive Analysis approach (Thomas 2006), I built themes from interviews with 19 individuals with disabling conditions (Mulligan et al. 2012b). From these interviews, I constructed a conceptual model (see Fig. 27.1) of the processes that influence physical activity for people with disabling conditions. This model illustrates how personal, social and physical factors together influence whether an individual will try physical activity. As an example, some participants explained how realization of a critical decline in their functional status (e.g., no longer being able to cross the road safely to get around in their community) had compelled them to take up physical activity, while others explained the influence of family members on their becoming physically active. While most of my participants described negative or de-motivating experiences that, in the past, had hindered their continuing with a particular type of physical activity, they also described how a combination of personal, social, and physical factors had encouraged them to try physical activity again.

I found two distinct patterns in the experiences of my participants with respect to physical activity. One group reported that, although engaged in physical activity, they found the experience limiting, frustrating, unfulfilling and somewhat disappointing because the type of physical activity was not what they had expected. In this group, neither the physical activity nor the recreational environment was the participant's preferred choice. All of the participants in this group exercised in programs offered specifically for people with disability. They had continued with the activity as a means to achieving both physical and psychological benefits. In addition, because the programs were provided by disability organizations, participants had joined in and sustained their attendance, not because they liked the physical activity, but because it was a way to build *social capital* by meeting with other people in similar circumstances. In contrast, a smaller second group of participants described engagement in their recreational activity as fully participatory and as an end in itself. This group of participants had been able to choose and control how they engaged in their preferred choice of recreation, and involvement in physical activity of their choice had become a totally fulfilling part of their lives. They described how this led to personal benefits such as the building of self-identity and vitality for life. This was named *self-capital* in the model to distinguish it from *social capital*. Participants who built self-capital were able to sustain motivation for physical activity by themselves, even though some of them required carer support to access the physical activity they had chosen. Therefore, although both groups received the physical and psychological benefits of being physically active, the two groups differed in how physical activity was sustained: one group did this via the receiving of social capital; and the other group did this via the building of self-capital. In summary, through this model, we came to see how combinations of choice, control and support can be powerful motivators for the sustaining of physical activity. Using these findings as evidence, health professionals should pay attention to the way that choice, control and support are offered to individuals with whom we work, as it appears that the building of self-capital is a powerful tool for people to be able to sustain engagement in physical activity for health and well-being.

27.6.1 Summary of Vignettes

These four vignettes illustrate three uniting themes (see Table 27.2) that arose as a result of our previous work. We used these themes as evidence to develop our Blue Prescription intervention for facilitating and sustaining participation in physical activity for people with chronic, disabling conditions such as MS.

The next section outlines development of the Blue Prescription approach, how we evaluated the feasibility and acceptability of this approach in people with MS, and how we plan to investigate the effectiveness of this approach in order to promote physical activity in populations with chronic, disabling conditions.

27.7 Blue Prescription

27.7.1.1 Key references:

Hale, L. A., Mulligan, H. F., Treharne, G. J., & Smith, C. M. (2013). The feasibility and short-term benefits of Blue Prescription: A novel intervention to enable physical activity for people with multiple sclerosis. *Disability and Rehabilitation, 35*(14):1213–20.

Mulligan, H., Treharne, G. J., Hale, L. A., & Smith, C. (2013). Combining self-help and professional help to minimize barriers to physical activity in persons with MS. *Journal of Neurologic Physical Therapy, 37*(2):51–57.

Smith, C. M., Hale, L. A., Mulligan, H. F., & Treharne, G. J. (2013). Participant perceptions of a novel physiotherapy approach ("Blue Prescription") for increasing levels of physical activity in people with multiple sclerosis: A qualitative study following intervention. *Disability and Rehabilitation*. 35(14): 1174–81.

"I thought it was about Viagra" (Blue Prescription participant 2010).

"I hadn't been doing any exercise and I wanted to" (Blue Prescription participant in Smith et al. 2013).

As discussed in previous sections, several factors led to the meeting and formation of our Blue Prescription research group: (1) unsuccessful bids for randomized controlled trials to explore the effects of exercise on people with MS; (2) wider expert patient and stakeholder consultation findings from the Ph.D. of Smith and Mulligan; and (3) the research findings and supervisory/advisory experiences of us all. We identified uniting themes from all of these processes, and following several planning sessions, the idea of Blue Prescription was born.

The name Blue Prescription began as a working title, and was proposed as an alternative to Green Prescription, a low cost scheme consisting of a prescription provided by a primary health-care provider such as a general practitioner to a patient in order to facilitate physical activity by that individual. The patient is then contacted by a support person—who is not a health-care professional—and offered options for physical activity participation, with support provided via telephone calls or community meetings (Sinclair and Hamlin 2007). We called our intervention Blue Prescription because blue is a color associated with physiotherapists' uniforms in New Zealand. Blue Prescription differs from Green Prescription as it involves a qualified health professional and an individual working collaboratively together in order to identify both activities and strategies for engaging in more physical activity. As an amusing yet important aside, one of the volunteers for our study associated the color *blue* and the term *prescription* with Viagra, a prescription drug for erectile dysfunction (which we were not offering). This indicated several implications for us to consider in the future: How do we ensure that volunteers are fully informed about the nature of a study? We currently issue a standardized two-page information sheet; it is clear to us that this document is seldom read in full, if at all. We plan to incorporate a discussion of this point in our stakeholder involvement process. Secondly, we wonder whether prescription is really the right term to use for an intervention that is underpinned by elements of choice and control. Traditionally the term prescription has been associated with a paternalistic model (health-care providers telling patients what they ought to be doing). We continue to refer to our use of Blue Prescription as a working title; however, as the approach has gained traction in publishing circles and global research networks, it has become difficult to decide upon and implement an alternative branding.

In the early days of Blue Prescription development, evidence was growing to support the positive effects of exercise on health in people with MS. These effects included cardiovascular fitness, muscle strength and endurance, and perceived quality of life (Dalgas et al. 2007; Rietburg et al. 2005). As discussed in Smith's vignette, the effects of exercise on fatigue are complex and through using the qualitative approach Interpretive Description, we were able to make tenuous links between a sense of perceived control and fatigue. Despite this mounting evidence, we were still acutely aware as clinicians that many people with MS, particularly those who experienced fatigue, were afraid to exercise. Furthermore, it is evident that people living with chronic, disabling conditions encounter many barriers that influence both external and internal motivation to exercise (Hyland et al. 2014; Mulligan et al. 2012a, b; Smith 2012). We therefore realized that control, choice and support would be vital elements of an intervention aimed towards increasing levels of physical activity/exercise in people with life-long or chronic conditions, and we used these elements to underpin the key aspects of the intervention further described in the following three sections.

27.7.1 Perceived Control

Perceived control is a central part of the concept of self-efficacy, and thus is theoretically linked to adherence or avoidance of positive health behaviors (Bandura 1997). In order to foster higher levels of self-efficacy with regard to exercise engagement we included aspects of motivational interviewing in our intervention, and to evaluate levels of self-efficacy, we included a validated self-efficacy questionnaire into our evaluation strategy (Rigby et al. 2003). Motivational interviewing is a range of communication and counseling techniques used widely in health care primarily to promote behavioral change (Rollnick et al. 2008). This approach is thought to help individuals identify and overcome intrinsic barriers to behavior change (Shannon and Hillsdon 2007). For example, the symptom of fatigue can elicit fear for people with MS and this (often unwarranted) fear can present a barrier to exercise.

27.7.2 Choice

Rather than prescribe a set of exercises or offer exercise choices limited by programs available, we incorporated choice into our intervention by asking participants how they would prefer to be physically active, and then helping them problem solve ways to engage in that activity. In collaboration with the individual we were prepared to help facilitate any activity chosen, even when the activity was far outside of our traditional professional sphere.

27.7.3 Support

Many of our expert patients and study participants had told us that, although they valued control and choice over their physical activities, the ongoing support of an empathetic and qualified health professional played a key role in their long-term participation in and enjoyment of exercise. We therefore included choice regarding the means by which the health professional and participant would communicate (telephone, e-mail, social networking site, or text) for the purposes of support. In addition, because we also wanted to develop an intervention that was low cost, we limited contact sessions to a maximum of four. An outline of session content is included in Table 27.3.

Table 27.3 Outline of Blue Prescription process

• First session
– Desired physical activities elicited using motivational interviewing
– Problem solving re access and participation in chosen activities
• Second and/or third session
– Goal setting and problem solving
• Fourth session
– Progress check
– Review of goals
• Final session
– Identification of barriers/facilitators to physical activity
• Throughout all sessions
– Contact through medium of choice, e.g., text messaging, e-mail, or telephone

Modified from Box 1 in Smith, C. M., Hale, L. A., Mulligan, H. F., & Treharne, G. J. (2013). Participant perceptions of a novel physiotherapy approach ("Blue Prescription") for increasing levels of physical activity in people with multiple sclerosis: a qualitative study following intervention. *Disability and Rehabilitation 35*(14), 1174–1181

Following the development of our Blue Prescription intervention, and with a small inter-institutional grant, we began the first stages of evaluation, with a feasibility and acceptability trial in 27 participants with MS (Hale et al. 2012a, b). We trained two physiotherapists with experience in neurological rehabilitation in two New Zealand centers. Training consisted of an introduction to the Blue Prescription approach and motivational interviewing. The physiotherapists had access to, and ongoing participation in, our research advisory group for support and advice. We also recruited two research assistants to complete pre- and post-intervention outcome measures and to conduct semi-structured evaluative interviews following the Blue Prescription period (3 months). Our primary outcome measure was the 26-item Multiple Sclerosis Impact Scale (MSIS-26) (Hobart et al. 2001).

We wanted to use an in-depth qualitative approach in order to best evaluate the experiences of our Blue Prescription participants. For this, we were guided by an analysis process designed to evaluate programs and interventions, the General Inductive Approach (Thomas 2006). This approach comprises a general evaluative method for the analysis of qualitative data. It does not have any philosophical underpinnings in comparison to other approaches such as Grounded Theory and Phenomenology, which have very strong theoretical foundations. The arguments and explanations for and against the use of the General Inductive Approach are discussed in this chapter's concluding section.

Quantitative results from our primary outcome measure, the 26-item Multiple Sclerosis Impact Scale (MSIS-26), demonstrated that the perceived negative impact of MS on the individual had significantly lessened following participation in Blue Prescription ($p = 0.02$, effect size = 0.3) (Hale et al. 2012a, b). None of our secondary outcome measures including the Multiple Sclerosis Self-Efficacy Scale demonstrated any significant changes. From our qualitative data we identified three themes: motivation to participate; support; and improving the Blue Prescription approach. The theme support encompassed three subthemes: the therapeutic relationship; the Blue Prescription approach; and supporting themselves (Smith 2012).

Many of our participants were ready and motivated to begin increasing their levels of physical activity. It seemed that Blue Prescription was a catalyst for many to consider doing so, as we had 74 volunteers for the study. Unfortunately we had obtained funding to provide the intervention for only one third of that number. An unanswered question is whether offering the Blue Prescription approach would be helpful for individuals who are not (yet) considering increasing their levels of physical activity. Our participants noted that the Blue Prescription approach was sensible as it appealed to the activities that held meaning for them. Our participants also gave us the strong message that the therapeutic relationship was an important motivator. Components of this relationship that were important from the standpoint of our participants included: physiotherapists being able to put participants at ease; learning to be non-judgmental; sharing a little of their personal lives; and projecting confidence in their professional knowledge. Possibly the most important aspect of the theme support was the indication that our participants, through Blue Prescription, were developing the ability to support themselves. This included descriptions of growing confidence and strengthening intrinsic motivation, constructs that are linked to self-efficacy. Our participants also gave us frank feedback on the aspects of Blue Prescription that they had enjoyed the least. We were given a very strong message that the outcome measures used often did not reflect the kind of changes (mostly positive) that the participants were experiencing. Indeed, the growth in confidence and extrinsic motivation evident in the qualitative evaluation was not reflected in the self-efficacy scores of the standardized measure we used.

We used a generic evaluative method to analyze our post-intervention interview data called the General Inductive Approach. This approach to data analysis has been adopted by several physiotherapy researchers as a pragmatic and no-nonsense way of analyzing qualitative data, and yet this approach has been criticized by some researchers due to the absence of any explicit philosophical basis. The General Inductive Approach is appealing to both novice and highly pragmatic researchers as it offers a “cookbook” of very clear steps and processes for identifying themes that are meaningful in the context of the research question. Thomas (2006) argues that, “many evaluators need an analytical approach that is easy to use, does not require in-depth understanding of a specialist approach, and produces findings that defensibly address evaluation objectives and questions” (p. 246). Researchers do however need to be aware that the General Inductive Approach is designed to evaluate experiences in relation to programs and/or interventions and that other phenomena might best be explored through a design underpinned by a particular philosophy, for example, illness symptoms might be best explored through the lens of Interpretive Description which is underpinned by the ways in which health professionals seek and act upon knowledge. The absence or presence of explicit philosophical underpinnings in qualitative research design is a topic fiercely debated. Gullifer (1997) argued that whilst there might be examples where philosophical underpinnings are not required, any project that offers generalizable conclusions and recommendations should have both a philosophical and theoretical base. Gullifer illustrates this point by expanding upon the theoretical and philosophical underpinnings of the nursing profession and how these influence the types of knowledge sought and the interpretations produced. He argued that project conclusions and recommendations need to be judged with reference to the historical and intellectual focus of the researcher.

Physiotherapy researchers may wish to use the General Inductive Approach because there are few qualitative approaches that are underpinned by philosophy and ways of knowing that are important to a physiotherapist (Parry 1991). It has long been argued, for example, that the physiotherapy profession has aligned itself with the medical worldview and Parry warns that, “so long as physiotherapists base their claim for legitimacy on the medical model, they will never be the authority for their own knowledge" (p. 435). Parry continues: "real progress in physiotherapy will come with the generation of theory that explains practice from a perspective that is unique to physiotherapy" (p. 437). Thorne strongly challenges applied health researchers to develop and trial qualitative approaches that reflect the objectives of applied health research and argues that the final phase of Interpretive Description can include using the theoretical and philosophical underpinnings of one's discipline as a lens through which to consider the findings and their implications for practice (Thorne 2008). Frequently Thorne has taken this recommendation further and argued that, to really make a difference in health care, we might need to abandon traditional qualitative research methodologies that were developed in other disciplines such as anthropology and sociology (Thorne 2010). Whilst Thorne has made huge progress in this endeavor through the development of methodologies such as Interpretive Description, we would like to see physiotherapists and other rehabilitation health professionals pay more attention to what they know and how they know it, in order to develop qualitative research approaches that help them to produce the kind of knowledge that will improve their own practice and the health and rehabilitation outcomes of their patients.

27.8 Future Challenges

Our story is not yet concluded. We pause for reflection on how profoundly qualitative research has influenced our research path. We have used a variety of approaches. Some of us have chosen approaches with a strong philosophical foundation; others have explored an intuitive mix of ingredients. One thing we have in common is that we have attempted to use approaches that best address our research question. As health professionals engaged in research directed at engaging people with chronic conditions in more physical activity, it is not always easy to find a qualitative recipe that satisfies the requirements of both the research question and researcher worldview. We strongly recommend that researchers engage in and develop best practices around stakeholder consultation processes. To this end, we call for journal editorial boards to consider publication of robustly conducted stakeholder consultation programs so that we can all learn more about how to develop rehabilitation interventions that are relevant and meaningful to individuals.

Whilst we have developed an approach based on tenets of control, choice, and support, we have struggled to persuade our peers in the public health domain to become involved in the translational development of this approach. How do we convince hospital and community-based physiotherapists to trial Blue Prescription as an alternative to the delivery of more traditional home exercise programs? Whilst we consider how best to address this challenge, we continue to recommend that health-care providers ask how their clients would like to exercise; connect with organizations that can assist with transport, finance, and access; use strategies (such as Motivational Interviewing) to build exercise self-efficacy; and be aware that a little health provider support (so long as it is sustained) can make a big difference to ongoing exercise commitment and engagement.

We also need to explore how the Blue Prescription approach would work in populations with a chronic health condition other than MS and have yet to fully test the (cost) effectiveness of Blue Prescription, but we believe that, through our exploratory and evaluative qualitative studies and stakeholder consultation processes, this intervention will be more meaningful to the participants who engage with it. We hope that our story will give the reader some insights into the ways in which the evidence generated by researchers using qualitative designs can be used to develop research groups, interventions for people with chronic conditions, and evaluation protocols for those interventions. We look forward to reading your stories.

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The Contribution of Qualitative Research to Medication Adherence

28

Colleen A. McHorney

28.1 Medication Adherence: Definitions and Classifications

Dictionary definitions of compliance include the act or fact of complying with a wish, request, or demand and a disposition or tendency to yield to the will of others. Common synonyms of compliance include acquiescence, concession, deference, obedience, passivity, and submissiveness. In medicine, compliance refers to the extent to which a patient's behavior (in terms of taking medicine, executing lifestyle changes, or medical appointment-keeping) coincides with medical or health advice (McDonald et al. 2002). The word compliance dominated the literature on medication taking until the late 1980s when it was gradually replaced by the word adherence. A perfect storm of trends, all of which supported the salience of the *patients' perspective* on health and treatment, facilitated this change in language and judgment, including the emergence of the biopsychosocial model of health and illness, the health outcomes movement, patient-centeredness in health care, and growing respect for patient autonomy and self-determination. Like its synonyms, the word compliance implies (1) passivity, powerlessness, and dependence on the part of the patient; (2) an asymmetrical relationship between the patient and provider; and (3) paternalism in the doctor–patient relationship. The word compliance also implicitly blames patients for making decisions about their health and treatment. In this chapter, I use the term adherence deliberately because it is less judgmental and value laden than the word compliance. Adherence suggests more active participation by the patient in the treatment process, implies a more collaborative doctor–patient relationship, and implies respect for patient autonomy in decision-making.

In this chapter, I discuss classifications of medication non-adherence, the scope and consequences of non-adherence, the history of medication adherence research, and the Ten Tenets of Medication Adherence. Throughout the exposition of the Ten Tenets of Medication Adherence, I underscore the role of qualitative inquiry in furthering our understanding of medication non-adherence from the *patient point of view*. Qualitative research has yielded many key insights into patients' decision making about their prescription medications and how patients make value propositions about medication taking

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(Benson and Britten 2002; Britten 1994; Conrad 1985; Donovan and Blake 1992; Donovan et al. 1989; Dowell and Hudson 1997; Hall et al. 2007; Mazor et al. 2010; Nair et al. 2007; Sale et al. 2011; Williams et al. 2008). The chapter is concluded by discussing the implications of the Ten Tenets of Medication Adherence for teaching and education.

28.2 Classifications of Medication Non-Adherence

Researchers have differentiated between two types of medication non-adherence. Intentional non-adherence is an active decision on the part of patients to forego prescribed therapy (Lehane and McCarthy 2007). Unintentional non-adherence, on the other hand, is a passive process whereby patients fail to adhere to prescribing instructions through random forgetfulness or carelessness or through circumstances out of their control such as health literacy or cognitive impairment (Wroe 2002). Patients can exhibit both types of non-adherent behaviors for the same as well as different medications (Sewitch et al. 2003). While unintentional non-adherence is common, it represents episodic, and often random, slips and lapses of medication taking, while intentional non-adherence is the deliberate decision to not proceed with prescribed therapy. It is intentional, deliberate non-adherence that compromises patients' ability to achieve optimal health outcomes as clinically defined.

Researchers have also classified different types of medication non-adherence by the timing of medication decisions (Gadkari and McHorney 2010; Karter et al. 2009). Primary non-adherence, or medication non-fulfillment, is the act of patients failing to fill a new prescription after it has been written by a health care provider. Early non-persistence occurs when patients fail to obtain the first refill after the new prescription has been initially filled (first-refill non-adherence). Secondary non-adherence occurs when patients continue to take medications but do not follow medication instructions (e.g., take lower than prescribed doses, take medications less frequently than prescribed, or fail to follow usage instructions). Finally, secondary non-persistence occurs when patients discontinue a medication at some point after obtaining the first refill.

28.2.1 Scope and Consequences of Medication Non-Adherence

Non-adherence to prescription medications is a problem of international importance that knows no demographic, geographic, or political boundaries. Non-adherence to prescription medications has been labeled as America's other drug problem (NCPIE 1997) and a worldwide problem of striking magnitude (WHO 2003). Research across 40 years has documented that adherence to prescription medications, regardless of diagnosis, is poor. A recent systematic review reported that, across 79 studies, approximately 16 % of patients fail to fill a new prescription (primary non-adherence) (Gadkari and McHorney 2010). In a recent meta-analysis of 58 studies, a meta-analytic mean of 20 % of patients with chronic conditions failed to obtain the first prescribed refill (Atkinson et al. 2014). All told, approximately one half of patients who fill a new prescription discontinue therapy in the first six months (Chapman et al. 2005; Yeaw et al. 2009).

Non-adherence thwarts the ability of patients to reach their clinical goals and can result in disease progression, untoward clinical sequelae, and suboptimal patient outcomes. Non-adherent patients with chronic disease have a significantly higher risk of mortality (Fitzgerald et al. 2011), hospitalization (Pittman et al. 2011; Sokol et al. 2005; Wu et al. 2011), and emergency-department utilization (Wu et al. 2011) often resulting increased health care costs (Pittman et al. 2011; Sokol et al. 2005; Wu et al. 2011). Across both symptomatic and asymptomatic diseases, patients who are non-adherent have suboptimal clinical outcomes (Chapman et al. 2010; Penning-van Beest et al. 2008). For providers, non-adherence yields frustration in clinical management and can result in economic loss for those reimbursed under pay-for-performance.

Non-adherence increases health care costs for payers and employers. The direct costs of non-adherence for the USA alone are up to $300 billion each year in terms of unnecessary or excessive outpatient visits, hospitalizations, emergency-department use, nursing-home admissions, and diagnostic testing (DiMatteo 2004). For pharmaceutical companies that discover and manufacture prescription medications and pharmacies that sell them, non-adherence results in significant revenue loss. The cost of primary non-adherence to pharmacies alone has been estimated to be more than one-half billion each year (Shrank et al. 2010), and failure to obtain the first refill adds significantly more revenue loss to pharmacies. Revenue loss attributable to non-adherence to pharmaceutical companies has been estimated to be $188 billion each year (CapgeminiConsulting 2013).

28.3 History of Adherence Research

Over 32,000 articles have been published on adherence to prescription medications (Martin et al. 2005), and as many as 200 factors have been hypothesized to influence adherence (Haynes et al. 1979). Becker and Maiman (1975) coined non-adherence as the “best documented, but least understood, health-related behavior” (p. 11). The origins of published research on medication adherence began in earnest in the early 1960s. The tone of early research was paternalistic—authors wrote that patients were expected to comply with the doctor’s medical directives (Davis 1966) and were obligated to cooperate with their physician (Marston 1970). Non-adherent patients were called uncooperative (Davis 1966) and drug defaulters (Kasl 1975). The problem of medication non-adherence was largely framed as one of conformity (unquestioning and passive obedience) versus deviancy (patient autonomy). The blame for non-adherence lay squarely on the patient. As a result, researchers failed to consider the larger social setting in which medication taking takes place (Stimson 1974) and failed to consider the *patient point of view*: that patients have ideas and beliefs—whether erroneous or not—about their diagnoses and prescribed medications. The exclusive focus on patients made it appear to be unnecessary to study the physician—and physicians were largely overlooked as a contributing factor in patients’ non-adherence (Kasl 1975). As an example of this one-sided framing of non-adherence, Davis (1966) solicited from 131 physicians their perceived reasons for patient non-adherence. A full 65 % of surveyed physicians attributed patient non-adherence to personality, 43 % to patients being unable to understand doctor’s advice, and 38 % to patients being in a difficult life situation.

Early research on medication adherence searched for trait-based characteristics of non-adherence (personality and sociodemographic characteristics) (Hevey 2007; Kasl 1975). The focus on trait characteristics fastened responsibility on the patient (i.e., blamed the victim) and failed to generate meaningful recommendations for action, amelioration, or intervention. Several other themes characterized the early phases of medication adherence research. First, researchers began investigating different methods of measuring adherence and comparing obtained results to one another (Park and Lipman 1964). Across 50 years of research, no one method of measuring adherence has surfaced as the gold standard—each adherence metric has its own set of unique limitations. However, agreement has emerged that when patients report non-adherence (non-fulfillment or non-persistence), their reports are generally quite accurate and reliable (Cook et al. 2005; Liu et al. 2001). When patients report adherence, their reports are likely over-estimates of their actual medication-taking by at least 15 % (Cook et al. 2005) if not higher (Liu et al. 2001). Secondly, research started in the 1960s on how well clinicians could predict the medication adherence of individual patients (Charney et al. 1967). To date, dozens of studies have been published on this topic. Across five decades of research, the overarching conclusion is that clinicians are poor judges of patients’ adherence: they tend to over-estimate patients’ adherence (Copher et al. 2010) and, in general, they cannot predict the adherence of individual patients with any more than chance accuracy (Gilbert et al. 1980).

Thirdly, when research on trait characteristics provided limited insight into medication adherence, researchers began to focus on patient education (if we could just educate them, patients will adhere) and aspects of the medication regimen (if we could just make it easier to take medications, patients will adhere). Both of these factors proved to play a modest role in adherence. Throughout the early stages of adherence research, the unit of analysis was the patient and his/her single disease or diagnosis. Comorbidity was rarely studied, and examination of medication use across different diseases was rare. Much of this work was descriptive in nature, documenting the extent of non-adherence in different disease and demographic groups (Caldwell et al. 1970; Cooper et al. 1982; Cummings et al. 1982; German et al. 1982; Marston 1970).

Prior to the 1970s, research on medication adherence was dominated by the perspective of the medical model generally and the sick role specifically: that patients have an obligation to comply with physicians' orders. However, in the 1970s, a paradigm shift occurred in research on medication adherence. Social and behavioral scientists began studying the social psychology of medication taking using theoretical models that were evolving to explain patients' health-related behaviors in numerous health realms, from medication adherence to preventive health behaviors. A short listing of models that have been conceptualized and tested in relation to medication adherence across the past 40 years include the Health Belief Model (Becker and Maiman 1975), the Theory of Reasoned Action (Fumaz et al. 2008), the Theory of Planned Behavior (Farmer et al. 2006), the Transtheoretical Model (Johnson et al. 2006), the Necessity-Concerns Framework (Horne 1997), the Information-Motivation-Behavioral Skills model (Amico et al. 2005), the Information-Motivation-Strategy model (DiMatteo et al. 2012), and the Proximal-Distal Continuum of Adherence Drivers (McHorney 2009; McHorney et al. 2012). At the heart of all of these frameworks are two guiding assumptions: (1) individuals make decisions about prescription medications (i.e., patients do not passively and unreflectively obey physician recommendations about prescription medications); and (2) medication adherence is influenced by an array of patient beliefs, attitudes, skills, and experiences.

Early on, the various theoretical frameworks studied more generic patient beliefs in relation to adherence. For example, researchers using the Health Belief Model studied such concepts as perceived susceptibility to disease, perceived susceptibility to sequelae, perceived disease severity, perceived treatment benefits, and perceived treatment barriers (Brownlee-Duffeck et al. 1987; Chao et al. 2005; Fincham and Wertheimer 1985; Gao et al. 2000). Over time, though, the focus of adherence research moved from generic beliefs to medication-specific beliefs. Horne's pivotal work on the Necessity-Concerns Framework (Horne 1997) helped to move the field to focus on patients' beliefs about the prescribed medication rather than more generic health beliefs.

In 2009, the Proximal-Distal Continuum of Adherence Drivers was proposed (McHorney 2009), and a formal test of it using structural equation modeling was recently published (McHorney et al. 2012). In the proximal-distal continuum, it is asserted that some adherence determinants are nearer or closer to patients' medication-taking decisions—proximal—while others are more removed—further from—patients' adherence decisions. The aim of the proximal–distal continuum was to locate the body of hypothesized medication adherence drivers along an etiological continuum of determinants from those that have been consistently shown to have strong empirical relationships with adherence (proximal drivers) to those with weaker relationships (distal drivers). In short, the proximal–distal continuum consists of an etiological hierarchy of hypothesized adherence drivers in order to account for medication adherence in a multifactorial manner.

At the proximal end of the continuum are patients' beliefs about the prescribed treatment (Fig. 28.1). Research over the past 20 years has repeatedly demonstrated that patients' beliefs about a prescribed medication are potent predictors of medication adherence (McHorney 2009). Next, etiologically, are patients' disease-related

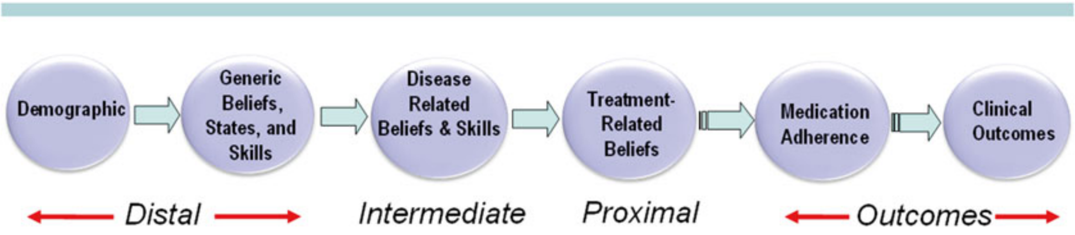

Fig. 28.1 The proximal-distal continuum of adherence drivers

beliefs and skills—these are hypothesized to be direct determinants of patients' treatment beliefs. Patients' generic beliefs and skills are hypothesized to directly influence the sociomedical beliefs. Finally, the distal variables encompass demographic characteristics. Meta-analytic research has demonstrated weak associations between sociodemographic characteristics and adherence (DiMatteo 2004).

At the same time that theoretical models were evolving to explain medication adherence, researchers began to use qualitative methods to understand the *patient perspective* on medication taking. To date, over 200 articles have been published that use qualitative methods to understand medication adherence from the insider's view (Conrad 1985)—the patient him- or herself. One of the early breakthroughs in this work was gradually shifting the unit of analysis from the patient to the prescription, recognizing that chronically ill patients can take multiple medications for a given disease and multiple medications for different diseases and can have different beliefs and adherence to different medications. Arluke (1980) published one of the first articles that investigated adherence from the lay perspective. He underscored that "patients think about the treatment they are given" (p. 84) and "make continuous assessments of whether a certain product […] is working for them as they anticipated" (p. 84). He argued that patients have their own conceptions of therapeutic efficacy that may be distinct from that of the prescriber, the pharmacist, or the manufacturer. Arluke was one of the first researchers to document that patients experiment with their medications to test their subjective definition of therapeutic efficacy. He was also one of the first researchers to describe medication taking as a situation involving uncertainty and ambiguity for patients.

The ensuing body of qualitative research on medication adherence sought to understand adherence *within* and *between* patients using their stories and testimonials. The themes that emerged paid tribute to the patient perspective on medications by highlighting that: (1) patients have their own *ideas* about medicines (Britten 1994); (2) patients attach *meanings* to medications (Conrad 1985); (3) there is *logic* to non-adherence from the patient point of view (Trostle et al. 1983); (4) non-adherence represents *reasoned* decision making (Donovan and Blake 1992); and (5) medication-taking needs to *make sense* to patients (Bajcar 2006). Instead of blaming the patient, this body of research underscored that "the patient is the ultimate decision maker about his or her own health" (Donovan 1995 p. 452). I return to these themes in greater detail in the ensuing sections.

Throughout the remaining sections, I describe insights and learnings derived from qualitative research about medication adherence. Qualitative research is able to make medication taking uniquely visible and palpable from the insider perspective by constructing the reality of medication taking from the patient perspective. The qualitative research cited included focus groups, individual interviews, ethnographic research, and case studies. Many of the cited studies used a grounded-theory approach to organizing and interpreting the collected qualitative data. The qualitative research cited focuses largely on the patient but also includes some qualitative studies of health care providers. I also share insights from over 200 focus groups I have conducted with over 2000 chronically ill patients.

28.4 The Ten Tenets of Medication Adherence

In 2009, the Ten Tenets of Medication Adherence were published (McHorney 2009). The Ten Tenets serve three principal purposes: (1) they expose common misperceptions regarding medication adherence (adherence-myth busters); (2) they provide useful insights about patients' medication decision-making; and (3) they underscore the importance of patient beliefs in determining adherence behaviors. All of the tenets have deep roots in peer-reviewed literature. Several of the tenets are based in part or entirely on qualitative research. The Ten Tenets are:

1. Patients do not communicate their adherence intentions to their health care providers
2. Health care providers assume that *their* patients are adherent.
3. A "non-adherent personality" does not exist.
4. Adherence to prescription medications behavior is largely unrelated to adherence to self-care and lifestyle recommendations.
5. There is no consistent relationship between demographic characteristics and adherence.
6. Patients want information about their prescription medications and feel frustrated that not enough information is provided to them.
7. Health care providers are inconsistent communicators about prescription medications.
8. Medication-taking is a decision-making process, and patients actively make decisions about their medications.
9. Non-adherence is rational behavior—it is driven by patient beliefs about their treatment, disease, and prognosis as well as their objective experiences with their treatment and disease.
10. Adherence represents shades of grey—patients can be faithfully adherent to one medication, non-fulfill on another, and be non-persistent to another because they hold different beliefs about medications to which they adhere, non-fulfill, and non-persist (McHorney 2009, p. 217).

28.4.1 Don't Ask, Don't Tell

Tenet # 1 holds that patients do not communicate their adherence intentions to their health care providers. Across five studies (Fung et al. 2010; Kremer and Ironson 2006; Maddox et al. 1994; Stevenson et al. 2000; Van Geffen et al. 2011), a mean of 57 % and a median of 56 % of patients did not tell their providers when they discontinued their medications. Lapane et al. (2007) reported that 83 % of adult patients surveyed in six US states reported they would never tell their provider if they did not plan on buying a prescribed drug. Qualitative research has illustrated how patients do not tell their provider if they do not want a prescription (Britten et al. 2000) and how patients choose not to discuss their non-adherence decisions with their providers (Donovan and Blake, 1992; Fung et al. 2010; Kremer and Ironson 2006; Laws et al. 2000; Rifkin et al., 2010; Stevenson et al. 2000; Van Geffen et al. 2011). Tenet #2 holds that health care providers tend to assume that *their* patients are adherent. In three studies, from 75 to 95 % of surveyed physicians believed that the majority of their patients were adherent to their recommendations (Davis 1966; Goldberg et al. 1998; Huas et al. 2010). Qualitative research has depicted how physicians simply presume their patients are adherent (Bollini et al. 2004; Davidson et al. 2007) and that they do not proactively ask patients about medication adherence (Bokhour et al. 2006; Bollini et al. 2004; Davidson et al. 2007). As an example of such research, in an observational linguistic qualitative study, Davidson (Davidson et al. 2007) studied provider–patient communication between oncologists and patients with breast cancer taking adjuvant hormonal therapy. Oncologists did not meaningfully addressed adherence to adjuvant treatment whose recommended course is 5 or more years. Davidson and colleagues (2007) concluded that "oncologists believed that adherence was not an issue for their patients, although they had no way of knowing this without asking the question" (p. 141).

28.4.2 There Is no Such Thing as an Adherent Personality

Tenet # 3 states that “non-adherent personality” does not exist. Empirical research has been unable to consistently link medication adherence to personality type, temperament, or other trait characteristics (Bruce et al. 2010; Ironson et al. 2008). Concepts that have been tested in relation to medication adherence include neuroticism, impulsivity, hedonism, extraversion, assertiveness, openness, hostility, cooperativeness, novelty seeking, and friendliness. The peer-reviewed literature is ripe with dismissive opinions about the influence of personality on adherence (Elliott et al. 2007; Hevey 2007), including the following quote by Hevey, “There is little evidence of personality traits influencing adherence, and the search for the ‘non-adherent’ personality type has provided limited insight” (Hevey 2007 p. 295).

28.4.3 You Can’t Judge a Book By Its Cover

Tenets #4 and #5 dispel commonly held misconceptions about adherence. Tenet # 4 holds that adherence to prescription medications behavior is largely unrelated to adherence to self-care and lifestyle recommendations, while Tenet #5 holds that there is no consistent relationship between demographic characteristics and adherence. For Tenet #4, both across (Kravitz et al. 1993) and within (Broadbent et al. 2011; Lahdenpera et al. 2003) chronic diseases, research has revealed that there is weak correspondence between adherence to prescription medications and adherence to lifestyle or self-care recommendations. Thus, a marathon runner can be non-adherent to his or her lipid-lowering medication while an obese hypertensive smoker can be adherent to his or her antihypertensive therapy. Likewise, patients who conduct home blood-pressuring monitoring can be non-adherent to their antihypertensive therapy, while patients who regularly test their blood sugar can be non-adherent to their oral antidiabetic therapy.

For Tenet # 5, myriad reviews of the adherence literature by both clinical and behavioral scientists have concluded that sociodemographic characteristics offer few, if any, consistent conclusions about adherence (Hevey 2007; Kasl 1975; McDonald et al. 2002). Sociodemographic characteristics explain less than 7 % of the variance in adherence as measured by pharmacy-claims data or self-report (Carnahan et al. 2008; Steiner et al. 2009; Venturini et al. 1999; Wong et al. 2012). C statistics, which are an indicator of model predictive ability, have tended to be poor as well (Steiner et al. 2009). DiMatteo (2004) took this research one step further in a meta-analysis on sociodemographic characteristics and adherence involving 164 published studies. In her meta-analytic findings, the correlation between age and gender and adherence was essentially zero (−0.01 for age and 0.02 for gender), and the correlation between education and income and adherence was small (0.07 and 0.09, respectively). Steiner and colleagues (Steiner 2010) elegantly summed up the misplaced sociodemographic quest for adherence predictors:

> Researchers have persisted in attempts to identify a profile of socio-demographic and personality characteristics that would identify patients at particularly high risk of nonadherence. Summaries of this vast and often contradictory literature have concluded that few clinical characteristics, including demographics, are strongly associated with nonadherence[…]. The search for clinical predictors of adherence in administrative datasets [including demographics] is probably futile” (p. 193–194).

28.4.4 The Provider, The Patient, and Their Relationship and Communication

Tenet #6 holds that patients want information about their prescription medications and feel frustrated that not enough information is provided to them. Tenet #7 maintains that health care providers are inconsistent communicators about prescription medications. These two tenets call attention to the discrepancy that exists between patients’ desire for information about their medications and physicians' satisfying those information needs. Across five studies, patient reports of receiving side-effect information from their physicians ranged from 7 to 40 % with a mean and median of only 24 % and 26 %, respectively (Baker et al. 1991; Gardner et al. 1988; McMahon et al. 1987; Morris et al. 1997; Richard and Lussier 2006). Other studies have documented, from the patient point of view, variable discussions about the purpose of the medication (Baker et al. 1991; Gardner et al. 1988) and duration of therapy (Bowskill et al. 2007; Gardner et al. 1988; McMahon et al. 1987; Moshkovska et al. 2009; Parham et al. 2009; Richard and Lussier 2006). Research has detailed the extent of patient dissatisfaction with prescription-medication information (Bowskill et al. 2007; Moshkovska et al. 2009; Parham et al. 2009). Finally, when asked their preferences for prescription-medication information, a substantial proportion of patients say they want information on benefits (Faden et al. 1981), risks (Faden et al. 1981; Gardner et al. 1988; Ridout et al. 1986), duration of therapy (Gardner et al. 1988; Ridout et al. 1986), and purpose of therapy (Ridout et al. 1986).

Qualitative research has elegantly depicted patients' dissatisfaction and frustration with the information they receive from their prescribers about newly prescribed medications (Coulter et al. 1999; Gardner et al. 1988; Gordon et al. 2007; Happell et al. 2004; Nair et al. 2002, 2007). For example, in a home-interview study, Gordon (Gordon et al. 2007) reported that lack of information was a key concern for many participants with cardiovascular disease. Participants described how doctors seemed unable or unwilling to communicate information. Those who wanted more information described how their requests were met by "apathetic, inadequate, or unacceptable" (p. 411) responses from the provider. Dissatisfaction with prescription-medication information was reported in relation to all aspects of their medications and their use.

An equally impressive body of research has demonstrated that health care providers are inconsistent in providing patients with information about newly prescribed medications (Braddock et al. 1997; Katz et al. 1992; Makoul et al. 1995; Richard and Lussier 2006; Tarn et al. 2006, 2008; Young et al. 2006). Audiotaped and videotaped studies of doctor–patient communication at the time of prescribing have revealed that prescribers frequently discuss the name of the medication, its purpose, and instructions for use (Makoul et al. 1995; Richard and Lussier 2006; Tarn et al. 2006; Young et al. 2006). In only about one third of consultations involving a newly prescribed medication do prescribers discuss duration of treatment or other treatment options (Richard and Lussier 2006; Tarn et al. 2006). Prescribers very infrequently discuss benefits, side effects, efficacy, medication costs, ability to adhere, and consequences of non-adherence (Braddock et al. 1997; Katz et al. 1992; Richard and Lussier 2006; Tarn et al. 2006, 2008; Young et al. 2006). In addition, physicians routinely over-estimate the amount of information they provide to patients about newly prescribed medications. In one study, 42 % of physicians said they discussed the potential risks of the prescribed medication, but only 3 % actually did so based on videotapes of the consultation (Makoul et al. 1995).

Non-adherence rates have remained constant throughout our various eras of medicine: the eras of expansion, cost containment, accountability and assessment, and—now—informed decision-making and patient-centered care. It is plausible that adherence rates have not improved appreciably over 40 years, despite the introduction of therapy with less frequency dosing as well as combination therapies, because physician–patient communication about prescription medications at the time of prescribing has not changed.

The practice of medicine in the USA is "low touch" in content and tone, i.e, characterized more by technical competency than interpersonal skills and connections. When asked what attributes of medical care matter most, patients emphasize interpersonal over technical competencies (Laine et al. 1996). A recent meta-analytic study (Zolnierek and Dimatteo 2009) demonstrated a substantial association between physician communication skills and style and patient adherence to medications. These findings are consistent with discourses about the therapeutic benefits to patients of an effective doctor–patient relationship (DiMatteo and DiNicola 1982), and the prescribing physician can be a potent therapeutic agent in and of him- and herself (Culbertson 1901).

Providers need to appreciate that a new prescription heralds uncertainty. Patients may question the results of diagnostic tests, they may question the diagnosis, they may question the rationale behind the prescribed therapy vs. alternative prescription or non-prescription therapy, they may question their provider's skills, and they may question their prognosis provided they are even aware of it. Lack of information or conflicting information can exacerbate patients' uncertainty.

In 2008, Tarn and colleagues (2008) reported that, on average, physicians spend 49 s introducing and discussing all aspects of newly prescribed medications: 49 s is not enough time to reduce patients' uncertainty and ambivalence about the need for newly prescribed medications, allay their concerns, allow for questions, and offer reassurance. Medication non-fulfillment is a perfect example of doctor–patient communication gone awry at the point of prescribing. A recent review of 79 studies estimated that approximately 16 % of patients fail to fill a new prescription (Gadkari and McHorney 2010). The same review abstracted patient-reported reasons for medication non-fulfillment. The principal patient-centered reasons for primary non-adherence were lack of perceived need for the medication, concerns about the medication, and perceived medication affordability (Gadkari and McHorney 2010). It is precisely these three topics that physicians communicate inconsistently, infrequently, or not at all at the time of prescribing (Braddock et al. 1997; Katz et al. 1992; Makoul et al. 1995; Richard and Lussier 2006; Tarn et al. 2006; Young et al. 2006). One of the only ways to prevent medication non-fulfillment is more effective patient-centered communication at the time of prescribing or patient-centered prescribing.

Physicians may not always be able to reduce patients' uncertainty but they can help to *manage* the uncertainty. One way to manage uncertainty about prescription medications is to prescribe with confidence. Qualitative research has suggested that patients question their prescriber's expertise and credibility and lose trust in their prescribers when they perceived prescribing as trial and error (Ledford et al. 2010) such as when a prescriber says, "let's *try* this and see if it works." In my focus-group research, patients universally reported negative visceral reactions to "let's *try* this." Patient's subjective interpretations of physician uncertainty can exacerbate their own uncertainty and ambivalence. On the other hand, the following quote from one of my focus-group participants reflects the subliminal power of perceived confidence: "He told me the history of the medication, that there had been long-term studies, and that he felt confident that the medication would help me. It made me feel good. It made me have more confidence in the doctor." This empowering dialogue probably took an additional 15 s of consultation time.

Another way to manage uncertainty and increase patient involvement in prescribing and adherence is to ask patients their thoughts about a new prescription medication—to actively involve patients in the prescribing process. One of my focus-group participants relayed that his physician "didn't tell me, he asked me if it was okay if we put you on this medication. I felt good about that." Such behavior is consistent with recognized elements of patient-centered communication and informed decision making—eliciting patient's values and finding common ground (Politi and Street 2011).

Qualitative research has elegantly depicted patients' dissatisfaction and frustration with the information they receive from their prescribers about newly prescribed medications (Coulter et al. 1999; Gardner et al. 1988; Gordon et al. 2007; Happell et al. 2004; Nair et al. 2002, 2007). Patients need usable information about risks and benefits through which uncertainty and ambivalence can be managed and informed decisions made. Patients need to learn the pros and cons of a newly prescribed medication before they make their non-fulfillment or non-persistence decision outside of the practice setting. Consistent with elements of informed decision making and patient-centered communication (Politi and Street 2011), patients need information about the clinical situation, treatment alternatives, and risks and benefits. Patients' understanding needs to be assessed and their concerns and ambiguities elicited. One focus group participant's story may be illuminating. A middle-age Hispanic male was diagnosed with diabetes, and his physician prescribed an oral antihyperglycemic medication. The patients stopped taking medication after a few days due to perceived side effects. After several months, the patient went back to the physician, a different oral antihyperglycemic medication was prescribed, and the patient stopped that drug as well after a week. After a few more months, the patient returned to the physician and the doctor gave him "*logical* information for why I should take the medication"—what diabetes is, what it does, and how the oral antihyperglycemic medication works. The patient has been faithfully adherent to his oral antihyperglycemic medication ever since. The third dialogue between the prescriber and patient probably closely resembled recommended elements of patient-centered communication (Politi and Street 2011): providing a clear logical understanding, checking for understanding, eliciting patients' perspective, finding common ground, and reaching mutual consensus.

Dan Gottlieb, Ph.D., of National Public Radio's Voices in the Family, recommends navigating patients through *thoughtful risk taking*—helping them let go of what is familiar, that is, the health status quo. In my focus-group research, I ask patients to share reasons why they faithfully adhere to some their medication regimens. Patients rarely discuss their adherence in terms of biomedical indicators such as getting to a goal or averting clinical complications such as a stroke or myocardial infarction. Rather, patients explain their adherence in terms of salient life goals, such as being the breadwinner and needing to stay independent to provide for their family or wanting to enjoy their family and friends for years to come. In short, patients situate their adherence behaviors in terms of what constitutes a good life for them—their own subjective priorities and passions. It is plausible that patients' medication taking behaviors could be ameliorated if they understood they were placing *themselves at risk* by non-adherence. Framing non-adherence as a risky behavior could shift patients' health status quo from one of optimism to one of doubt and could motivate patients to maintain their health status quo. By exploring patients' conceptions of *their* good life, providers could explain the *consequences of non-adherence* in vocabulary intimately relevant to patients.

28.4.5 Patients' Value Proposition About Prescription Medications

Tenet #8 maintains that medication-taking is a decision-making process, and patients actively make decisions about their medications, while Tenet #9 holds that non-adherence is rational behavior—it is driven by patient beliefs about their treatment, disease, and prognosis as well as their objective experiences with their treatment and disease. Tenets #8 and #9 reflect the accumulated knowledge about medication decision-making and adherence gleaned from the past 25 years of research. Conceptual work has described adherence as a reasoned decision (Donovan and Blake 1992) and that consumers differentially value different medications (DiMatteo 1995). Qualitative research has shed light on how medication taking is an active, rational, and reasoned decision-making process (Bajcar 2006; Conrad 1985; Donovan 1995; Donovan and Blake 1992; Dowell and Hudson 1997; Svensson et al. 2000) and has illustrated how patients carry out their own cost–benefit analysis by balancing their concerns about medications against their perceived need for the therapy and its perceived benefits based on the information available to them, the lay beliefs they have formed about their illness and the prescribed therapy, and the constraints of their daily life (Bajcar 2006; Benson and Britten 2002; Conrad 1985; Donovan and Blake 1992; Dowell and Hudson 1997; Elliott et al. 2007; Goeman et al. 2002; Gordon et al. 2007; Lau et al. 2008; Mazor et al. 2010; Nair et al. 2007;

Rifkin et al. 2010; Sale et al. 2011; Svensson et al. 2000). For example, Ballard (2002) described cost–benefit analyses among women in regard to preventive hormone replacement therapy—for many women the perceived risk associated with hormone replacement therapy outweighed its potential benefits in reducing menopause-related symptoms. Goeman and colleagues (2002) explained how individual patients with asthma made their own assessment as to whether the side effects of asthma medications were a greater risk than another asthma attack. In patients with chronic kidney disease, Rifkin and colleagues (2010) illustrated how burden was weighed against the perceived rationale for the medication: patients weighed possible side effects and risks of polypharmacy against the information they received about the benefits of the medication.

Patients conduct adherence value propositions for each medication prescribed (Donovan and Blake 1992), and they conduct their adherence value proposition disproportionately outside of the clinician's office and without input from clinicians (Elliott et al. 2007; Gordon et al. 2007; Rifkin et al. 2010). Patients' adherence value propositions are ongoing and dynamic (Connell et al. 2005; Harrold et al. 2010; Remien et al. 2003; Sale et al. 2011). Both qualitative (Connell et al. 2005; Remien et al. 2003) and quantitative research (Harrold et al. 2010) have demonstrated that patients can have variable adherence behaviors for the same medication over time. As Dowell and Hudson (1997) describe: "Medication use was not static. Patients' symptoms, knowledge, and attitudes change, which sometimes led them to review their medication use, the cycle being re-entered when new information or treatment required evaluation" (p. 373). Similarly, Arluke (1980) argued that: "[Patients] do, in fact, think about the treatment they are given and, as a consequence of their thinking, modify or abandon recommended therapy from time to time" (p. 84). "Patients […] make continuous assessments of whether a certain product […] is 'working' for them as they anticipated" (p. 84).

Some of my focus-group participants have described their adherence value propositions as a medication totem pole, with some current medications high on the totem pole and others lower (Bloom and McHorney 2013; McHorney 2011a, b). When life changes happen—such as a loss of a job, change in pharmacy benefits, prescription-medication copayment increases, a new diagnosis, or add-on therapy—the medication totem pole can be shifted, with some medications triaged out and other new medications triaged in. Other focus-group participants have likened their medications to an apple cart, and similar life circumstances can upset the apple cart, necessitating that patients reinitiate the value proposition for the bolus of medications in the apple cart (Bloom and McHorney 2013; McHorney 2011a, b). Elliott (Elliott et al. 2007) drew similar analogies in her qualitative research—patients make trade-offs *between* and *among* medications as life circumstances change. She found that patients choose between medicines for different diseases and choose between medicines for the same disease (Elliott et al. 2007). Other qualitative research has depicted how patients assign differential worth and importance to their bolus of medications (Dolovich et al. 2008; Rifkin et al. 2010; Williams et al. 2008), often subjectively assessing which medications they could get away with not taking (Williams et al. 2008).

As described by qualitative research (Donovan and Blake 1992), advice from clinicians competes with other advice from one's social network, the media, and the internet. Advice from clinicians also competes with patients' lay beliefs about the illness and prescribed therapy, beliefs that may be based upon absent or faulty information or inaccurate guesses and assumptions (Britten et al. 2000). For example, in one of my focus groups, a woman adamantly refused to believe that she had hypertension because she was a personal trainer who exercised 6 days a week. Her diagnosis did not make sense to her given her level of physical activity and fitness. She never filled her prescription for antihypertensive therapy and remained untreated. Research has documented that patients report poor knowledge of their disease (Gascon et al. 2004), and they often fail to understand the rationale for prescription-medication therapy (Moen et al. 2009). Thus, while patients carry out their own cost–benefit analysis for prescription-medication therapy, they are doing do using non-biomedical criteria—criteria that make sense to them given the information available to them, whether it is accurate or not.

In addition to making a value proposition about each prescription medication, qualitative research has shown how patients *resist* taking prescription medications. The concept of resisting medications emerged when researchers moved toward understanding the patient perspective on medication taking vs. the biomedical perspective. Resisting medications implies patients' active engagement with their medication as well as their deliberate thoughts about their medications (Pound et al. 2005). The following quote by Marinker (1997) succinctly summarizes patients' near-universal reaction to taking medications for chronic disease—resistance: "Resistance to taking medicine seems to be quite profound and pervades different cultures and categories of disease. It is instinctual and complex" (p. 747).

I have conducted focus groups with over 2000 chronically ill patients, and resisting medications has been a ubiquitous theme in the focus groups. My focus-group participants describe starting prescription medications for a chronic disease as embarking on the point of no return (Bloom and McHorney 2013; McHorney 2011a, b). Other qualitative research has described the initiation of prescription medications as a last resort (Britten 1994; Donovan and Blake 1992; Mazor et al. 2010). Patients often liken starting long-term prescription medication therapy to being on the precipice of a cliff—once they jump off, there is no turning back. Many patients with asymptomatic chronic disease acknowledge they will have to eventually start prescription-medication therapy, but they want to hold out for the last possible moment. Once they start long-term prescription-medication therapy, patients express concern about dose escalation, therapy intensification, and about being prescribed multiple medications in a given therapeutic class. In qualitative interviews, patients report fear of being stuck with medications for the rest of their life (Britten 1994; Gascon et al. 2004).

Another way in which patients resist medications is articulating the desire, although not necessarily the behaviors, to fix their conditions themselves. Qualitative interviews have revealed patients' desire to sort their problems out themselves without medications (Britten 1994) and that attempted lifestyle change suppresses one's perceived need for mediations (Fung et al. 2010). I also have observed a tremendous amount of trying to effect lifestyle change among chronically ill adults in order to postpone having to take prescription medications.

People resist prescription medications largely because they have concerns about them (Pound et al. 2005). Qualitative research has described a variety of patient concerns, including that medications are seen as dangerous and addictive and that the treatment could be worse than the disease (Britten 1994). Descriptions of fear of side effects (Beune et al. 2008; Donovan and Blake 1992; Fung et al. 2010; Gascon et al. 2004; Hall et al. 2007; Mazor et al. 2010; Williams et al. 2008), fear of becoming dependent on, addicted, or tolerant to the medication (Beune et al. 2008; Conrad 1985; Donovan and Blake 1992; Gordon et al. 2007; Hall et al. 2007; Verbeek-Heida and Mathot 2006), and long-term safety concerns (such as organ damage) (Connell et al. 2005; Fung et al. 2010; Morgan 1995) are common in the qualitative literature on adherence. Emotions from patients about prescription medications that qualitative research has revealed include skepticism (Mazor et al. 2010), ambivalence (Remien et al. 2003), suspicion (Britten 1994), distrust (Britten 1994; Mazor et al. 2010), and antipathy (Britten 1994). Common adjectives for prescription medications unearthed from qualitative research with patients include unnatural (Britten 1994), harmful (Britten 1994), alien (Britten 1994), poison (Lumme-Sandt et al. 2000), damaging (Gascon et al. 2004), and artificial (Lau et al. 2008).

Patients' resistance to medications, by trying lifestyle modification, can be accounted for by Prospect Theory. Every choice made in life, including taking prescription medications, comes with uncertainty (Kahneman 2011). Uncertainty increases as the choice outcome is more remote as with prescription medications for chronic disease.

Prospect Theory holds that losses loom larger than corresponding gains—most people dislike losing more than they like winning (Kahneman 2011). This is called *loss aversion or risk aversion*. People evaluate options (losses and gains) relative to a reference point—usually the status quo. Status-quo bias is substantial, and uncertainty can intensify status-quo inertia (Samuelson and Zeckhauser 1988). Loss aversion favors stability over change and favors small rather than large changes. People tend to be more loss adverse when they perceive their current options as good (Kahneman 2011), such as "I can function just fine now" or my "high cholesterol is only borderline" or "I'm just pre-diabetic." It is loss aversion that leads many patients to try to effect lifestyle change to self-manage conditions such as diabetes, hypertension, and hyperlipidemia. By slightly modifying their diet or slightly increasing their physical activity, patients feel as if they are making self-determined progress toward risk reduction without prescription medications. A small daily goal, such as trying to consume less fat or salt or walking for 20 min, is easier to achieve than a long-term probabilistic goal, such as reduction in the risk of a myocardial infarction or stroke.

Prospect Theory can also explain patients' intentional non-adherence. For many patients, a new diagnosis and the attendant prescribed therapy represents uncertainty and ambiguity—it is a threat to the status quo. In situations involving uncertainty, most people value what they currently have more than what they might probabilistically achieve. Uncertainty adaptively causes people to be risk adverse, leading them to make safer bets. With prescription medications, the safer bet *from the patient perspective* may be to avoid risk through intentional non-fulfillment or non-persistence. The long-term benefits of prescription-medication therapy can seem intangible to patients, especially to patients with asymptomatic chronic disease. The long-term benefits of prescription medications are probabilistic and can be so far off in the future that they may be heavily discounted. Intentional non-adherence makes sense *from the patient perspective* because taking prescription medications represents a risky prospect in the short term (short-term financial and psychological costs, risk of side effects, opportunity costs) with uncertain long-term benefits (probabilistic reductions in mortality, morbidity, and complications) compared to the status quo (health as it is).

Due to status-quo bias and risk aversion, many people choose a sure thing (status quo or health as it is at the present time) over a gamble (uncertain health with prescription medications). Because of status-quo bias, patients might prefer to take chances with the health condition rather than take risks associated with prescription medications (Kucukarslan et al. 2012). Although the status quo without prescription medications may be second best from biomedical perspective, to many patients it represents a surer bet—health as it is at the present time.

Prospect Theory also holds that, in comparing choice options, people pay greater attention to and are influenced more by negative information than by comparable positive information (Levin et al. 1998). On the one hand, patients are deluged with negative information about medication side effects in direct-to-consumer advertising and patient–product inserts, while benefits are communicated mutedly. Negative press events about prescription medications can exacerbate patients' uncertainty about prescription medications. On the other hand, patients are inundated with positive information about nutraceuticals (over-the-counter or mail-order vitamins, minerals, supplements, and herbal remedies) in print advertisements and the internet. These products are not regulated by the US Food and Drug Administration and are not subject to fair-balance messaging or to clinical trials-based evidence of their efficacy.

My team recently reported that patients who placed more value on nutraceuticals (vitamins, supplements, and minerals) had lower perceived need for medications, more medication concerns, and less perceived medication affordability (McHorney et al. 2012). Qualitative research has revealed that many adults believe that over-the-counter and herbal remedies are less risky than prescription medications and that they are natural, safe, harmless, trustworthy, and familiar and can be used with less risk and with more confidence (Beune et al. 2008; Connell et al. 2005; Donovan and Blake 1992; Gascon et al. 2004; Lau et al. 2008; Lumme-Sandt et al. 2000; Morgan 1995). In resisting prescription medications, some patients alternate between prescriptions and nutraceuticals (Norreslet et al. 2010), others supplement pharmaceuticals with nutraceuticals (Connell et al. 2005; Donovan and Blake 1992; Donovan et al. 1989; Lumme-Sandt et al. 2000; Morgan 1995; Sale et al. 2006; Verbeek-Heida and Mathot 2006), while still others substitute pharmaceuticals with nutraceuticals (Donovan and Blake 1992). A loss-aversion lens helps to explain why patients migrate toward nutraceuticals and alternative medicine for the self-management of chronic disease—they are viewed as doing something good for oneself (natural remedies) and as actions involving little risk and little threat to the status quo.

In addition to resisting medications, qualitative research has also revealed that many patients *experiment* with medications in order to test their efficacy or assess the tractability or permanency of side effects (Arluke 1980; Bollini et al. 2004; Conrad 1985; Dowell and Hudson 1997). As Donovan and Blake (1992) found in their study of patients with rheumatoid arthritis, patients experiment with dosages and timing, and they choose to ignore their provider's advice by altering doses or timing on their own. Conrad observed the same dose and timing experimentation practices in patients with epilepsy (Conrad 1985). Both Conrad (1985) and Bollini (Bollini et al. 2004) observed in epilepsy and depression, respectively, that, by self-regulating doses or timing, patients were testing to see if they still had the condition, or if the medication was still working for them. As Marinker (1997) quips, "Just as all prescribing is an experiment carried out by the doctor so all medication taking is an experiment carried out by the patient" (p. 748). While most patients may have a difficult time assessing clinical efficacy outside of highly symptomatic conditions, adherence experimentation allows patients to test the disruptive effects of medications and to assess whether continuing to take medications, in the face of unpleasant side effects, is worth the effort or whether discontinuing the medication is worth the reoccurrence of symptoms (Dowell and Hudson 1997). With adherence experimentation, patients assess whether, in the short term, the medication is worse than the disease for which it was prescribed.

28.4.6 Shades of Gray

Finally, because adherence is neither personality, demographically, nor lifestyle driven, it is futile to label patients as adherers or non-adherers. Thus, as expressed in Tenet # 10, adherence represents shades of gray—patients can be adherent to some medications, non-persistent to others, and fail to fill others because they make separate decisions about each prescribed medication. A small, but growing, body of research has demonstrated that individual patients have selective or differential adherence to different medications within the same therapeutic class (Gardner et al. 2008; Marcellin et al. 2011) as well as those across different therapeutic areas (Batchelder et al. 2014; Chapman et al. 2005; Piette et al. 2007). Further, for a given medication, the same individual patient can exhibit different adherence over time (Viller et al. 1999).

Qualitative research has deftly shown how patients assign implicit priorities and worth to different medications (Dolovich et al. 2008; Lau et al. 2008; Rifkin et al. 2010) and make their own subjective trade-offs among them (Elliott et al. 2007), thereby leading to selective adherence to different medications (Rifkin et al. 2010; Williams et al. 2008). For example, in studying patients with chronic kidney disease, Rifkin found that most participants had implicit prioritization of their medications and this prioritization ranking was associated with likelihood of adherence. Multiple respondents had identified medications that they believed could be taken less frequently than prescribed. Medications that were less well understood by patients received lower priority and, sometimes, lower adherence. Similarly, Williams and colleagues (2008) described how some patients decided which medications they were going to take daily according to their perceived importance and that there were other medications they could get away with not taking. Elliott and colleagues (2007) also depicted how adherence to individual medications varied widely within individual patients, including non-adherence to some medications but not others and experimenting with medication regimens across different individual medications. An important conclusion of Elliott's research, consistent with Tenet #10, is that patients choose between and among their medications.

28.5 Implications of the Ten Tenets of Medication Adherence for Teaching and Education

A shroud of silence surrounds adherence in clinical practice—patients do not inform their clinicians when they fail to fill a newly prescribed prescription or intentionally stop taking one, and clinicians do not proactively discuss adherence, even when patients are not reaching their goals (Bokhour et al. 2006). Non-adherence is neither deviant nor irrational behavior on the part of patients. Non-adherence is a psychosocial marker for the fact that issues important to the patient were not addressed—that patients have unvoiced concerns and uncertainties about the condition and the prescribed therapy. Patients are alone with their doubts and uncertainty. The silence barrier that surrounds medication-taking and medication adherence needs to be broken. To achieve this, changes must take place in both teaching and education.

Clinicians need to be educated about the science of adherence just as they are educated about the science of pharmacology. While most physicians will call out non-adherence as a major contributor to patients, panels, and populations failing to reach their clinical goals, they are distressingly ignorant about the high rates of non-fulfillment, failure to obtain the first refill, and non-persistence, the fact that non-adherence is virtually invariant across diagnoses, and the fact that there are two principal determinants of non-adherence: (1) patients' lack of perceived need for a prescribed medication and (2) patients' side-effect and long-term safety concerns about a prescribed medication (McHorney 2009). As Tenet # 2 informed us, clinicians assume that *their* patients are adherent to their recommendations. It might be possible to neutralize this unproductive assumption through required courses on medication adherence for medical, nursing, and pharmacy students. While in practice, clinicians should be required to take continuing medical education on medication adherence every 5 years.

Clinicians are educated about the science of pharmacology, but they receive little or no training in *how* to prescribe. Current prescribing practices are as paternalistic and patriarchal as they were 25 and 50 years ago. Prescribing is one of the last tasks that are done during a visit, and, quite often, a prescription is given to a patient while the physician is exiting the examining room. Worse yet, in the twenty-first century, many clinicians use e-prescribing and prescribe in front of the computer and send the prescription to the reception area to be printed or directly to the designated pharmacy, thereby limiting even further the opportunity to satisfy patients' prescription medication information needs.

Clinicians need to be taught and mentored in both patient-centered prescribing and adherence communication in order to assess patients' health and medication beliefs at the time of prescribing and during the first few weeks of therapy when patients are establishing attitudes and beliefs about the diagnosis and the prescribed therapy and when the risk of non-persistence looms largest. Just as standardized patients are used in medical schools to evaluate a medical student's diagnostic skills, they can also be used to evaluate medical students' prescribing skills. Given the high rates of primary non-adherence and lack of first refill, clinicians must consider non-adherence as a rule-out condition, not a rule-in condition, and be taught the communication skills and styles necessary to have adherence discussions at the time of prescribing. Research has found that treatment-naïve patients have a twofold to fivefold greater risk of non-fulfillment, failure to obtain the first refill, and non-persistence compared to treatment-experienced patients (Shrank et al. 2010;

Vanelli et al. 2009). For this reason, clinicians need to prioritize treatment-naïve patients for patient-centered prescription-medication and adherence communication.

Two-thirds of all ambulatory visits involve a provided, prescribed, or continued medication (Raofi and Schappert 2006). Assuming most clinicians see 20–25 patients a day, approximately 13–17 patient visits a day involve one or more prescription medications. There is a fallibility of human memory when it comes to mundane, routine matters (Gawande 2009), such as when two-thirds of all patient visits involve a prescription medication. With mundane, routine matters (such as prescribing medications), clinicians can lull themselves into skipping steps (Gawande 2009), such as providing patient-centered information about the medication. Tenets #6 and #7 informed us of the dichotomy that exists in clinical practice between the information patients' desire about their prescription medications and what clinicians actually tell them, and the chasm is enormous. To close the information abyss that exists in clinical practice, clinicians need to adopt a vital-sign approach to prescribing. Vital signs are a routinized checklist for clinical examinations—missing one vital sign can be dangerous. As described by Atul Gawande in his book *The Checklist Manifesto* (2009), it is the seemingly simple clinical tasks that can be, and often are, routinely neglected by clinicians. Clinical checklists, not unlike aviation checklists, are a cognitive net: they make behavior and communication habitual, prevent simple failures of communication, and catch flaws of memory, attention, and thoroughness (Gawande 2009). Therefore, what is needed to standardize and formalize the act of prescribing and improve the consistency of prescription-medication information is a prescribing checklist to get the simple communication tasks—rationale for therapy, side effects, benefits, and alternative therapies—right 100 % of the time.

In addition to deeper teaching, coaching, and training on prescribing and adherence communication, physicians need access to data on the adherence of their patients or panels in order to demonstrate to them that non-adherence is indeed a palpable problem in their practice. Many health plans and systems routinely feedback to clinicians data on their care bundles, often for pay-for-performance purposes. With the growth of electronic medical records in US health care, along with e-prescribing and centralized pharmacy records, it is increasingly possible for clinicians to receive periodic reports on the adherence of individual patients and/or panels of patients. Feeding back to clinicians the adherence of their patients relative to other providers in the practice is a necessary, but not sufficient, condition for adherence enhancement. However, it offers a teachable moment to introduce continuing medical education on medication adherence, patient-centered prescribing, and a prescribing checklist. Further, physicians have been found to respond well to academic detailing or peer-to-peer teaching/educational outreach among and between clinicians. The generation of periodic adherence reports could identify the top and worst-performing clinicians in terms of medication adherence. The top-performing clinicians could assume the role of an opinion leader and effect clinician behavior and communication change by leading through example and sharing best practices vis à vis patient-centered prescribing and adherence communication.

Finally, because medication non-adherence is such a ubiquitous problem, there needs to be sustained public education about non-adherence. The National Consumers League has launched a public education campaign called Script Your Future that is being piloted in six US cities. The intent of the campaign is to help patients understand their condition and how to take medications correctly. The campaign provides patients with tools to manage their medicines and sample questions to help start a conversation with their doctor, pharmacist or nurse about prescription medications. Such a public-awareness campaign is long overdue. Instead of pharmaceutical companies spending five billion dollars each year on broadcast direct-to-consumer advertising and another billion dollars on internet promotion (Ventola 2011), imagine the types of public-awareness initiatives that could be piloted and evaluated with this amount of money.

If we seek to encourage evidence-based choice and consent for patients, physicians need to act as genuine and credible learned intermediaries by discussing with patients the rationale, benefits, risks, and alternatives of prescription-medication therapy. Until physician–patient communication at the time of prescribing is enhanced to address patients' unmet information needs and to manage their uncertainties about the diagnosis and the prescribed therapy, we inevitably face little measurable or sustainable improvement in medication non-fulfillment and non-persistence, which takes a $300 billion a year toll on the US health care system through unnecessary utilization, tests, and procedures and disease complications and morbidity (DiMatteo 2004). Adherence enhancement must not be viewed as adjunctive to treatment—it must be viewed as central to treatment and reimbursed accordingly. Toward that end, physicians need to be reimbursed for providing usable information about prescription-medication therapy instead of reimbursed solely for procedures and diagnoses. Accordingly, a CPT code needs to be instituted for medication adherence. Not assessing adherence in clinical practice is analogous to having the general internist manage hypertension without a blood pressure cuff; that is, having to predict blood pressure based on eyeballing the patient.

28.6 Conclusion

Qualitative research is a critical tool for discovering the insider perspective about disease, treatment, and adherence. As a result of the body of qualitative research on medication non-adherence, it is now understood that non-adherence is neither deviant nor irrational behavior on the part of patients. Non-adherence is a psychosocial marker for the fact that issues important to the patient were not addressed, and that patients have unvoiced concerns and uncertainties about the condition and the prescribed therapy. Moving forward, qualitative discovery research is needed on how disease and treatment beliefs are formed and what triggers improvements or deteriorations in those beliefs over time. Additional qualitative research is needed on how patients prioritize their health conditions and their prescribed medications. Qualitative research can also help inform future adherence interventions by understanding, from the patient perspective, the specific barriers that thwart adherence, and the specific facilitators that would enhance it.

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29

At Diagnosis and at Death: Using Qualitative Evidence to Inform Psychosocial Interventions in Oncology

Thomas F. Hack and Susan E. McClement

29.1 Introduction

Qualitative research has been conducted extensively to advance the field of psychosocial oncology, with numerous articles having been published based on qualitative inquiries into the experiences of cancer patients and their families. It may be argued, however, that qualitative research has not received sufficient credit for its contributions in the psychosocial oncology arena, relative to its quantitative research cousin. Psychosocial interventions are often validated in quantitative studies, primarily through randomized controlled trials (RCTs), and it is usually RCTs that are cited by researchers when referring to these interventions. Many clinicians will never come to understand or appreciate the critical role that qualitative research has played in the advancement and use of psychosocial interventions. The purpose of this chapter is to elucidate this role, using two case examples to demonstrate the significance of qualitative research evidence in the development, implementation, and evaluation of psychosocial interventions for cancer patients. The first case study addresses the period of diagnosis and treatment planning, specifically, the role of qualitative research evidence in advancing the use of consultation recordings in oncology practice. The second case study addresses the palliative phase of disease, describing the important contribution that qualitative research has made in the development, evaluation, and use of dignity therapy.

29.2 Case 1: Diagnosis and Treatment Planning, Use of Consultation Recordings

Over the past decade, there has been an increase in empirical examinations of consultation recording use in oncology. Cancer patients are bringing recording devices into consultation rooms in increasing numbers, to capture the important information imparted by oncology professionals. Cancer centers across the globe, and in some cases individual oncologists, are grappling with how best to respond to this growing patient demand, a demand facilitated in part by technological advances that make it possible to record consultations easily with cellular phones and small, portable computers. Consultation recordings provide patients with several benefits, including enhanced recall of information, reduced anxiety, and improved communication with family members and friends. The mounting

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evidence in support of consultation recording use comes from both qualitative and quantitative sources. The role of qualitative research efforts in this process is likely to be overshadowed in the future as increasing numbers of RCTs are conducted and reported in the literature. The purpose of this first case is to demonstrate the significant impact that qualitative research has had in establishing the need for, and value of, consultation recording use in oncology practice.

Our discussion of the growth in the use of consultation recordings in oncology begins over 35 years ago. At that time, Weisman and Worden (1976–1977) published a landmark research paper showing that the first 90 days following a cancer diagnosis is a critical period in the adjustment effort, a time period unlike any other when psychosocial well-being is particularly compromised. It is during this period that patients come to terms with a life-threatening diagnosis, are provided with treatment alternative(s), and commence treatment. During this time patients disclose their diagnosis to family, friends, and colleagues, may become too ill to work, and are, not surprisingly, likely to experience uncommonly high levels of anxiety and depression. Weisman and Worden (1976–1977) conducted interviews with 120 cancer patients at approximately 1-month intervals over a period of 3–4 months. Their rich, qualitative data is among the earliest studies in the field of psychosocial oncology to show that patients are highly vulnerable to distress during the first 100 days and that emotional distress is associated with regret, pessimistic mood, and social concerns including marital instability.

It is during this especially vulnerable period of time post-diagnosis when cancer patients have the greatest opportunity to exercise involvement in decision-making if they so desire and to the extent that they are able. In 1987, one decade after the publication of Weisman and Worden's (1976–1977) influential paper, Dr. Lesley Degner, Distinguished Professor Emeritus from the University of Manitoba, and her colleague Dr. Janet Beaton published the book *Life-death decisions in health care*, a grounded theory account of the contextual factors that influence how treatment decisions are made (Degner and Beaton 1987). Their theory—a product of qualitative interviews with cancer patients—forms the basis of the Control Preferences and Information Needs Scales, measurement tools which are employed internationally to capture the degree of involvement in treatment decision-making patients prefer, as well as their preferences for information. The Control Preferences Scale (Degner and Russell 1988; Degner and Sloan 1992) assesses the role in decision-making that a patient prefers. The scale is composed of five card statements that correspond to active, collaborative, and passive roles in decision-making. Patients rank the five cards from the most to least preferred role they wish to play in decision-making. The five card statements include the following: active role ("I prefer to make the decision about which treatment I will receive," "I prefer to make the final decision about my treatment after seriously considering my doctor's opinion"); collaborative role ("I prefer that my doctor and I share responsibility for deciding which treatment is best for me"); and passive role ("I prefer that my doctor makes the final decision about which treatment will be used, but seriously considers my opinion," "I prefer to leave all decisions regarding treatment to my doctor"). The Information Needs Scale (Degner et al. 1997) is comprised of nine items that patients rank in order according to preference. These nine items include the following:

1. Information about how far advanced the disease is and how far it has spread
2. Information about the likelihood of cure from the disease
3. Information about how the treatment may affect my ability to carry on my usual social activities
4. Information about how my family and close friends may be affected by the disease
5. Information about caring for myself at home
6. Information about how the treatment may affect my feelings about my body and my sexual attractiveness
7. Information about different types of treatment and the advantages and disadvantages of each treatment

8. Information about whether my children or other members of the family are at risk of getting breast cancer
9. Information about possible unpleasant side effects of treatment

These influential scales, and the empirical studies surrounding them, have made a large impact on psychosocial oncology research. In a recent citation analysis of Canadian psychosocial oncology researchers (Hack et al. 2014), Dr. Degner was listed as having the top two most highly cited journal articles in the history of psychosocial oncology. These publications (Degner et al. 1997; Degner and Sloan 1992), detailing the information needs and decisional preferences of cancer patients, have influenced the shift from a paternalistic clinical practice style to one of consumerism and patient empowerment. We are again, however, reminded that any associated shifts in attitude and practice associated with the uptake of Dr. Degner's research have her qualitative grounded theory work as its origin.

Dr. Degner's groundbreaking book and subsequent research studies over the next decade played an influential role in shaping the design of a mixed methods analysis of the decisional roles and information preferences of women diagnosed with breast cancer (Hack et al. 1994). This work demonstrated that while almost all women with breast cancer who desire active involvement in decision-making also want to receive detailed information about their disease and treatment, women who desire less decisional control are divided, with half wanting detailed information and half desiring minimal information or no information at all. The content analysis of the transcripts of patient interviews detailed the reasons for patients' preferences for decisional control and information. Patients said their degree of preferred involvement in decision-making was shaped by the severity of their diagnosis, educational attainment, coping style, personality, faith in their oncologist, and will to live. These qualitative findings spawned future studies into the relationship between coping response, decisional role, and psychological adjustment in women with breast cancer (Hack and Degner 1999, 2004; Hack et al. 2006a). Collectively, these studies generated findings that shaped emerging typologies of patients coping with life-threatening cancer. Of particular clinical importance was a group of patients characterized by avoidance and passivity, seemingly depressed, relatively less educated, and not wanting to receive disease or treatment information or be involved in treatment decision-making. These patients emerged as a vulnerable cohort, a group at risk for depression and decreased cancer-specific quality of life. These findings raised the question, "What can be done to assist these vulnerable, depression-prone patients who react to their cancer diagnosis with avoidance?" If not wanting to receive information, i.e., avoidance coping, is associated with poor psychological adjustment during the first few months following a cancer diagnosis and if this low level of adjustment may persist over time, is there an intervention that can be administered to empower these patients, to increase their desire for information and decisional control? The answer to this research question appeared to be yes. The provision of recordings of initial treatment consultations to these newly diagnosed patients seemed a likely intervention that might equip patients with the information and support needed to understand their disease, prognosis, and treatment options, thereby enhancing their ability to be more actively involved in making decisions affecting their health and well-being.

Most of the research studies aimed at evaluating the consultation recording intervention took place during the period from 1989 to the present, with the first observational study reported in 1989 (Hobgin and Fallowfield 1989) and the first RCT reported in 1992 (Deutsch 1992). Several other RCTs and observational studies were conducted during this period, with a sufficient pool of studies to warrant two review articles (McClement and Hack 1999; Tattersall and Butow 2002) and two Cochrane Collaboration systematic reviews (Scott et al. 2007; Pitkethly et al. 2008). From among the many psychoeducational interventions that have been developed to assist cancer patients with their information needs, decision support needs, and psychosocial needs, the Cochrane Collaboration systematic reviews identified the provision of audio-recordings of the initial oncology consultation as empirically justified. Considering all of the research findings generated in evaluations of consultation recording use, it can be concluded that consultation recordings enhance information recall, reduce anxiety, enhance the degree to which patients feel informed about their disease and treatment, and increase patient satisfaction with communication (Bruera et al. 1999; Davison and Degner 1997; Deutsch 1992; Dunn et al. 1993; Ford et al. 1995; Hack et al. 1999, 2003, 2006b, 2007; Hobgin and Fallowfield 1989; Johnson and Adelstein 1991; McHugh et al. 1995; North et al. 1992; Reynolds et al. 1981; Ong et al. 2000; Tattersall et al. 1994).

The Cochrane review identified information recall and satisfaction with care as the patient outcomes with the strongest empirical support. The authors concluded that recordings and written summaries of consultations in oncology "may benefit most adults with cancer [...] most patients find them very useful" (Pitkethly et al. 2008, p. 2), and "if recordings/summaries are useful to people and improve their satisfaction with care and their information recall, perhaps this is sufficient to justify their wider use in cancer care" (Pitkethly et al. 2008, p. 10). Despite this positive clinical recommendation, the authors of the review pointed out that limitations and inconsistencies of methods across studies produced evidence that is sometimes weak. Several research gaps were noted, including the need for "more rigorous trials" addressing outcomes such as "psychosocial adaptation and coping behavior and the quality of relationships between patients and their families and healthcare providers" and studies addressing "differential effects on cancer sub-populations," determining the value of consultations/summaries at "later stages of cancer care," and identifying "which groups of patients will most benefit from receiving summaries/recordings" (Pitkethly et al. 2008, p. 10). The authors also called for qualitative research "to explore the ways in which patients use and value these interventions" (Pitkethly et al. 2008, p. 10). These summary points of the Cochrane review highlight that, despite promising empirical evidence generated from primarily quantitative studies, there is a gap in the evidence base that is perhaps best addressed using qualitative research methods. Research addressing the impact of consultation recordings on relationships between cancer patients and their families and oncology professionals, differential benefits realized by different subgroups of patients, and ways that patients use and value their recordings are all best addressed with qualitative research techniques.

Despite the empirical evidence supporting the provision of consultation recordings, uptake of this intervention into clinical oncology practice has not been widespread. Following the Cochrane review recommendation for wider use of consultation recordings in clinical practice, a knowledge translation study was conducted to systematically and prospectively examine the process of implementing consultation recording practice into primary treatment consultations in oncology (Hack et al. 2013). This study identified critical implementation factors, including the provision of evidence to oncology staff; addressing medicolegal concerns; securing the support of consultation recording "champions" from among the chief executive officer (CEO), disease site chairs, and senior administrative nurses of the cancer centers where consultation recording was going to be used; and securing the commitment of resources to pay for digital recorders and Universal Serial Bus (USB) memory storage keys.

The methods used in this knowledge translation study were mostly qualitative. Extensive interviews with oncology patients and staff were conducted to identify implementation barriers and ways to remove them. Patient interviews were conducted to explore the ways that patients use and value consultation recordings, including the benefits derived from listening to them (Hack et al. 2013). This latter research aim is significant because it marks the first study of its kind, to our knowledge, to elicit from patients in a systematic way the benefits derived from listening to the consultation recording. Previous RCTs used patient outcome measures based on assumptions of what the benefits were to patients. These listed benefits tended to be those that could be measured with existing psychometrically sound quantitative-based questionnaires. It is not surprising, therefore, that outcome measures in previous studies measured patient outcomes such as quality of life and psychosocial well-being, in addition to quantifiable outcome indicators, such as the amount of information recalled from the consultation and the number of times that patients listened to a portion of the recorded consultation. That the use of validated psychometric instruments would be so prevalent in earlier consultation recording studies, or most studies in psychosocial oncology generally, may be a function of the difficulties in securing research funds from granting agencies for studies that lack such measures. A researcher takes a risk in wanting to utilize mostly qualitative methods in a research study, with some grant reviewers viewing such applications with relative disfavor in comparison to proposals with quantitative methods.

The qualitative methods used in this treatment consultation audio-recording knowledge translation study enabled the identification of four categories of benefit that were consistently reported by patients: (1) reduced anxiety, (2) increased recall of information, (3) improved communication with family members and the oncology professional team, and (4) more informed decision-making (Hack et al. 2013). These benefits, and the patient exemplars describing each of them, have proven invaluable in the service of advancing the case for consultation recording use in oncology. This study was successful in facilitating the standard, routine offering of consultation recordings to newly diagnosed prostate cancer patients in the Genitourinary Tumor Site Group at the Tom Baker Cancer Centre in Calgary, Alberta, Canada, and women newly diagnosed with breast cancer in the surgical oncology clinic at the Breast Health Centre in Winnipeg, Manitoba, Canada. Most recently, CancerCare Manitoba in Winnipeg, Manitoba, Canada, became the first provincial cancer agency to support the implementation of consultation recordings of "pivotal" treatment consultations for all patients throughout the province. "Pivotal" appointments are those during which a new treatment regimen is discussed, such as the initial treatment consultation, the disease recurrence consultation, or the consultation to discuss a switch from curative to palliative care.

Thirty-seven years have passed since Weisman and Worden (1976–1977) used qualitative methods to establish the first 100 days post-diagnosis as a time of emotional vulnerability for cancer patients. After approximately 25 years of research into decisional control preferences and information needs of cancer patients and several observational studies and RCTs, it was a qualitative study of the benefits derived by cancer patients from listening to consultation recordings that led to the adoption of consultation recording use throughout a cancer center. Quantitative studies generate key evidence in support of psychosocial interventions, but we must not lose sight of the value of qualitative research evidence in supporting the development, evaluation, and implementation of these tools. While consultation recording RCTs are ongoing, we should be mindful of the integral value of qualitative research to these efforts and of the particular necessity of incorporating qualitative methods into program implementation trials.

29.3 Case 2: Palliative Care, Dignity Therapy

Dignity Therapy (DT) (Chochinov 2012) is a new, brief, individualized intervention designed to create a sense of meaning and purpose, and thereby reduce suffering, in patients nearing death. Through a series of semi-structured conversations with someone trained in the delivery techniques of DT, this novel therapeutic approach guides patients through a reflection of their lives lived, in a manner that creates meaning and peace for them. One tangible product of DT is a legacy document that summarizes the value and meaning of the patient's life that is created to enhance meaning for both the patient and family. This legacy document can be read and shared by successive generations after the death of a patient, serving a generativity function for the patient and family.

DT is regarded as a successful psychosocial intervention among clinicians in palliative care, having been studied and used in more than a dozen countries to help palliative patients and their caregivers prepare emotionally for impending death. International DT training workshops are held annually by Dr. Chochinov's team. The effectiveness of DT has been established against the gold standard of the randomized controlled trial, but a review of the program of research that led to the development of DT shows the critical role played by qualitative research. Qualitative research has shaped the content and practice of DT and has been influential in the development of related dignity-themed interventions.

DT has its roots in the late 1990s, when the founder of DT, Harvey Max Chochinov, Distinguished Professor from the University of Manitoba, was inspired by a Dutch study (Van der Maas et al. 1991) that reported on physicians' accounts of their patients' requests for a hastened death. The number one reason (mentioned in 57 % of cases) identified by these physicians was that their patients expressed a loss of dignity. This finding was as perplexing as it was informative. Though it might have been true that patients felt they no longer had sufficient dignity to continue living, physicians were unclear as to why patients felt this way. Obviously, but ironically, the deceased patients could not be contacted to determine why they felt a loss of dignity. Regardless of the degree of insight that patients had into their failing medical conditions and the extent to which patients felt that they "owned" the decision to have a hastened death, the critical question raised by Dr. Chochinov was, "What is dignity from the perspective of dying patients?" The concept of dignity felt as clinically meaningful and fundamental as it was nebulous and challenging to define.

The work to define and delineate the concept of dignity is important in palliative care, because it provides an overarching framework that can guide physicians, patients, and families in defining the objectives and therapeutic considerations fundamental to end-of-life care. With this in mind, Dr. Chochinov decided to generate a definition of dignity based on the experiences of dying patients themselves. He and his team conducted semi-structured interviews with 50 patients with advanced cancer. Given that this qualitative study is the cornerstone to 15 years of subsequent research into understanding dignity and developing practical interventions to bolster it, the questions that composed the semi-structured interview guide are presented below:

1. In terms of your own illness experience, how do you define the term dignity?
2. What supports your sense of dignity?
3. What undermines your sense of dignity?
4. Are there specific experiences you can recall in which your dignity was compromised?
5. Are there specific experiences you can recall in which your dignity was supported?
6. What would have to happen in your life for you to feel that you no longer have a sense of dignity?
7. Some people feel that life without dignity is a life no longer worth living. How do you feel about that?
8. Do you believe that dignity is something you hold within you, and/or is it something that can be given or taken away by others?

(Chochinov et al. 2002a)

The qualitative analysis of interview transcripts emerged in the form of the Dignity Model—an empirically derived theoretical framework for understanding the construct of dignity and the related complexities of psychological distress in those nearing death (Chochinov et al. 2002a). The Dignity Model describes three primary domains that influence a dying patient's sense of dignity. These include: (1) illness-related concerns (issues derived from the illness itself which can impinge on the patient's sense of dignity); (2) the dignity-conserving repertoire, comprised of two themes, dignity-conserving perspectives (internally held beliefs and attitudes that help to promote dignity) and dignity-conserving practices (personal approaches or techniques that patients use to bolster or maintain their sense of dignity); and (3) the social dignity inventory (the quality of interactions with others which enhance or detract from a patient's sense of dignity).

The various domains and themes subsumed within the Dignity Model provide a broad and inclusive range of issues and concerns that may influence a dying patient's sense of dignity and psychological distress. The first domain, illness-related concerns, has two themes: (1) level of independence, which is influenced heavily by cognitive acuity and functional capacity, and (2) symptom distress, which encompasses physical and psychological distress. The two themes of the dignity-conserving repertoire domain have subthemes. Within the dignity-conserving perspectives theme are the following subthemes:

1) Continuity of Self
2) Role Preservation
3) Generativity
4) Maintenance of Pride
5) Hopefulness
6) Autonomy/Control
7) Acceptance
8) Resilience/Fighting Spirit

The subthemes within the dignity-conserving practices theme include the following:

1) Living in the Moment
2) Maintaining Normalcy
3) Seeking Spiritual Comfort

The third domain, The Social Dignity Inventory, is composed of the following themes:

1) Privacy Boundaries
2) Social Support
3) Care Tenor
4) Burden to Others
5) Aftermath Concerns

(Chochinov et al. 2002a)

Qualitative research made it possible to explicate the construct of patient dignity, using a grounded theory approach. With the Dignity Model in hand, Dr. Chochinov set out to validate the model in a series of studies that employed primarily quantitative methods. The first step in this process was to administer measures to patients that appeared to capture the domains and themes of the Dignity Model and compare the scores on these measures to a single item that had patients rate their degree of dignity (Chochinov et al. 2002b). In addition, a factor analysis of these administered measures was performed and the factors in the factor solution were used to predict dignity, as measured by the single dignity item (Hack et al. 2004). These studies showed that 46 % of patients reported at least some, or occasional, loss of dignity with 7.5 % of patients reporting that dignity was a great source of concern. These latter patients were more likely than the other patients to report psychological and symptom distress, heightened dependency needs, and loss of will to live (Chochinov et al. 2002b). The factor analysis study showed that dignity was best predicted by hopelessness/depression and intimate dependency (Hack et al. 2004). The practice applications of the Dignity Model have been detailed by McClement et al. (2004).

The second step in the model validation process was to construct a list of 22 dignity-related items that represented the themes and subthemes of the Dignity Model, to determine the extent to which patients receiving palliative care felt the items were related to their sense of dignity. All but one of the 22 items were endorsed by more than 50 % of the patients; the two most heavily endorsed items (both at 87.1 %) were "not being treated with respect or understanding" and "feeling a burden to others" (Chochinov et al. 2006).

Having validated the Dignity Model, Chochinov and his team set out to develop and validate a questionnaire to measure dignity-related distress in palliative care patients. This process involved writing questionnaire items based on the themes and subthemes of the Dignity Model, administering the questionnaire to a large sample of patients in palliative care, and determining the psychometric strength of the questionnaire. The 25-item questionnaire—the Patient Dignity Inventory (PDI)—was administered to 253 palliative care patients and shown to have strong psychometric properties (Chochinov et al. 2008, 2009).

Dignity Therapy (DT) was introduced in the first paragraph of this case example, and it is at this point in the chapter where we revisit it. DT is based on qualitative data obtained from dying cancer patient's reflections on dignity—how it is defined, what enhances it, and what detracts from it. The Dignity Model was created from the rich data provided in the transcripts of these patient interviews. The model has been validated, and from it the PDI was created and validated. With a model and associated PDI in hand, the next goal of

Chochinov and his team was to develop a psychotherapeutic approach to enhance the psychological and existential well-being of patients in the palliative phase of their disease. While DT borrows from other psychotherapeutic traditions such as supportive therapy, logotherapy, existential psychotherapy, and the approaches of life review and life narrative, DT is unique in being grounded in a qualitatively developed and empirically evaluated model, based on patients' self-reported perceptions of dignity (Chochinov et al. 2004). Furthermore, the process of DT is qualitative in its process and outcome deliverable. With respect to process, DT is guided by a question protocol, a series of questions designed to elicit salient aspects of the patient's life history, descriptions of important roles played in life, accomplishments, wishes and dreams, life lessons, and advice and final words for loved ones. The question protocol for DT appears below:

- Tell me a little about your life history; particularly the parts that you either remember most or think are the most important? When did you feel most alive?
- Are there specific things that you would want your family to know about you, and are there particular things you would want them to remember?
- What are the most important roles you have played in life (family roles, vocational roles, community service roles, etc)? Why were they so important to you, and what do you think you accomplished in those roles?
- What are your most important accomplishments, and what do you feel most proud of?
- Are there particular things that you feel still need to be said to your loved ones, or things that you would want to take the time to say once again?
- What are your hopes and dreams for your loved ones?
- What have you learned about life that you would want to pass along to others? What advice or words of guidance would you wish to pass along to your (son, daughter, husband, wife, parents, others)?
- Are there words or perhaps even instructions that you would like to offer your family to help prepare them for the future?
- In creating this permanent record, are there other things you would like included?

(Chochinov 2012)

With respect to outcome, patients are given an edited, "cleaned," typed copy of their responses to the protocol questions. This is a legacy or generativity document they can share or bequeath to family and loved ones. Patients play an active role in editing their legacy document and have final say in approving its content. This legacy document has proven a powerful tangible outcome of DT, with patients sometimes choosing to have portions of the document read aloud at their funeral. In this way, the power of the patient word, obtained qualitatively through patient interviews, can speak volumes even after a patient's death, sustaining comfort and meaning to loved ones left behind.

In a randomized controlled trial of DT effectiveness, those who received DT experienced significant reductions in suffering and depression. DT, in comparison to both client-centered care and standard palliative care, was significantly more likely to be helpful to patients and family members and to enhance dignity and quality of life (Chochinov et al. 2011). DT has proven popular among palliative care patients, with 91 % of those receiving DT expressing satisfaction with it (Chochinov et al. 2005). Results from a qualitative analysis of post-DT interviews with patients showed that patients used DT to express affirmations of love, expressions of regret, and the recounting of memories. Post-DT interviews with family members elicited equally positive feedback, indicating that DT improves the grief process and that the legacy document will provide comfort to them in the future (McClement et al. 2007).

Qualitative research played a very important role in the next dignity-related project undertaken by Dr. Chochinov's team (Hack et al. 2010). The team conducted a qualitative analysis, using a grounded theory approach to code 50 DT legacy documents of cancer patients. The goal was to review these documents to determine what matters most to dying cancer patients as they approach death. Without preconceived notions or hypotheses driving this exploratory exercise, the aim was to capture the voices of the dying, to learn whether there were defining features or common themes in these legacy documents. As the legacy documents began to be coded and analyzed, a defining feature of the documents began to emerge. The passages of patient text revealed core values that appeared to capture the meaning of the patients' lives. When checked against the existing empirical literature, these values were strikingly similar to the "terminal" values outlined in the seminal writing of Rokeach (1973) on the topic of values. The most common core value in the legacy documents was "family," appearing in 92 % of the transcripts. The next most common core values were "pleasure" (36 %), "caring" (32 %), "a sense of accomplishment" (26 %), "true friendship" (22 %), and "rich experiences" (16 %). Most of the documents were defined by one or two core values, though there were occasionally one to four core values observed. These findings are important in suggesting that meaning-making interventions in palliative care, including DT, may be beneficial for patients by providing patients an opportunity to clarify their values and to articulate the values that serve as personal benchmarks of meaning in their lives. Indeed, Viktor Frankl, the founder of logotherapy, said that we should not pity the elderly because, despite not having a future to look forward to, "they have realities in the past – the potentialities they have actualized, the meanings they have fulfilled, the values they have realized." (Frankl 1985, p. 175).

The next research study conducted by Dr. Chochinov's team was an examination of 90 psychosocial oncology professionals' perceptions of the value of using Patient Dignity Inventory (PDI) in informing their clinical practice and, more specifically, in identifying distress in their patients (Chochinov et al. 2012). The results of this quantitative study showed that the PDI facilitated their clinical work (reported by 81 % of clinicians) and that it revealed previously unreported concerns of the patient (76 %). This study is significant to our examination of the value of qualitative research to informing psychosocial interventions given the study that followed. The findings of this study raised the question of whether psychosocial clinicians could identify the therapeutic factors that are most helpful in mitigating patient psychosocial distress. With this aim in mind, Chochinov and his team conducted focus groups with 78 experienced psychosocial clinicians from across Canada. Each clinician participated in three focus groups, and 29 focus groups were held across Canada over a 2-year period. Transcripts of the focus groups were analyzed using content analysis and constant comparative analysis techniques. The product of this analysis was a Model of Therapeutic Effectiveness (Chochinov et al. 2013). According to this model, there are three primary domains that contribute to therapeutic effectiveness. These include: (1) personal growth and self-care, (2) therapeutic approaches, and (3) creation of a safe space. Three overlapping or hybrid domains are the product of combinations of two of these domains. The hybrid domains include: (1) therapeutic humility, (2) therapeutic pacing, and (3) therapeutic presence. Therapeutic effectiveness is optimized when all three primary domains (and by inference hybrid domains) are operating to their maximum potential. Member checking with the participating clinicians was performed to validate this model, and item agreement percentages were calculated. These validation efforts proved positive, and this model is now used as a teaching and evaluative tool in education and health service delivery.

What began 15 years earlier as an attempt to solicit perceptions on dignity from patients receiving palliative care contributed over subsequent years to the development of a Dignity Model (informed by patient perspectives), the Patient Dignity Inventory (a psychometrically sound tool to capture areas of dignity-related distress), the Dignity Therapy psychotherapeutic intervention, and the Model of Therapeutic Effectiveness. These interventions would not have been possible without the qualitative research that underpins the Dignity Model, and upon which all subsequent interventions were derived.

29.4 Conclusion

Clinicians, administrators, and researchers alike look to gold standard evidence to support healthcare interventions. The gold standard in research continues to be the RCT, with the contributions of qualitative research too commonly left behind to gather dust on bookshelves or reside unviewed in a digital library. The field of psychosocial oncology has been populated over the past two decades with a plethora of interventions designed to satisfy the needs of cancer patients and their families. These interventions were designed with patient needs in mind, and the instruments used to evaluate the success of these interventions are commonly those that measure patient outcomes. Given that these psychosocial interventions, and the measures used to assess their impact on patient outcomes, have been developed in the service of patient need, it is worthwhile to ponder how these patient needs initially came to be known. In the majority of cases, these needs were demonstrated using qualitative—not quantitative—research methods.

In the years to come, as RCTs and other quantitative approaches are used to demonstrate the effectiveness of consultation recording use, Dignity Therapy, and other psychosocial interventions in oncology, it is likely that some of the essential, foundational qualitative research findings that inform these interventions will be ignored or forgotten. The two case examples illustrated in this chapter will hopefully serve as reminders of the often critical, yet frequently undervalued, role that qualitative research plays in the development, implementation, and evaluation of psychosocial interventions in oncology.

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Change Process Research in Psychotherapy

30

Jeanne C. Watson and Evelyn J. McMullen

30.1 Change Process Research: A Qualitative Approach

Change process research dates back to the 1950s when Carl Rogers and his colleagues at the University of Chicago began to study the process of change as they listened to audio recordings of clients' sessions. The advent of the new technology had made it possible to review what actually transpired between clients and therapists in order to observe and understand the different activities in which they engaged, and begin to isolate more effective ways of intervening from less effective ones. Change process research is rooted in a description of processes that are central to psychotherapy. As such they draw on the investigators' understanding of the phenomenon under study as well as his or her attempt to make sense of the data that is being examined. Qualitative research is an empirical undertaking that seeks to illuminate "the *how* or *what* (i.e., a process) versus *why* (i.e., etiology of outcome) aspects of a phenomena" (Hays and Singh 2011, p. 4). This type of process research analysis is an attempt to find meaning and order in a complex amount of data so that it can be more easily comprehensible and contribute to our understanding of the process of psychotherapy as well as the roles of the different participants and their impact on each other.

Greenberg and Pinsof (1986) observed in their classic text on Process Research, that the word "process" encompasses a range of meanings. They noted that: "Dictionary definitions emphasize three related aspects of process: activity over time, directional change, and movement towards completion" (Greenberg and Pinsof 1986, p. 3). Heppner et al. (1992) captured some of the complexity of process research in their definition, and described it as:

> […] attempts to characterize what changes occur during counseling. Thus, process research may attempt to (1) describe the client, counselor, group, family, or interactions, (2) specific change in the behavior or actions of the client, counselor, group, or family over time, or (3) link one or more of these process variables to client outcome." (p. 320)

The goal of process researchers is to better understand and identify the active ingredients of different therapeutic approaches so as to develop more effective treatments. Research on the process of change and the identification and development of process outcome links can inform the development of theory as well as test it in order to improve the effectiveness of treatments (Greenberg and Pinsof 1986; Greenberg and

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Watson 2006a; Hill and Lambert 2004; Lambert and Hill 1994; Orlinsky et al. 1994). Process research highlights differences between good and poor outcome clients leading to more responsive treatment interventions that are more broadly applicable to a range of client groups.

Two main streams of inquiry inform process research, one is the study of clients' and therapists' *subjective or covert experience* and the second is the study of clients' and therapists' *observable or overt experience and behavior* during the change process. Both of these streams use a qualitative approach to study phenomena in order to describe and understand them and to find meaning in the data. By incorporating the study of therapists and clients overt behavior in psychotherapy we are broadening the usual definition of qualitative inquiry to include an analysis of texts as well as, "[…] the study of a phenomenon or research topic in context" as proposed by Hays and Singh (2011 p. 4). Corbin and Strauss (2009) propose a similar view of qualitative analysis defining it as: "A process of examining and interpreting data in order to elicit meaning, gain understanding, and develop empirical knowledge" (p. 1). This is one of the primary objectives of process research.

30.2 Quantitative Versus Qualitative Approaches to Change

Psychotherapy research consists of two distinct strands to investigate what works: outcome research and change process research. Outcome research relies on conventional quantitative methods to evaluate outcome, whereas change process research is conducted using a variety of qualitative approaches to study change. Outcome research is focused on predicting outcomes and identifying which type of psychotherapy is most effective and is less concerned with describing processes and procedures. The question of which psychotherapy is more effective is often explored using Randomized Clinical Trials (RCT), a method used in pharmacotherapy to test the effectiveness of different drug treatments.

A number of problems have been identified with outcome studies using quantitative methodologies. One problem is that psychotherapy approaches that have not been tested or received much empirical attention are deemed ineffective in the absence of information. Another problem is that of the researcher allegiance effect. Research has shown that studies that have been conducted by therapists and/or researchers with an allegiance to the specific approach being investigated show a higher likelihood that their preferred approach will be supported as more effective than the alternative or control treatment (Elliott and Freire 2008; Luborsky et al. 1975). Moreover, it has been suggested that control treatments may be negatively impacted if non-experts or therapists without adequate training in the approach deliver the therapy (Hollon 1999; Lambert 1999; Luborsky et al. 1975, 1999). Treatments that are delivered by therapists without sufficient training cannot be considered bona fide or authentic. Therapist allegiance effects call into question the findings that one treatment is more effective than another.

Another problem with RCTs is that the findings are molar, and thus, the active ingredients of how treatments work are not clearly visible. In an attempt to address this question researchers have investigated whether the common, or so-called relational, aspects or the more specific aspects of treatment (e.g., interventions like thought records, homework, two-chair work, or transference interpretations) lead to change (Beutler 1995; Greenberg and Rice 1981; Grencavage and Norcross 1990; Messer and Wampold 2002). While this debate is important and has contributed valuable findings to the field, psychotherapy research continues to identify processes that are generally effective but has not yet adequately addressed questions raised more that 40 years ago related to which treatment for which client, and when (Beutler et al. 2012; Critchfield 2012; Lambert and Barley 2001; Norcross and Wampold 2011; Smith and Grawe 2005). These questions remain pressing, especially if we consider the number of people who do not respond to treatments (Edlund et al. 2002; Mash and Hunsley 1993; Wang 2007; Wierzbicki and Pekarik 1993).

If psychotherapies are to be optimally effective, it would be helpful to be able to differentiate among client populations as well as treatments methods to develop ways of working that could be tailored for specific clients.

30.3 The Study of Clients' Subjective Experience

A number of different methods have been used to study clients' and therapists' inner subjective experiences of participating in psychotherapy. Qualitative approaches to the study of the change process in psychotherapy use interviews with the participants to gain access to and develop an understanding of clients' inner, subjective experience. These interviews can be conducted at any point in time either immediately after a session, perhaps with the assistance of a video-recording of the session to assist with recall, at the end of therapy or some time thereafter. The information gleaned from these interviews is then subject to qualitative analysis to try to distill common themes, categories, and views of the experience to inform psychotherapy process research and illuminate the subjective experience of the participants in the psychotherapy encounter.

Examples of this type of work include: *grounded theory* studies conducted by Rennie (1994, 2001), Watson (Watson and Rennie 1994), Bolger (Bolger 1999; Greenberg and Bolger 2001), and Timulák and Lietaer (2001); *theme analyses* studies conducted by Goldman (1997) and Kagan (2003); *content analysis* employed by Bachelor and colleagues (Bachelor 1995; Bachelor et al. 2007), as well as Lietaer and colleagues (Lietaer 1992; Lietaer and Neirinck 1986; Vanaerschot and Lietaer 2007, 2010).

In his studies of the clients' subjective experience during psychotherapy, Rennie (1994, 2001) highlighted how many aspects of clients' inner experiences are not revealed or shared with therapists. Using the method of Interpersonal Process Recall (IPR; Kagan 1975), Rennie (1994, 2001) conducted post-therapy interviews with clients to better understand their subjective experience of participating in psychotherapy. The interview data was analyzed using grounded theory methodology (Glaser and Strauss 1967). His analyses highlighted the role of clients' deference (Rennie 1994) and clients' reflexivity (Rennie 2001) in the change process. Rennie's analyses (1994) revealed a general tendency in clients to be deferential to the therapist, which he suggested was one way in which the clients protected and fostered the therapeutic alliance. Some of the reasons clients shared for being deferential were being concerned about their therapist's approach, being fearful of criticizing their therapist, wanting to understand the therapist's frame of reference, and wishing to meet their perceived expectations of the therapist (Rennie 1994). Findings from his inquiry also showed that clients' responses to therapists' operations depended on what they desired and what the felt they could safely disclose, and were very much tied to how comfortable they felt about approaching inner experiences (Rennie 2001).

Rennie's findings underscore the importance of forging an alliance with clients about the goals and tasks of psychotherapy. However, Rennie (1994) observed that the strength of clients' deference suggests that it is up to the therapist to take the initiative. Therapists and clients need to negotiate how they will work together drawing on the clients' goals and current resources and the therapists' techniques and expertise. Metacommunication was suggested as a way to negotiate the therapeutic relationship and the goals and tasks of therapy (Rennie 1998). Rennie suggested that clients need to understand the therapists' perspective of where the therapy is directed as much as therapists need to understand whether or not clients are in agreement with the process and whether they feel that the therapist understands their goals. If these are made explicit then participants are more likely to establish overt agreement on the tasks and goals of therapy (Weerasekera et al. 2001).

Furthering the inquiry into clients' responses to specific therapeutic operations or interventions, Watson and Rennie (1994) studied the subjective experience of eight clients who participated in the task of systematic evocative unfolding in experiential psychotherapy to explore and understand a personal reaction that they found problematic or perplexing. Using interpersonal process recall (Kagan 1975) and grounded theory (Glaser and Strauss 1967), the authors developed a model of clients' cognitive-affective processes during the session (Watson and Rennie 1994). The model of clients' experience that emerged highlighted the role of the representation of experience in consciousness as an important process that enhances understanding and reflection on self and experience to change behavior and ways of being (Watson and Rennie 1994). The authors observed that it was clients' curiosity to understand why they acted and felt the way they did that spurred their engagement in the task and that, as new information and understandings emerged, they would engage in a process of verification to examine and check the validity of their conceptualizations across a variety of situations (Watson and Rennie 1994). This would often lead to the development of alternative perspectives. As clients' perspectives changed, they reported experiencing a surge of energy and an elevation in their mood that fuelled their capacity to imagine solutions and develop alternative ways of being (Watson and Rennie 1994). Consistent with Rennie's earlier work, it became clear that when clients do not understand why therapists are intervening in certain ways they are more reluctant to engage and actively work to regulate the amount and intensity of pain that they experience in a session. The model of the clients' experience provided a more comprehensive understanding of systematic evocative unfolding as an intervention and suggested ways that it might be improved so that clients might be able to engage with the process. The model highlighted alternative paths to change in the resolution of problematic reactions.

In addition to using interviews for data collection, several researchers have administered semi-structured questionnaires to clients and or therapists and then followed up with intensive investigations using various qualitative methods for *categorizing* meaningful in-session processes including helpful and non-helpful events (Elliott 1985; Elliott et al. 1985; Timulak 2011), clients' reactions to therapists' interventions (Hill et al. 1988), misunderstandings in the alliance (Rhodes et al. 1994), and clients' covert processes (Hill Thompson & Corbett 1993). Hill et al. (1993) conducted a study of clients' and therapists' covert processes in long-term therapy. They found that not only did clients hide their negative reactions, thoughts and feelings from their therapists, but also that therapists were frequently unaware of how clients had been reacting in the session to what they were saying. This was moderated by experience, as more experienced therapists in long-term therapy appeared to be somewhat more adept at recognizing and managing therapeutic work and negative reactions than inexperienced therapists (Hill et al. 1992). Their findings also revealed that clients often hid things from their therapists, about which their therapists were unaware and unable to deduce (Hill et al. 1993). Reasons clients' gave for selective sharing were feeling too overwhelmed, wanting to avoid, and fearing being misunderstood (Hill et al. 1993). An important goal of meta-communication is to try to foster a therapeutic environment that is experienced as non-judgmental, to try to increase clients' sense of safety and the possibility for greater disclosure.

Rhodes and colleagues (1994) invited clients to select and describe a major misunderstanding event that occurred during therapy. The retrospective reports were then analyzed using a combination of grounded analysis (Rennie et al. 1988) and comprehensive process analysis (Elliott 1989). The reports were categorized as *resolved* when clients felt the issue had been processed sufficiently so that they could continue the work of therapy; and as *unresolved* when clients felt the rupture continued to hinder their communication with their therapist. Outlining a model for the resolved and unresolved pathways, Rhodes and colleagues (1994) stated that in resolved cases clients tended to have good relationships with their therapists and were willing to disclose negative feelings about the misunderstanding. As well, therapists tended to facilitate a mutual repair process maintaining a flexible and accepting manner. In the unresolved cases, however, clients tended to have poor relationships with their therapist and the therapist was either unaware of or unwilling to accept clients' assertion of negative reactions. In cases where misunderstanding events were not resolved clients often quit therapy.

Misunderstanding events appeared to occur as a result of clients perceiving their therapists as failing to meet their expectations (Rhodes et al. 1994). Tinsley et al. (1991) reported that clients had certain expectations of how they thought therapists should behave. In the Rhodes et al. (1994 p. 476, 478) study clients reported "something the therapist did that clients did not like (e.g., therapist was critical of client choice, therapist was not paying attention to the client, and therapist gave unwanted advice) or something therapists did not do that the client expected or wanted (e.g., therapist missed importance of issue, and therapist failed to remember important details)." Also, in both of the resolved and unresolved events clients indicated that they experienced negative feelings, e.g., anger, frustration, resentment, feeling discounted, and feeling disconnected, about their therapists in response to the rupture.

Rhodes and colleagues (1994) emphasize that the findings highlight the importance of ensuring that clients feel safe in therapy and that therapists should actively encourage clients to assert their feelings and reactions. Their study revealed that when clients did not feel safe they did not share their dissatisfaction about their therapist's behavior. The findings suggest that an important part of the change process is to assist clients to bring suppressed and unarticulated negative feelings into awareness (Rhodes et al. 1994). Most of the clients in the resolved misunderstanding cases immediately shared their negative feelings with their therapists, whereas in the unresolved cases clients tended to go underground. The rich data gathered in Rhodes and colleague's (1994) study suggest that "misunderstanding" events are specific types of alliance ruptures that can lead to drop out and should not be merely viewed as weaknesses in the strength of the quality of the alliance.

It is clear that one of the challenges clients sometimes face in psychotherapy when attempting to resolve difficulties is confronting painful emotional experiences, then disclosing and talking about their experiences. Clients sometimes overregulate and avoid painful experiences perpetuating distress out of fear that the feelings will be too overwhelming or that they may have difficulty finding the right distance from their emotional experiences in order to be able to explore them effectively (Greenberg and Safran 1987; Leijssen 1990).

In a study of pain, Bolger (1999) conducted retrospective interviews with adult children of alcoholic parent(s) to explore both the phenomenon of emotional pain as well as the steps involved in the resolution of painful experiences. In her qualitative inquiry Bolger (1999) identified that clients perceived the essence of pain as a feeling of "brokenness" or a "shattering" of the self. Greenberg and Bolger (2001) developed a model of the processing of emotional pain. They showed that clients' performances of resolving painful feelings occurred in stages that included allowing and accepting the feelings, and the reprocessing of emotional experiences within a safe therapeutic context. When clients were able to allow and acknowledge their feelings of "brokenness" they reported experiencing a sense of release and relief, and adopted a more caring, self-validating way of being with themselves (Greenberg and Bolger 2001).

The work of Rennie, Rhodes, Hill, Watson and Bolger highlights that clients are self-reflective agents in the therapeutic encounter and that they as well as their therapists are making decisions moment-to-moment, consciously and unconsciously, about what they will and will not attend to; what they will or will not disclose or how they will participate in the process of therapy at any given moment (Rennie 1994, 2001; Greenberg and Bolger 2001; Watson and Rennie 1994). Thus, therapists need to be attentive to the process and inquire into clients' subjective experience and work with them to explicate it in order to enhance the efficacy of treatment as well as the therapeutic alliance.

To further understand clients' involvement in the development of the therapeutic alliance, Bachelor and colleagues (Bachelor 1995; Bachelor et al. 2007) investigated clients' perceptions of collaboration in psychotherapy. Clients' phenomenological accounts revealed that different clients viewed and experienced collaboration in various ways (Bachelor 1995; Bachelor et al. 2007). Whereas some clients viewed collaboration as a joint effort, other clients viewed themselves or their therapist as the primary change agent, playing a significant role in the process of change (Bachelor et al. 2007). These findings highlight the need for clarification from the onset of therapy regarding the role and responsibility of participants to avoid possible misconceptions (Bachelor et al. 2007). The authors reported that irrespective of clients' perspective of the collaborative process, they consistently valued therapists who facilitated emotional expression, self-understanding and insight, and who initiated exploration of the clients' experiences (Bachelor et al. 2007).

Research on events that clients and therapists experience as helpful shows that the depth of experiential self-exploration is central to the change process in experiential psychotherapies and that these processes discriminate between "very good" and "rather poor" sessions (Dierick and Lietaer 2008; Lietaer and Neirinck 1986; Timulak 2007; Vanaerschot and Lietaer 2010). In addition, studies by Lietaer and colleagues using content analyses (Lietaer 1992; Vanaerschot and Lietaer 2007, 2010) showed that the therapist stimulating the client to explore more deeply, the client focusing on and exploring his/her experience more deeply, and the client intensively living through his or her experience were viewed as helpful by therapists and clients. In another investigation of brief person-centered counseling with six clients, Timulák and Lietaer (2001) observed that clients' experiences in experiential psychotherapy fall into two domains: strengthening of the therapeutic relationship and clients' self-empowerment. The authors found that the therapeutic alliance was strengthened when therapists attended to the therapeutic relationship, were transparent, and communicated about the goals and tasks in therapy (Timulák and Lietaer 2001).

30.4 The Study of Observable or Overt Experience and Behavior

The study of clients' and therapists' overt behavior in the session and over the course of treatment is another area that has been explored to try to understand the process of change in psychotherapy. This intensive study of the psychotherapy process using video and audiotapes as well as transcripts of psychotherapy sessions allows for the examination and intensive study of clients' and therapists performances in the session. This type of analysis is part of the humanistic client-centered tradition that developed with Rogers. This method of intensive observation and description has led to the development of a number of "process measures" to describe the type, quality and quantity of change. Process measures emerge from the intensive study of psychotherapy process, their application involves the intensive study of overt behavior in context. They have a greater capacity to capture client experience than would be possible from generating items of clinical and theoretical knowledge alone. Most importantly, this work has contributed to the refinement of theory as well as the development of therapeutic interventions and the evolution of client-centered and experiential psychotherapy, including the development of focusing-oriented psychotherapy and emotion-focused psychotherapy—the process-experiential approach.

An excellent example of the impact of process research on the development of psychotherapy approaches is provided by the work of Rogers and colleagues. Early in the development of client-centered psychotherapy, Rogers called for the study of in-session process. Technological advancements made it possible to record psychotherapy sessions so that there would be exact records of what occurred in the psychotherapy hour. This enabled Rogers, and his colleague Gendlin and their research team at the University of Chicago to examine audio recordings and observe and identify specific in-session processes that contributed to change (Rogers 1959b). They observed that clients who did well in short term psychotherapy engaged in a different process than those who did not respond well to treatment. Good outcome clients attended to their inner organismic experience and used it as a referent for evaluating their behavior and that of others as well as a guide to future actions and ways of being. This work led to the development of *focusing* a technique used in client-centered psychotherapy and that was later elaborated in the development of focusing-oriented psychotherapy (Rogers 1959a; Gendlin 1969, 1996).

Focusing describes how clients can become aware of their inner bodily felt experience, symbolize it in awareness either with images or words and use it to understand the impact of events. Once the process was clearly described, it could be taught and shared with clients so that they could engage more productively in psychotherapy (Hinterkopf and Brunswick 1981). Subsequently focusing has been incorporated into experiential and emotion-focused approaches and has formed the basis of the work done by the focusing organization to become a distinct way of working with clients (Gendlin 1996). In a review of the literature, Hendricks (2002) reported 23 studies supporting that better focusing processes positively correlated with successful outcome, and only one study with non-significant findings (Loynes 1984). Gendlin developed the focusing institute in 1972 and focusing is currently being taught in over 40 countries around the world (The Focusing Institute 2013).

It has been suggested that focusing contributes to the development of clients' emotional processing skills (Hinterkopf and Brunswick 1981). Emotions have been described as brain representations based on internal bodily states (Damasio 1999) that have an evolutionary adaptive function (Lang et al. 1997), thus providing people with essential information as they negotiate interactions with their environments. The importance of emotional processing has been investigated across research domains including neuroscience (Beitman et al. 2006; Etkin and Wager 2007), health (Pennebaker and Chung 2007), well-being (Gross and John 2003; Koydemir and Schütz 2012; Nyklíček et al. 2011; Saxena et al. 2011), personality (Newman and McKinney 2002), attachment (Karreman and Vingerhoets 2012), and psychotherapy research (Hunt 1998; Pascual-Leone and Greenberg 2007; Pos et al. 2009). Emotional pain is often a catalyst prompting individuals to seek psychological help, and the processing of emotional pain in psychotherapy has been a particularly important focus in experiential therapies (Elliott et al. 2004; Kennedy-Moore and Watson 1999).

The study of in-session change by Rogers and his colleagues started a tradition of change process research in humanistic and experiential psychotherapy (Greenberg and Pinsof 1986; Kiesler 1973; Lambert and Hill 1994). It is change process research that has contributed to the ongoing evolution and development of these approaches. Since Rogers' and Gendlin's first studies, research in this area has developed with the goal of understanding and describing clients' and therapists' in-session behaviors. Process researchers work to identify the little o's or mini-outcomes that can be observed during a session and that contribute to change at the end of sessions and over the course of therapy, and they examine how these build to form more enduring changes by the end of treatment (Greenberg 1986). As a result of this work, and the numerous process measures developed to identify different types of change, researchers now have a means to link the specific client and therapist processes that are occurring in-session to post session and final therapy outcome. Whereas quantitative efficacy studies provide a way to determine treatment effectiveness, change process research provides a way to link "what" is happening in the therapy, and how that relates to good and poor outcome.

Rice (1992), a student of Carl Rogers, believed that understanding productive client process was essential to improving the effectiveness of psychotherapy. Listening intently to psychotherapy tapes of client-centered therapy and analyzing transcripts, Rice and Wagstaff (1967) classified clients' style of exploration and involvement in therapy moment-by-moment with minimal inferences about meaning or content. Employing a factor analytic methodology to locate meaning clusters of process categories from an intensive exploration of therapy transcripts, Rice and Wagstaff (1967) developed classification systems for aspects of client behavior identified as important client processes in the prediction of outcome.

Rice and Wagstaff (1967) observed that in successful cases the client's voice had two qualities, one of turning inward, exploring inside, and another, involving intermittent disruption of the vocal pattern by emotional expression (Rice 1992). In unsuccessful cases, however, the client's voice tended to either have a strong focus outward, or a thin quality with little energy (Rice 1992). They labeled these four *Client Vocal Quality* categories: focused, emotional, externalizing, and limited, respectively. They also observed four mutually exclusive verbal categories identifying the level at which the client was engaged with the subject matter of the discourse (Rice 1992). They called this system *Expressive Stance* and labeled these categories: objective analysis, subjective reaction, static feeling description, and differentiated exploration of feeling.

Following the same methodology of listening to audiotapes and studying therapy transcripts, Rice and Watstaff (1967) focused on therapist processes that facilitated these client behaviors. They identified three therapist process systems: freshness of the therapists' language, level of the therapist's involvement with regard to the clients' frame of reference, and therapist vocal quality. *Therapist Vocal Quality* was classified into seven mutually exclusive and qualitatively different categories of vocal (Rice and Kerr 1986) with softened, irregular and natural, considered to be facilitative of productive client processing, while restricted, patterned and limited voice qualities tended to dampen clients' productive engagement in the therapeutic process (Kerr 1983; Rice and Kerr 1986). The seventh category, definitive voice quality, appeared to depend on context. In studies investigating therapists' vocal quality, Rice (1965) and Kerr (1983) found that when therapists' voices tended to be energetic, controlled, or searching, clients tended to have better outcomes, and Duncan and colleagues (1968) found that a softer voice with a lower pitch was positively associated with better outcomes in psychotherapy.

In a subsequent study, Wiseman and Rice (1989) found evidence for client in-session behavior as a function of therapist style. They used psychotherapy transcripts to investigate the sequential nature of therapist-client interactions in the context of clinical micro-theories of change events. Participants were treated in client-centered therapy and excerpts from transcripts that focused on clients' attempts to resolve problematic reactions. The results indicated that when therapists were speaking in a softened voice with an irregular fluctuation pattern, clients were significantly more likely to shift from an externalizing to focused voice quality, thus attending to their own experiences and feelings in an exploratory fashion (Wiseman and Rice 1989). Focusing their investigation on a specific change event, Wiseman and Rice (1989) were able to demonstrate a context in which the sequential findings could be meaningfully interpreted by testing particular hypotheses derived from a conceptual model of client change.

The early work of Rice and colleagues revealed that not only are client and therapist processes, as well as the sequencing of these behaviors important in psychotherapy, but also that some client and therapist behaviors are more productive than others. The study of clients' and therapists' overt behavior in psychotherapy at the micro level, particularly in experiential psychotherapies, has demonstrated the importance of promoting emotional processing and delineated several models depicting clients' and therapists' performances associated with successful therapeutic outcomes (Greenberg et al. 2003).

Rogers and Gendlin's early work was integral to the development of the *Experiencing Scale* (EXP; Klein et al. 1986), a measure of *clients' emotional processing*. This scale assesses multiple aspects of clients' emotional processing, but of particular interest is the immediacy and quality of the clients' relationship to their experience, and the quality and stage of the exploration with regard to their experience. Emotional processing, as measured by the EXP scale has been extensively studied in client-centered, process-experiential, and other humanistic therapies (Goldman 1997; Goldman et al. 2005;

Hendrix 2002; Pos et al. 2003, 2009; Warwar 1996; Watson and Bedard 2006).

Overwhelmingly, the results of these studies indicated that better emotional processing predicted better therapy outcomes (Hendricks 2002; Pos et al. 2009; Watson and Bedard 2006), and that clients with poor emotional processing capacities at baseline could improve over the course of therapy (Pos et al. 2009; Watson and Bedard 2006). Studies have shown that when controlling for early emotional processing capacities, clients' scores at mid or late therapy predicted outcome on indices of depression, general distress, and self-esteem (Goldman et al. 2005; Missirlian 2011; Pos et al. 2003, 2009; Warwar 2003). Pos and colleagues (2003) stated that 70 % of clients' emotional processing during the working phase of therapy was not explained by clients' baseline capacities. Thus, both clients who have the capacity to process their emotional experience, as well as those who develop this capacity during therapy, have a greater likelihood of good outcome (Goldman 1997; Goldman et al. 2005; Tomlinson and Hart 1962).

The research conducted on the EXP scale indicates that clients vary in their capacity for emotional processing; that clients' emotional processing capacity can be improved during the course of psychotherapy; that clients' emotional processing appears to deepen across therapy; and that clients' level of investigation, exploration, and resolution of their difficulties is deepest during the middle or working stage of therapy (Pos et al. 2003, 2009; Watson and Bedard 2006). Further clarification is needed to determine which therapist techniques best facilitate emotional processing.

Another productive client process measure is that of clients' perceptual processing. Toukmanian (2004) developed the *Levels of Client Perceptual Processing Scale* (LCPP-Revised) consisting of seven mutually exclusive categories of schematic processing including recognition; elaboration; external, analytical, or internal differentiation; reevaluation; and integration. Using the LCPP in a comparative study of process-experiential (EFT-PE) and cognitive-behavioral therapy (CBT) for depression, Gordon (2007) found that clients in both therapies demonstrated improvements in perceptual processing over the course of treatment, becoming more re-evaluative and integrating new perspectives. In a similar study examining clients' self-relevant topics, comparing EFT-PE and CBT for depression, Missirlian (2011) extended these findings, showing that clients' quality of perceptual processing in conjunction with depth of emotional processing during the working phase of therapy proved to be the best predictor of outcome for EFT-PE, in comparison to either alone.

Some evidence has been found to support therapists' capacity to facilitate improvements in clients' perceptual processing levels (Macaulay et al. 2007). Using the *York Therapist Process Measure* (Toukmanian and Armstrong 1998), an instrument assessing therapists' level of *attunement*, *tentativeness* and *meaning exploration* style in relation to clients' moment-to-moment experience, Macaulay et al. (2007) examined the impact of therapists' behavior on clients' depth of emotional processing and level of perceptual processing in a treatment of EFT-PE for depression. Results of this investigation were twofold: a greater expression of *attunement* and *tentativeness* was associated with greater complexity in the manner of perceptual processing, i.e., more internal differentiation, re-evaluation, and integration, whereas greater expression of *meaning exploration* was associated with a greater depth of emotional processing. These findings confirm that therapists' style of interacting with their clients in the treatment of depression using EFT-PE, has a significant impact on improvements in clients' in-session emotional and perceptual processing.

Researchers propose that promoting awareness and symbolization of experience that leads to new understanding and insight is beneficial; however, greater therapeutic effectiveness is expected when these processes are accompanied by emotional arousal and expression (Fosha 2000; Freud 1963; Greenberg 2002; Greenberg and Safran 1987; Perls 1969; Rogers 1951; Samoilov and Goldfried 2000; Watson 1996). In other words, productive processing of emotion involves "feeling the feeling" in awareness (Greenberg 2008).

Some support for clients' emotional arousal as an important process in short-term client-centered and process-experiential therapy was found in two studies demonstrating a significant relationship between clients' expressed emotional arousal and symptom improvement at the end of treatment (Missirlian et al. 2005; Warwar 2003). It is noteworthy that the mere frequency or degree of *aroused expressed emotion* has not been sufficient in and of itself to lead to successful outcome (Greenberg et al. 2007), as the research investigating the association between in-session expression or arousal and outcome has been mixed (Greenberg and Malcolm 2002; Kennedy-Moore and Watson 1999; Nichols and Zax 1977; Warwar and Greenberg 2000).

Several researchers have claimed that emotional arousal is not always productive (Greenberg 2002; Kennedy-Moore and Watson 1999; Wexler and Rice 1974). Kennedy-Moore and Watson (1999) stress that what is important is not so much the amount of arousal, but the client's ability to engage in therapy so as to process their experience and to complete the expression. Kennedy-Moore and Watson (1999) propose that expression of emotion in and of itself is not necessarily beneficial: rather expression is beneficial when it facilitates adaptation and leads to the resolution of distress. Resolution may involve either an increase in the experience of positive feelings and/or the accessing and processing of negative feelings (Kennedy-Moore and Watson 1999).

Greenberg and colleagues (2007) suggest that merely measuring the degree of arousal of expressed emotion appears to be too general to be a valid indicator of productive processing in therapy, and that it seems to be the manner in which the emotional experience is processed, once activated, that is important in producing emotional change. Warwar (2003) in a study investigating the relationship between emotional processing using the experiencing scale, expressed arousal, and outcome found that the best predictor of improvement in depression and general symptoms of distress was the combination of both arousal and differentiated experiencing.

Greenberg and colleagues suggest that activation of primary emotions is key (Greenberg et al. 2007). Greenberg and Paivio (1997) define primary emotions as an individual's very first automatic core emotional response to a situation, such as fear at threat or anger at violation, whereas secondary emotions are responses to more primary emotional or cognitive processes such as anger in response to shame, fear of fear, or anxiety from ruminating or anticipating catastrophe (Greenberg 2002; Greenberg et al. 2007). Greenberg and colleagues emphasize that activation of primary emotions and hot cognitions is essential in order to further activate the underlying cognitive-affective meaning structure (scheme) and the personal meaning of these experiences in need of exploration (Elliott et al. 2004; Greenberg et al. 2007; Greenberg and Safran 1987; Greenberg and Watson 2006b; Whelton 2004; Wiser and Arnow 2001).

Using a newly developed measure of productive arousal, the *Productive Scale* (Greenberg et al. 2004), Greenberg et al. (2007) found that, as expected, production of more *highly aroused expressed emotion*, rather than *arousal alone* facilitated therapeutic change and discriminated better from poorer outcome cases, even though there were no differences between better and poorer outcome groups on overall degree of expressed emotional arousal. Highly aroused expressed emotion was shown to be more productive when characterized by certain emotion-related features: (a) the emotional response was classified as a primary emotion in order to activate the underlying cognitive-affective scheme; (b) the client experienced the emotion in the present; (c) the emotion was fluid, moving forward, and not blocked (or alternately overwhelming); and (d) the emotion was related to a therapeutically relevant theme (Greenberg et al. 2007). In addition, the client had to be mindfully aware, which entailed (e) taking responsibility for his or her emotional experience, owning it as his or her feeling rather than blaming others for it, and thus (f) experienced self as an agent, willing and motivated to contact the emotion and actively work with it (Greenberg et al. 2007).

Watson and colleagues (Kennedy-Moore and Watson 1999; Leijssen 1998; Greenberg et al. 2007; Watson 2011; Watson et al. 2007) explain that when clients' emotional experience is either blocked, or alternately, overwhelming so that they are flooded, they may have difficulty maintaining a productive working distance from their experience. Thus, there may be an optimal level of arousal (Carryer and Greenberg 2010) for effective therapeutic work to occur. With too little emotional arousal clients are limited in their capacity to both connect with themselves and their therapists regarding their experiences, and with too much emotional arousal clients may be unable to adequately reflect on their experiences (Kennedy-Moore and Watson 1999; Greenberg et al. 2007; Watson 2011; Watson et al. 2007).

Kennedy-Moore and Watson (1999) describe how expression of negative feelings is both a sign of distress and a possible means of coping with distress; therefore, when a person floods with intense physical, cognitive and affective experience, therapists may need to intervene by either down regulating emotional expression or processing the affective material, depending on what appears to be most beneficial for the client (Briere 1989; Leijssen 1998; McCann and Pearlman 1990; van der Kolk et al. 1996). Without being able to adequately process their experience the client has less control over expression and the action generation process (Kennedy-Moore and Watson 1999; Greenberg et al. 2007). The function of emotion is to ready the body in response to environmental stimuli resulting in an action tendency: a physiological readiness to respond (Arnold 1960; Frijda 1987, 2005). However, it is the integration of bodily arousal and conscious evaluation of the situation that leads to an effective response (Beitman et al. 2006; LeDoux 1996). For example, the exploration of both *primary*, "Is the situation relevant to my well being?" and, *secondary* "Of the possible ways of coping with this situation, which would I like to choose at this time?" appraisals are needed (Lazarus 1991).

30.5 Task Analysis: Modeling Change

Task analysis is an investigative approach that integrates both theory and rigorous observation, and analysis of clients, therapists, and/or the relational dyad (Greenberg 2007; Pascual-Leone 1978; Rice and Greenberg 1984). Task analysis involves the use video—and audio—tapes of sessions, as well as therapy transcripts to intensively analyze and describe clients' and therapists' performances in situ (Greenberg 2007; Rice and Greenberg 1984). Specifically, researchers using task analysis are interested in describing successful performances of both clients and therapists, and identifying the steps that clients perform to resolve specific problem issues in psychotherapy. This has resulted in a number of performance models that could be tested with larger samples to determine whether the steps were component aspects of resolution. The performance models in turn have served as guides for clinicians for how to intervene at specific junctures in the session to facilitate clients' emotional processing.

The task analytic method unfolds in three phases: discovery, validation, and dynamic modeling (Greenberg 2007; Pascual-Leone et al. 2009). In the discovery phase the researcher uses qualitative methods, a mix of expert clinical experience, intense observation, and an understanding of the psychological literature, to develop a model of the resolution of specific tasks such as resolving unfinished business with a significant other (Greenberg 2007; A. Pascual-Leone et al. 2009). This is followed by an empirical test of the model using a separate sample, and comparing and contrasting cases of resolution and non-resolution of the specific task being analyzed (Greenberg 2007; Pascual-Leone et al. 2009).

Rice and Greenberg (1984) developed models of clients and therapists' performances in psychotherapy to delineate the change processes for specific *change events* using *task analysis*. An event was defined as, "[…] a clinically meaningful client-therapist interactional sequence that involved a beginning point, a working-through process, and an end point" (Greenberg 2007, p. 16). An event begins with the client's statement of a particular cognitive-affect problem referred to as a "marker," followed by a number of observable or inferred client and therapist behaviors that lead to resolution of the problem (Elliott et al. 2004).

A number of different performance models have been developed including models for the resolution of problematic reactions (Rice and Saperia 1984; Watson 1996), self-critical splits (Greenberg 1983), decisional conflicts (Clarke and Greenberg 1986), creation of meaning (Clarke 1996), unfinished business with a significant other (Foerster 1990; Greenberg and Foerster 1996; Greenberg and Malcolm 2002), self-interruption (Elliott et al. 2004), and states of hopelessness (Sicoli 2005). Early studies of task analyses tested the hypothesized rational-empirical model by relating the presence of key components in the model to good task outcome (Greenberg 2007; Rice and Greenberg 1984).

More recently, task analysis has been extended to include a dynamic modeling phase, to relate a sequential pattern of processes to outcome (Pascual-Leone et al. 2009). In this phase, the sequential structure or patterns identified by the models are tested (Pascual-Leone et al. 2009). The intensive qualitative analysis of clients' performances is followed with quantitative methods and analysis to validate the clinical significance of these processes in relation to client outcomes at the end of therapy (Pascual-Leone et al. 2009).

Process studies investigating two-chair dialogue for conflict splits have shown that the micro-processes involved in resolution are clients' deeper experiencing of feelings and needs, as well as the softening of their internal critical voice (Greenberg 1979, 1983; Sicoli and Hallberg 1998). Using theme analysis, Goldman (1997) and Kagan (2003) demonstrated the inner critical voices of depressed clients revealed self-oriented themes including *self-criticism, shutdown, lack of direction, and hopelessness* (Kagan 2003) and other-oriented themes of *abandonment or rejection, isolation, loss, and blame* (Kagan 2003). The vast majority of subjects in these studies had both self and other related themes suggesting that depression involves both intrapersonal and interpersonal issues (Goldman 1997; Greenberg and Watson 2006b; Kagan 2003). In addition, researchers have noted that self-criticism in particular is not a single process, rather there are different forms, with some being more benevolent than others, and that these serve different purposes for people (Gilbert et al. 2004; Greenberg and Watson 2006b).

Following intensive analysis of psychotherapy transcripts, Rice (1974) recognized the importance of having clients' vividly describe external events in order to enhance and facilitate in-session change processes. Rice (1973) observed that therapists' styles influence clients' in-session processes, and ultimately outcome. As a result, Rice and Saperia (1984), developed a performance model describing the steps in the resolution of problematic reactions using *Systematic Evocative Unfolding*. Problematic reactions were identified as moments when clients viewed their own responses to an event, person, or situation as puzzling, confusing, unreasonable, or exaggerated. An important step in the path to resolution was to help clients bring the memory of the scene alive by having clients describe it concretely and vividly (Rice and Saperia 1984; Watson and Greenberg 1996). Using vivid description helps to evoke the episodic memory and helps clients to pinpoint when their reaction occurred and to identify the trigger (Watson and Greenberg 1996).

Safran and colleagues (1990, 1994) used task analysis to study ruptures in psychotherapy. They developed a sophisticated model of the resolution of alliance ruptures in therapy. After listening repeatedly to audio-taped therapy sessions, they identified different themes including: overt expressions of negative sentiments; indirect communication of negative sentiments or hostility; disagreements about the goals and tasks of therapy; compliance; avoidance maneuvers; self-esteem-enhancing operations; and non-responsiveness to interventions. The advantage of operationalizing ruptures using clearly defined "markers" (Rice and Greenberg 1984) in this manner was that it enabled researchers to reliably code categories meeting inter-rater reliability, and allowed for testing of the model across modalities. The authors conceptualized a range of possible therapeutic alliance intervention strategies that appeared important in resolving each aspect of the alliance including the therapeutic bond, and collaboration on goals and tasks of therapy. An important objective was to assist therapists in identifying ruptures and to points in the session when greater attention to the alliance might be necessary.

Another group of researchers, Stiles and colleagues (2005) employed a theory-building case study research approach using transcripts and audio recordings to conduct intensive qualitative analyses of clients' assimilation of problematic experiences (e.g., Brinegar et al. 2006). This particular approach to modeling change tracks and examines small changes observable in the psychotherapeutic process related to therapeutic outcome (Stiles 2002; Stiles and Angus 2001). This work has resulted in a pan-theoretical theory of change processes and the articulation of an 8-stage sequence (Assimilation of Problematic Experiences Sequence, APES; Stiles 2002) that describes how problematic experiences can become integrated into the clients' sense of self.

The qualitative approach of assimilation analysis is an intensive, interpretive, iterative procedure for studying client data that involves four steps: scrutinizing therapy data and creating a summary catalogue; identifying problematic and dominant voices representing distinct cognitive-affective positions within the self; selecting passages relevant to these voices, describing the relationship of the dominate voices with the other voices, and determining whether the voices were or were not assimilated during the therapy; and then rating units based on the APES stages (e.g., Brinegar et al. 2006).

The APES rating system provided a tool to follow the developmental sequence of therapeutic progress. Osatuke and Stiles (2011 p. 215) argue that, "numbers and words are compatible for building scientific knowledge and can be used in mutually complementary ways rather than being pitted against each other." Osatuke and Stiles (2011) suggest that the numeric properties of the APES make it suitable for use as a metric of therapeutic progress, particularly because of its capacity to identify symptomatic change sequentially and within the broader context of psychological change.

30.6 Conclusion

The review of qualitative research approaches that use client interview data as well as transcript data of clients during psychotherapy shows that this type of work and methodology has provided a rich source of information about clients' and therapists' experience of psychotherapy. Qualitative research has illuminated aspects of the psychotherapeutic process not visible from clinical trials or from quantitative methods alone. Studies using more qualitative methods have contributed to the refinement of thinking about the therapeutic alliance and stressed the importance of meta-communication, the need for therapists to be more responsive and aware of clients' agency in the session, and different therapist behaviors that clients experience as empathic. Intense observation of performances in the session has led to the development of numerous techniques and ways of working with clients to facilitate clients' change processes in psychotherapy. Many of the techniques in experiential and emotion-focused psychotherapy have developed from intense observation and qualitative analysis of therapists' and clients' performances to develop performance models and increase understanding of how to facilitate clients' emotional processing during the session. The assumptive framework of humanistic and experiential psychotherapies fits well with that of qualitative research methodologies as both emphasize clients' reflexivity, autonomy, and capacity for growth. Going forward it will be important to continue to investigate psychotherapy process and outcome using a variety of methodologies in an attempt to capture as holistically as possible all the aspects of this complex phenomenon.

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Qualitative Evidence in Health Policy Analysis

31

Susan M. Jack

31.1 Introduction

In the development and analysis of health policy, we continue to require in-depth, detailed descriptions of what happens in the policy environment, within implementing agencies, and to different policy actors. It is increasingly recognized that human, social, cultural, and political factors significantly influence the transferability of a policy or program from one context to the next. Further, what we often lack is an understanding of the interplay between these factors. Decision-makers can use qualitative research evidence to respond to these gaps in knowledge and gain a deep conceptual understanding of the factors that influence the identification, selection, implementation, and evaluation of health policies. In this chapter, the contribution of qualitative research evidence to the health policy process is discussed. First, the health policy work cycle is defined. Next the types of evidence that policy makers consider in developing and evaluating health policies are identified, and there is a discussion of the role of research evidence in the full health policy work cycle. Next, strategies and designs to consider when planning policy relevant qualitative research studies are suggested. Finally, the chapter concludes with a brief discussion of the different ways that qualitative evidence can be utilized in decision making. The information in this chapter is intended for the qualitative health researcher new to health policy work, or the novice qualitative researcher, who is committed to finding opportunities to inform policy decisions through the introduction of qualitative evidence or to actively participate in health policy and systems research (HPSR).

When qualitative findings are reviewed in conjunction with other evidence types, a more nuanced understanding of the implications of a health policy on different stakeholders is realized. Basing decisions solely on the best available quantitative evidence would limit our understanding and identification of important conditions and influences that may ultimately define the success, or failure, of a health policy. In Canada, the allocation of federal funds to provinces and territories to deliver human papilloma virus (HPV) immunization programs provides a rich case study to examine not only the complexity of the policy process, but also insight into the contribution that qualitative research evidence can have. The estimated prevalence of HPV among Canadian women is 16.8 % with the highest rates reported in sexually active females under the age of 20 years (Moore et al. 2009). HPV-associated cancers occur in both males and

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females, with demonstrated causation between HPV type 16 and genital, oral cavity, and oropharynx cancers (Public Health Agency of Canada (PHAC) 2012). There is strong empirical evidence that HPV vaccines are efficacious in preventing certain HPV infections, including genital warts and cervical cancer (PHAC). Therefore, PHAC recommends the administration of HPV vaccine to all females and males between the ages of 9 and 26 years old, with priority given to vaccinating children age 9–13 years. It is assumed that vaccinating girls at this age will provide coverage before the commencement of sexual activity. However, as part of routine immunization schedules in Canada, all provinces and territories publically fund HPV vaccine for adolescent females only (PHAC).

If the public health policy process was simple and based solely on empirical quantitative data, decision-makers would determine that the research evidence suggests that HPV vaccines are efficacious, that few adverse events are reported post-vaccination and that implementing a public health policy to vaccinate all young adults would result in improved health outcomes for both men and women. However, the process of selecting and implementing a policy is complex and the prevailing quantitative evidence must be balanced with other sources and types of evidence. Decision-makers within the health policy arena are influenced by: the availability of resources; competing political agendas; the fit with existing health policies and service delivery systems; and the values, beliefs positions held by, and associated evidence referred to, a range of policy actors, including the government, health care providers, civil society, researchers and the private sector. In response to funding of HPV vaccination programs, federal and provincial government agencies, health care providers, and vaccine manufacturers were in strong support of this policy whereas some members of the scientific community and specific civil society organizations were opposed (Torgerson and MacAdam 2007). However, it is by reading the qualitative research conducted to explore different stakeholder perceptions about the vaccine that we develop a clearer understanding of what underlies some of this opposition, as well as an opportunity to identify those barriers or cues to action that may significantly influence parents' decisions to vaccinate their daughters. What emerges is a general low level of awareness about HPV, and its link to certain cancers; disagreement about the optimal age to vaccinate; recommendations to vaccinate boys as well as girls (Olshen et al. 2005); and fears that HPV vaccination may promote overconfidence in its protection and lead to either early sexual engagement or unsafe sexual health behaviors (Brewer and Fazekas 2007; Friedman and Shepeard 2007). Additionally, despite the evidence of effectiveness, findings from a meta-ethnography of four qualitative studies illuminate that policy makers also experience uncertainty about: (1) the acceptability of the vaccine by the public; (2) the intentions and motives of the manufacturer of the vaccine, (3) the characteristics of the vaccine including length of immunity and long-term safety; and (4) the ability of the public health sector to support vaccine delivery systems (Hafid 2012). Insight into these important contextual issues, identified through the use of qualitative methods, provides decision-makers with valuable information that can ultimately inform the selection, implementation, and evaluation of a novel program, intervention, or policy.

A systematic and comprehensive search strategy was used to locate the most current literature related to the role of qualitative evidence and evidence-informed policy making and adapted for each different database or resource searched. Search terms were identified based on the chapter objectives and included the following MeSH terms: Qualitative Research, Evidence-Based Health Care, Evidence-Based Practice, Health Policy, Policy Making; key terms included *evidence-informed, policymaking models* and *research utilization*. The databases searched (from 2000 to October 2013) included MEDLINE, CINAHL, and the Web of Science. Given the prevalence of policy relevant documents published in the gray literature, a search was conducted also using general internet search engines (e.g., Google, Google Scholar) and websites of relevant Canadian organizations engaged in supporting decision makers and researchers in developing and evaluating evidence-informed health policy (e.g., National Collaborating Centre for Methods and Tools, National Collaborating Centre for Healthy Public Policy).

31.2 Health Policy Analysis and Research

In the field of applied health research, researchers are increasingly motivated to conduct studies not only for the purpose of knowledge creation but to produce results that will inform practice or policy and lead to improved individual and population health outcomes. Health outcomes can be influenced by the implementation of evidence-informed interventions, programs, or health policies. These terms and other policy-related concepts are defined in Table 31.1. To achieve this goal, close collaboration and partnership is required among three sets of actors who traditionally have worked independently within their own unique cultural domains: (1) health policy analysts, often civil servants or administrators responsible for policy; (2) practitioners; and (3) researchers. The inherent challenge though is that

Table 31.1 Definitions of key terms

Term	Definition
Health care intervention	A type of treatment, preventive care, or diagnostic test, usually delivered to an individual with the goal of improving health or resolving a specific health problem. Examples could include medications, hospital or surgical treatment, diagnostic screening, or rehabilitation services (Agency for Healthcare Research and Quality 2013)
Public health intervention	Interventions focused on the prevention and management of diseases, injuries, physical and mental health conditions, through health surveillance and health promotion initiatives with the goal of improving the health of populations
Program	A group of activities implemented for the purpose of achieving policy objectives (WHO 2013)
Health policy	Decisions, plans, and actions undertaken to achieve specific health care delivery and health services goals within a society. Health policy goals may include defining a vision, establishing short-and long-term objectives, identifying priorities, describing the roles and functions of different actors, and informing individuals and populations of the planned process and outcomes (WHO 2013)
Public health policy	Health policy specifically focused on public health issues. Public health policy includes laws, regulations, guidelines, administrative practices, and funding decisions—developed and implemented by federal, provincial/state, or local levels of government or affiliated agencies and affecting outcomes and activities across multiple settings and sectors (Brownson et al. 2009). Examples may include mandatory seatbelt legislation, tobacco control measures, and vaccination programs
Health policy and systems research (HPSR)	Empirical research conducted to describe and understand health system policies, organizations, stakeholders, and programs. Interactions between these elements are also studied, as well as identification and exploration of contextual and system issues that influence decision-making. HPSR also addresses questions of how policy agendas can be influenced to promote policy options that promote health and lead to health system improvements. Included in this field of research are also evaluations of policy content, process, and outcomes (Gilson 2012)
Health policy analysis	A retrospective or prospective analysis to describe and explain the interactions between stakeholders, organizations, government, interests and ideas in the policy process (Walt et al. 2008)

these actors each have complementary, but different, work cycles and distinct definitions of evidence (Jansen et al. 2010). Therefore, it is essential for researchers motivated to engage with decision-makers to have a working understanding of the health policy cycle so that they can determine opportunities to collaborate as well as strategies to promote the uptake and utilization of their research evidence.

The health policy work cycle can be separated into four phases: (1) problem identification, (2) policy formulation and decision-making, (3) policy implementation, and (4) policy evaluation. Core activities associated with each stage are identified in Table 31.2. The role of health policy analysts, prior to the selection of a health policy, can vary from providing senior decision makers with balanced and unbiased information,

Table 31.2 Overview of the health policy work cycle

Health policy work cycle phases	Characteristics	Qualitative HSPR research questions
Problem identification	• Identify an important health, social or public health problem • Political agenda setting or bringing the problem to the attention of key decision makers	• What is the nature of the problem? • What happened previously in response to the problem? What were the perceived consequences? • How can popular and political support be established (or maintained) until the policy impacts are observable? • How do different stakeholders perceive the problem? Do stakeholders perceive the health issue targeted by the policy as one requiring intervention?
Policy formulation and decision making	• Conduct an assignment analysis by identifying the actors and sectors who need to be involved in the decision making process • Clarify goals and objectives • Identify, evaluate, and propose solutions and policy options • Conduct cost–benefit analysis and determine resource/budget availability • Engage in political decision-making process to negotiate and accommodate various interests • Select most appropriate policy option to adopt • Develop implementation plans	• What are the goals of the policy makers? Policy implementers? • Who needs to be involved in the decision-making process? • Which actors will be affected by the health policy being considered? • How will the different policy options create, reinforce, or adjust social inequalities in health? • What are stakeholders' perceptions and recommendations on how the problem should be addressed? • What are stakeholders' perceptions of the proposed policy solution? • Is it acceptable to implement a policy to address the targeted health problem? • How acceptable is the proposed health policy in comparison to other proposed policies? • What are stakeholders' perceptions about the feasibility, effectiveness, cost, and equitableness of implementing the proposed policy? • How acceptable is the degree of coercion associated with the health policy?

(continued)

Table 31.2 (continued)

Health policy work cycle phases	Characteristics	Qualitative HSPR research questions
Policy implementation	• Initiate process of putting policy solution into action • Monitor what, where, when, how, and by whom policy activities are implemented • Allocate and coordinate tasks	• What happens when the policy is implemented and why? • How is the organization or agency implementing the policy? • How is the organization or agency able to promote the uptake and sustain the policy? • What factors (individual, social, organizational, environmental, cultural, political) are influencing the policy implementation process?
Policy Evaluation	• Monitor and evaluate the results of the policy • Determine outcomes and effects of policy • Conduct performance and financial audits • Provide recommendations for policy modification	• What policy objectives were met? Unmet? • What were the unexpected outcomes or effects? • Was the policy implemented effectively? • How did the implementation context influence the effectiveness of the policy?

(Gilson 2012; Howlett and Ramesh 1995; Jansen et al. 2010; Rist 1998)

to advocating for a specific policy, to engaging in a process to compare the attributes and merits of competing policy options (Morestin 2012). Once a decision has been made and a health policy implemented, analysts have a role in evaluating the policy process and outcomes. In parallel to this process, researchers have the potential to engage with policy makers in two distinct ways: (1) to conduct, position and disseminate research evidence that is accessible, valuable, and relevant to inform the problem identification and policy development stages; or (2) to engage in health policy and systems research (HPSR) in collaboration with policy partners. As a health research field, HPSR has been developed to describe health policies and systems and to answer questions related to how they are implemented, how they work, and how can they be improved (Gilson 2012). More simply put, researchers can create the knowledge that informs the health policy analysis process or they can be involved in conducting health policy process and outcome evaluations.

In addition to substantial differences between the research, practice, and policy work cycles (Jansen et al. 2010), the actors within each of these domains hold different perceptions of what constitutes the evidence upon which decisions should be based.

31.3 Nature of Evidence in Health Policy Decision-Making

Since the introduction of the term evidence-based medicine into the cultural lexicon, this concept has been adapted and adopted by multiple clinical practice fields including nursing, social work, and rehabilitation sciences. As part of this natural expansion, interest and efforts have also focused on the development of evidence-based, or more appropriately, evidence-informed health policy-making. Within the health policy arena Segone (2008) suggests that, to improve trust in the policy development process, actors' decisions should be evidence-based and informed by high-quality, valid, and credible research evidence. This stands in stark contrast, he argues, to opinion-based policy where a decision is heavily influenced by the political ideology or values and beliefs of one group; and where, if research evidence is used, it is used politically to support a predetermined decision. The current reality however in developed nations, given the number and range of evidence types that policy makers must take into consideration, is a paradigm of evidence-informed policy where the political aspects of decision-making are acknowledged alongside an increasing use of research evidence within the policy process. There is overt consensus, however, that evidence-informed policy making is inherently a more complex process, and perhaps a less obtainable goal, compared to achieving evidence-based practice in clinical contexts at the level of the individual practitioner working with individuals, families or community groups (Black 2001; Lomas and Brown 2009; Oxman et al. 2009). Part of the complexity of this process is a result of how policy analysts define evidence and the diverse range of information sources that compete to inform health policy decisions.

Historically, researchers have narrowly defined evidence to be constituted from facts, results or findings represented as context-free research evidence (e.g., derived from quantitative studies) or context-sensitive research (e.g., derived from qualitative studies) that emanate from the conduct of systematic, explicit and rigorous scientific processes (Lomas et al. 2005). Within the paradigm of "evidence-based" practice, practitioners' interventions are informed by health research evidence but their decisions and actions are also influenced by the feasibility, acceptability, applicability, and cost of the interventions (Jansen et al. 2010). In comparison, policy decision makers have a broader definition of evidence. Lomas and Brown (2009) conclude that, where researchers equate the term "evidence" with the term "research" in health policy contexts, evidence is "synonymous with *data, analysis*, or *investigation*" (p. 914). So for this group of decision makers, sources of evidence may include findings and conclusions from empirical studies or "research" alongside colloquial evidence such as gray literature, opinion polls, stakeholder experiences and interests, raw data (Lomas and Brown 2009), best practices- or policies and programs from other jurisdictions determined to be beneficial (Lomas and Brown 2009; Orton et al. 2011), or personal or professional experiences (Black 2001; Brownson et al. 2009; Morestin 2012).

Several models have been developed that define evidence-informed policymaking and delineate the multiple types of evidence that inform population health or health policy decisions. The National Collaborating Centre for Methods and Tools (NCCMT) (2009) model for evidence-informed decision-making in public health broadly identifies that research evidence, surveillance data, information about community and political preferences and actions, combined with information about available government, organization, and program resources are filtered through decision-makers who use this public health knowledge to provide expert recommendations for policy or program decisions. Oxman and colleagues (2009) further refine our understanding of the role of research evidence in the policy development process. First, they make an important distinction between global and local research evidence. Global evidence consists of research findings from a range of contexts that presents information on effectiveness or impacts of policies, programs, or interventions; this evidence may be constructed through rigorous single studies or systematic syntheses of data in such forms as systematic reviews or meta-syntheses. In comparison, local evidence focuses on the collection of data within the context or jurisdiction where policy decisions must be made and includes data about the scope of the problem, contextual factors, stakeholder needs, values or beliefs, costs, and other resources. Secondly, their model distinguishes between sources of evidence and contextual influences or modifiable factors that have a strong influence on the identification, selection or rejection of a health policy. These factors include such phenomena as: organizational constraints; stakeholder or societal values; economic factors or the availability of resources; and the readiness of the social environment to change. Other contextual factors may also include: political ideology or agendas; the influence of prior policies; and established historical precedence (Lomas and Brown 2009). Finally, this model expands on the role of expert opinion in decision-making, with the authors emphasizing that all evidence must be

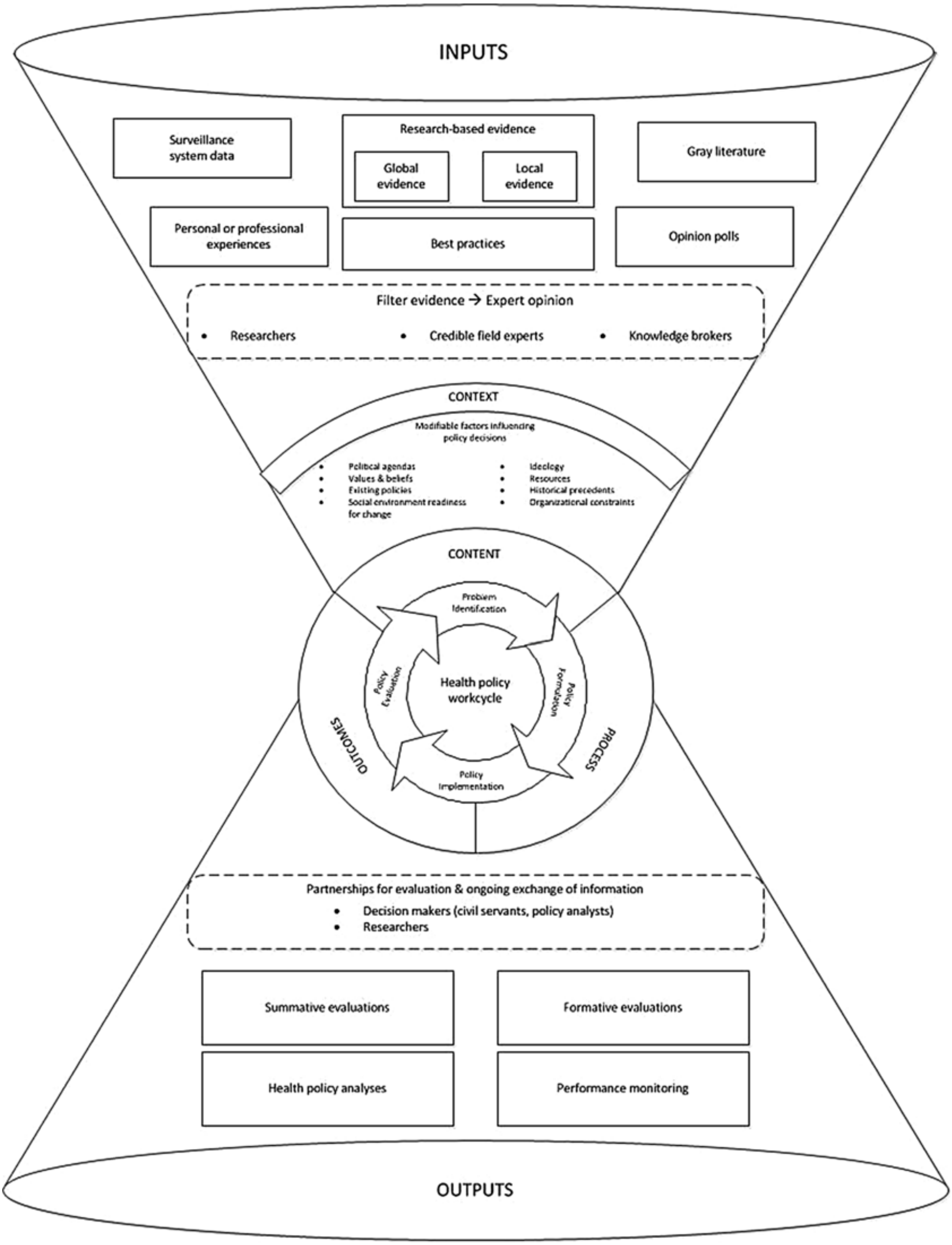

Fig. 31.1 Model of evidence-informed policymaking

accessed, appraised, synthesized and filtered by experts; and that they make explicit judgments about potential health policy options by examining the evidence and weighing the proposed benefits, harms or costs. The positioning of expert opinion as a filter, rather than solely another single source of information competing with other types of evidence to inform decisions, reaffirms the necessity of promoting opportunities for engagement and interaction between health policy decision makers or civil servants and experts in the field, including researchers (Lomas and Brown 2009). The emergence of expert opinion as having an essential role in shaping health policy was a significant finding in a systematic review of 18 studies examining the use of research evidence by public health decision makers within the context of universal health care systems (Orton et al. 2011).

Brownson et al. (2009) continue to add to the consensus that within the policy domain research evidence, both quantitative and qualitative, is only a single source of information, one that is considered within the context of other social, political, economic, and ideologic factors. In their framework however, they identify that research evidence informs three distinct domains of evidence-based policy and that there are specific types of research data most appropriate for informing each of these three domains. The first domain, *content*, involves identifying—from research data sources such as systematic reviews—the approaches and policy elements that are likely to lead to changes in health outcomes. The second domain is *process*, which involves locating evidence through local surveys or qualitative case studies on the best approaches to promote policy adoption and also collecting data to document the procedures involved in policy implementation. The final domain revolves around accessing surveillance system data or conducting policy evaluations to describe, measure, and interpret policy *outcomes.* The recognition of this third domain expands our discussion of the role of evidence within the health policy work cycle, moving from an exclusive focus on only how evidence informs problem identification and policy formulation, to a recognition that, within this cycle, research evidence can be a vital output from the process. What is helpful about the identification of these domains is that they can be directly mapped onto the phases of the health policy work cycle. This allows researchers and decision makers or policy analysts to distinguish what types of research evidence are most suitable for different policy activities. In a qualitative study conducted with 18 civil servants from the Ontario Ministry of Health and Long-Term Care, Lomas and Brown (2009) further add to our conceptual understanding of how evidence is used in each stage of the healthy policy work cycle and how policymakers engage with research evidence in those different phases. Specifically, in the stage of problem identification or “agenda setting,” researcher evidence is predominantly directed or “pushed” to decision makers by groups or individuals trying to influence the agenda; when decision makers however are actively engaged in policy formulation, the nature of the relationship and demand for information changes, with civil servants engaged in seeking and “pulling” evidence to inform, support, or validate their decisions. While many of the evolving models of evidence-informed policymaking focus on the inputs into the health policy work cycle, Lomas and Brown highlight the importance of research evidence—and the relationship between civil servants and researchers—in the policy evaluation phase, where research evidence becomes an output of the policy work cycle.

Using core elements from each of these models or conceptualizations, I have developed a more comprehensive framework (see Fig. 31.1) that specifically links evidence inputs and outputs to the different phases of the health policy work cycle and identifies opportunities for decision makers and researcher engagement and partnerships. The inputs include different information or data sources, including research-based evidence that is filtered through experts, who act as opinion leaders or trusted filters of what information or evidence is relevant to the process. Decision makers, generally civil servants, then balance this information with modifiable factors within the social, political, economic, organizational contexts in which decisions are made and policies are implemented. Once policies are implemented, there is a need to monitor the new or adapted programs and conduct formative and summative evaluations. This creates a second point of intersection for decision makers and researchers to work collaboratively on research outputs in the policy implementation and evaluation stages.

Challenges remain however on how to continually increase the influence that research-based evidence has overall on policymaking. Promoting the utilization of research evidence in the policy process is neither rational nor straightforward; thus researchers must be prepared to engage, collaborate and communicate with decision makers, in often-protracted processes, to see research evidence ultimately influence end-decisions. The attitudinal, knowledge and behavioral barriers that exist at both individual and organizational levels to accessing, appraising, adopting, and using research evidence in decision-making are well documented (e.g., Innvaer et al. 2002; Wallace et al. 2012). Furthermore, the technical language, complexity of interpreting results, variation in study quality, and the structure and length of research reports are commonly cited reasons limiting decision-makers' motivations or abilities to engage and utilize research evidence (Brownson et al. 2009; Dobbins et al. 2007). Numerous strategies and interventions however continue to be developed and tested to identify effective approaches for supporting the use of research evidence in policy making. However, what can be accomplished in this chapter is to outline for researchers the opportunities that exist for promoting qualitative evidence as an input into the health policy cycle and identifying how formative and summative evaluations of health policy can be enriched through the integration of qualitative methods.

31.3.1 Qualitative Research as Evidence in the Policy Work Cycle

Traditionally, research evidence has been categorized into three broad paradigms: quantitative, qualitative and mixed methods research. Within the field of health policy and systems research field, the question is no longer about the supremacy of one paradigm over another, but more about how the findings from each can be uniquely utilized by decision-makers. One methodology is not superior over another per se; instead what is important to establish is that researchers have a responsibility to pick the most appropriate research design to answer the policy question that is being posed. However, qualitative methods can be used to produce inputs into the health policy work cycle, particularly as a part of these data sources: surveillance evidence, global evidence, local evidence and embedded within the gray literature. As an output, qualitative methods are extensively used in formative evaluations of policies, particularly as process evaluations, and embedded into summative evaluations.

In the problem identification and policy formulation stages, healthy policy analysts will draw extensively on surveillance system data, primarily constructed thorough the collection, analysis and dissemination of quantitative data, to describe the incidence, prevalence, risk indicators, and health outcomes associated with a particular issue. However, some comprehensive surveillance systems may also collect qualitative data in response to open-ended questions. In Canada, the Canadian Hospitals Injury Reporting and Prevention Program (CHIRPP) is a computerized information system that collects data on intentional and unintentional injuries on predominantly children and youth 19 years of age and younger seen at emergency rooms in ten pediatric and four general hospitals. Data are collected via questionnaire and close-ended questions are posed to answer the questions: (1) What was the injured person doing when the injury happened? (2) What went wrong? and (3) Where did the injury occur? However, there are also three narrative fields that allow the respondent to provide information about the specific circumstances of the injury. I am currently involved in a research project with epidemiologists from the Public Health Agency of Canada to analyze narrative data with respect to intentional injury (e.g., suicide attempt or completion) cases. Using qualitative content and thematic analytic strategies we will be able to richly describe and answer questions about the context, social factors, and emotional state of youth prior to the injury. Combined with the quantitative data we anticipate this will provide a very in-depth and nuanced understanding of antecedent factors that contribute to youth suicide, with the long-term goal of developing programs or policies to prevent suicide.

Research-based evidence, both global and local, is most frequently employed to validate potential policy options or to inform policy formation. Typically, health policy analysts seeking policy solutions will seek data from typical global evidence sources such as systematic reviews, meta-analyses, and randomized controlled trials, which will be examined to answer questions about efficacy, effectiveness, cost, and adverse effects. Increasingly, qualitative evidence is being systematically collected, appraised, and included in systematic reviews to inform policy decisions. However, if quantitative findings are used in isolation, particularly those drawn from trials and systematic reviews, then there may be limits related to their relevance and utility for decision-makers attempting to select and implement solutions for contexts different from those in which the studies were conducted. It has been argued that quantitative findings intended to be generalizable at a population level may not meet the specific needs of policy makers at the local community level (Bell and Seidel 2012). Thus qualitative evidence plays a primary role in the development of local research-based evidence. It provides a counter-balance to this limitation, and particularly when conducted as part of a mixed methods study, provides the tools to describe and understand local and community level factors and conditions that may ultimately influence the implementation and implications of a health policy.

Qualitative research provides the tools to richly document the nuances of a range of human experiences and provide insight about perceptions unique and different compared to our own understanding of or experiences in the world. Thus a well-written qualitative narrative can become a powerful tool of persuasion in the policy process. Donmoyer (2012) suggests that policy makers can be influenced in their decision making by the emotional nature of a richly detailed narrative and concludes that "policymakers may value statistical data and analysis in their discourse; in private, however, if you want to convince them of something, tell them a good story" (p. 805). Brownson et al. (2009) argue that qualitative findings may act as "emotional hooks" and thus can be successful when used to influence the interpretation of a health problem, policy deliberations, and agenda setting (p. 1577). So if health policy decision-makers are deliberating on the option of implementing a model of midwife-led care for childbearing women, the results of a systematic review of 11 trials will provide them with a strong foundation of quantitative evidence that for low-risk pregnant women, midwife-led care is not only safe but, compared to other models of care, may result in reductions in the use of regional analgesia (risk ration [RR] 0.90), episiotomies (RR 0.82) and instrument deliveries (RR 0.86). Additional benefits of midwife-led care for women include an increased sense of control during labor (RR 1.74), increased likelihood of having a spontaneous vaginal birth (RR 1.04), and initiation of breastfeeding following delivery (RR 1.35) (Hatem et al. 2008). But what might "tip" a senior health decision-maker to advocate for this type of model of care is learning of women's experiences of being cared for by a midwife presented as qualitative themes. One would learn that women highly value the amount and quality of time that their midwife spends with them both through the pregnancy and the labor and that midwives work in a consultative manner, not directive, and provide holistic care that involves the engagement of all family members. As a result women feel empowered and supported (Moon et al. 1999).

Qualitative findings are also generally presented as written narratives, and more recently within the field of arts-based research expressed in such formats as photographs, paintings, dramatic plays, or other artistic forms. For policy analysts and senior political decision-makers, many of who lack training in epidemiology and research and thus the skills to interpret complex statistical findings, qualitative research may have an intuitive appeal to it. Essentially, it is easier to understand and often they can make sense of, or relate to, the stories being shared. Bell and Seidel (2012) conducted a mixed methods study that involved quantitative mapping of interview transcripts and a qualitative critical discourse analysis of interviews with 18 senior health policy decision-makers from nine countries to understand their perceptions of useful research evidence. There was consensus among their study participants that while quantitative evidence is valued, it is perceived as highly technical and thus perceived as less accessible for use in decision-making by those policy makers who lacked the knowledge and skill to interpret findings. In comparison, qualitative research was perceived to be less technical and easier for participants to interpret and use. It was noted however that a limitation of qualitative research evidence was that it was perceived to be a less credible form of evidence by clinicians and the practitioners who would ultimately be responsible for implementing the high-level health policies.

Think tanks, health agencies, nongovernmental organizations, or similar institutions who assume a mandate to advocate for the needs of a particular population may also readily engage in the conduct of qualitative research and publish their findings in the gray literature, or documents that are informally published or disseminated using communication channels outside of the traditional peer-reviewed journals or commercially published books. For example, one of the goals of The Change Foundation (2010) is to support the redesign of the Ontario health-care system, once that takes into consideration individual users' and their caregivers' perspectives, values and experiences. One of their strategies to advocate for change was to collect and share, using qualitative data collection techniques, the lived experiences of patients and their caregivers about their experiences in the health care system, as well as individuals' recommendations for improvements and changes to the system (The Change Foundation 2012). Their work is a very powerful example of how the views, experiences and values of a key stakeholder group can be systematically collected, synthesized and shared to inform the policy work cycle. Further, to develop their strategic plan, they also conducted an environmental scan that included key informant interviews and discussion forums with senior health and social care decision-makers, an advisory group, and representatives from primary, community, acute and long-term care sectors (The Change Foundation 2010). The collection and sharing of this qualitative evidence is one way to promote community engagement in informing the policy process.

While the challenges for moving research-based evidence into the policy arena have been acknowledged by many, for those continuing to seek avenues to have research influence policy, the goal of seeking both quantitative and qualitative evidence to present should be valued. To determine which type of evidence is more persuasive in influencing changes and attitudes, Allen and Preiss (1997) conducted an innovative meta-analysis of 16 studies comparing the influence of narrative accounts (qualitative findings) to statistical evidence (quantitative findings). They concluded that messages using statistical evidence were more persuasive than those that used a narrative approach. Based on this preliminary work, a subsequent study was undertaken to measure if messages containing a combination of both statistical and narrative evidence are more persuasive compared to messages containing only a single source of evidence (Allen et al. 2000). From a sample of 1270 undergraduate university students, they concluded that messages containing both narrative and statistical evidence were more persuasive than messages with statistical evidence only, followed by messages with narrative evidence only. Messages that contained neither form of evidence were the least persuasive.

The evolving conclusion then is that quantitative evidence provides proof of the effectiveness of a policy and a way to measure outcomes, and qualitative evidence provides a way to understand, interpret, and explain the human experience and context. This provides us with a compelling argument to use both types of research evidence to inform decision-making and a need to be able to articulate under which circumstances and when qualitative or quantitative evidence is most appropriate. Thus, for the novice researcher, it is essential to not only know how to develop and conduct qualitative studies, but also to be able to do so in a manner in which findings are of relevance to decision-makers.

Often neglected in discussions of evidence-informed policy making is the role of research in the policy implementation and evaluation components of the health policy work cycle. Lomas and Brown (2009) explain that civil servants engaged in health policy work desire collaborative, ongoing relationships with researchers for the purpose of evaluating policies and creating new evidence to inform the work cycle. Increasingly process evaluations, with a significant emphasis on using qualitative methods, are being designed and conducted to describe how a policy is being implemented and to contribute to the comprehensive evaluation of complex interventions or policies (Lewin 2009). Specifically, the conduct of a process evaluation can help to answer how and why a policy succeeds or fails within different contexts. The primary functions of a process evaluation are to: (1) describe the components of an intervention, program, or policy; (2) determine if it is being delivered with fidelity; (3) describe implementation processes, including variances across different contexts; (4) link policy outcomes with implementation processes and in the policy evaluation phase to; (5) explain unanticipated or varied outcomes between jurisdictions (Linnan and Steckler 2002). Process evaluations, while often qualitative in nature, may also be one component of a larger mixed methods study. For example, in British Columbia, researchers from the Children's Health Policy Centre, McMaster University, along with decision-makers from the BC Ministries of Health and Children and Family Development are leading an evaluation of the Nurse-Family Partnership home visitation program. The two components of this 5-year evaluation, called the British Columbia Healthy Connections Project, are (1) a randomized controlled trial to measure the effectiveness of the NFP, compared to usual services, to improve maternal and child health outcomes among young, socially disadvantaged Canadian mothers, and (2) a process evaluation. While we will be using a convergent parallel mixed methods research design to address the process evaluation objectives, the emphasis will be on the collection of longitudinal qualitative data from key stakeholders, including the public health nurses, supervisors, and Ministry of Health coordinators responsible for implementing this program: a key element of the new child health policy in that province.

31.4 Conducting Qualitative Health Policy Research

To address the perception that qualitative research is a less credible form of evidence, the onus is upon researchers to ensure that they adhere to the methodological rules of the designs they select and ensure that a qualitative approach is the most appropriate one to answer the questions being posed.

31.4.1 Policy Research Questions

The success of a health policy research study will depend on how clearly the researcher is able to articulate and focus the overarching research question. In qualitative research, the question ultimately guides the selection of the research design, the scope of the purposeful sample and perhaps even informs the type of data collection strategies to be employed. Reviewing the strategies listed below can assist novice qualitative researchers in designing their health policy research questions.

1. *Understand and establish stakeholder priorities.*

   To ensure that findings are relevant and usable by policy analysts and decision-makers, researchers should engage and partner with knowledge users early in the research process. This is essential for defining the research priorities and understanding the scope of the project. To ensure that data are relevant to policy-makers and will inform subsequent decisions, the knowledge users can also provide insight about the key policy actors who should be included in a study (Gilson 2012). In partnership, they establish which part of the policy work cycle the project will be informing; is the overall purpose to establish the acceptability of different policy options, to document the process by which a policy is implemented or to explain the impact (intended and unintended effects) that a policy has had on a specific stakeholder group.

2. *Determine what is already known about the topic.*

   Early qualitative methodologists, particularly within the realms of phenomenology and grounded theory, encouraged researchers to enter the field with all of their preexisting knowledge and assumptions set aside. This has created a holdover belief among some novice qualitative researchers that literature reviews should not be conducted prior to initiating a study. However, a literature review is essential, for the purposes of providing background information on the policy context, describing what is already known about a topic, limiting redundancy and then identifying specific gaps in knowledge (Gilson 2012). As qualitative research is grounded in context, researchers may identify that stakeholder perceptions of an issue may have been studied in contexts quite different from the environment in which a planned policy is to be implemented. For example, in Hafid's (2012) literature review of qualitative studies of decision-makers' perceptions of the HPV vaccine, it was noted that studies answering this question had been conducted in the USA, South Africa, Columbia, India, Peru, Uganda, and Vietnam, but not Canada. This then provides a strong rationale to conduct a study of Canadian stakeholders' perceptions within the context of their universal, provincially funded public health programs. Similarly, a review of the literature may expose that the issue has been substantially studied within a specific group of stakeholders, for example parents or health care providers, but the perspectives of another core group, such as the adolescents targeted to be vaccinated, have not been examined.

3. *Determine the study purpose.*

   Typically, the purpose of most qualitative policy research is descriptive, exploratory, explanatory, or emancipatory. Descriptive studies involve documenting the actions, events, perceptions, structures, and processes related to a health policy. They are most typically stated as *what* questions. Exploratory qualitative research is conducted to understand the meaning of phenomena, to discover novel perspectives, or to document process. Exploratory research questions, often stated as *how* questions, also allow us to identify key categories and understand the relationships between categories. In policy evaluation research, much emphasis is placed on conducting explanatory studies where the goal is to identify the contextual factors, events, and stakeholder actions that explain the implications of a policy. Emancipatory studies engage research as a political act, one that is conducted to promote change. Questions in these studies are often structured to understand how a specific stakeholder group defines or understands the health problem and then seeks to identify solutions to the problem. The study purpose will also be determined by the stage of the policy work cycle in which the question is being asked.

   Researchers working in the field of HPSR may collaborate with health policy analysts for the purpose of accessing and appraising preexisting research or conducting studies to provide policy makers with timely, contextually specific data. Morestin (2012) presents a framework for analyzing public policies that identifies six analytic components that influence decision-makers about their selection of public policies: effectiveness; unintended effects; equity; cost; feasibility; and acceptability. These dimensions can be useful in helping frame the overall study purpose. While the effectiveness of a policy will typically be measured using quantitative methods, when a policy is being considered for implementation in a context in which it has not been tested, Morestin recommends "to gather as much information as possible about the influence of the implementation context on effectiveness, to be able to form judgements [sic] about the transferability of a policy from one context to another" (p. 3). Similarly, when unintended effects of a policy are identified, qualitative methods are appropriate for examining the nature of those effects, the conditions that led to the development of the unanticipated outcomes, stakeholder perceptions of the impact, and to identify strategies that could be utilized in the future to minimize those effects that were perceived as having a negative impact (Morestin 2012). The issue of equity is important to explore as well, as public health policies tend to be implemented at the population level yet will have varying effects on subgroups. Therefore the purpose of a qualitative study may be to explore the nature of the social inequalities related to a policy and understand the contributing conditions. Finally, in terms of studying the implementation of a policy, qualitative methods can be integrated into feasibility studies and used as a dominant method to explore acceptability.

Little has been written about how to structure and conduct policy acceptability studies. Acceptability refers to exploring and describing how various stakeholders perceive and understand the components of a policy. It may include examining the social, psychological and ethical acceptability of a health policy. Data about acceptability is essential in the policy formulation and decision-making phase as it provides insight into components that may be problematic and impede implementation and uptake if not addressed. Once the key policy actors and stakeholders are identified, Morestin (2012) recommends asking the following acceptability questions: (1) Is it acceptable to implement a policy to address the targeted health problem? (2) How acceptable is the proposed health policy in comparison to other proposed policies? (3) What are stakeholders' perceptions about the feasibility, effectiveness, cost, and equitableness of implementing the proposed policy? and (4) How acceptable is the degree of coercion associated with the health policy? Stakeholder perspectives however are static and different contextual conditions may alter how a policy is viewed. Therefore, questions about how, why and when stakeholders may find a policy more acceptable should be explored. Returning to our case example of HPV vaccine, most parents may perceive administering the HPV vaccine to adolescents as acceptable but only if it is available to males and females, delivered as two doses versus three, and available to adolescents older than 13 years. In any process evaluations of the implementation of the policy, stakeholder perspectives may change over time and thus acceptability should be revisited due to the social, political, environmental, or technical changes within the society (Morestin 2012).

4. *Construct a focused, policy research question.*

A clearly articulated research question provides the reader with a sense of the scope and purpose of the study. The first step is to identify the appropriate qualitative words to briefly describe the purpose of the study. These may include: to explore (understand), to explain (develop), to describe (discover), or to emancipate (promote action) (Marshall and Rossman 2011). Alternatively, you may choose to emphasize that the research question is focused on the *perception* or *meaning* of a policy, the *context* in which the policy is (or was) implemented; or on documenting any processes associated with adopting, implementing or evaluating the health policy (Maxwell 2013).

A considerable amount of policy research will be contextually specific and about understanding the perceptions and needs of unique stakeholders within that environment. To guide this work, a good research question will then clearly articulate the population, phenomenon and context under study. Be as specific as possible in identifying the purposeful sample within the research question. Readers will be left with a sense of ambiguity if the research question incorporates such generic terms as "stakeholders" or "policy actors" (e.g., "What are stakeholders' perceptions of the acceptability of administering HPV vaccine to adolescent girls ages 9–13 years in the school setting?"). It is more meaningful to identify if you are most interested in examining the experiences specifically of parents, adolescents, health care providers, the general public, educators or public health policy decision-makers. The phenomenon refers to the situation, event, problem, or policy under study. Integrating language that refers to the relevant phase of the policy work cycle can also increase the specificity of the research question. In the following question, the phenomenon of interest is the process of implementing electronic health records: "How did Canadian provincial and territorial ministries of health coordinate the electronic health record adoption and implementation process?" Finally, as contextual influences are largely responsible for the success or failure of a health policy, research questions should specify the specific setting in which the phenomenon is situated. A setting could relate to any country, jurisdiction, province/territory, organization or agency that is implementing, or impacted by, a health policy. To conduct an evaluation around the implementation of electronic health records in Ontario, a jurisdiction where implementation has been significantly delayed by a lack of leadership, procurement scandals, and relatively little progress given the investment of resources to date (MacAdam 2009), the context within the following question would be limited to the province of Ontario: "In Ontario, how did the implementation context influence the implementation of electronic health records by the Ministry of Health and Long-Term Care?"

31.4.2 Health Policy Research Designs

Researchers have a broad range of robust qualitative research designs, or approaches, to choose from to answer their policy-relevant questions. The choice of design should be influenced primarily by the research question being asked, but is frequently informed by the researcher's training and field of discipline. It is essential at this stage in the evolution of health policy research to demand an increase in the quality and rigor in the qualitative studies being published in peer-reviewed journals. There are three primary problems. The first being a tremendous dearth of detail frequently provided about the qualitative methods used to guide the conduct of a study. In a systematic review conducted to describe the volume and characteristics of 329 empirical qualitative research articles published between 1998 and 2008 in major health service journals, fewer than 40 % of the articles provided an extensive description of the study's methods, and half of the articles (52 %) provided few details (less than one page of content) and omitted information on data collection, analysis, site selection, or study limitations. Shockingly, 9 % of the articles provided no account of the study methods (Weiner et al. 2011). The second related problem is that in some studies there was a complete absence of any apparent design to guide the conduct of the study. Weiner and colleagues concluded that approximately one-third (28 %) of the articles they reviewed described using a "general approach" to qualitative methods and did not follow a traditional qualitative approach. Finally, the third frequently observed problem is the articulation of the intent to use a particular qualitative design (e.g., grounded theory, case study, ethnography, narrative inquiry) followed by a description of procedures that do not align with the methodological rules of the intended approach, thus indicating perhaps a poor understanding of the philosophic tenets of the design or a lack of training in the development and conduct of qualitative research.

This section provides the novice health policy researcher with some ideas about common qualitative approaches that are most amenable to creating knowledge to inform policy content, achieving the goals of HPSR and two approaches (using stories and photovoice) that powerfully transform qualitative data into effective tools of persuasion.

31.4.3 Qualitative Meta-synthesis

There is increasing requirement for health policy analysts to understand stakeholders' perceptions of health problems, the factors that contribute to the problem and, following the implementation of a policy, their overall experiences. As the quantity of qualitative studies increases, tools for comparing, contrasting and synthesizing similar findings across studies are required. Synthesis of qualitative findings can assist in addressing common critiques of primary single studies: that is that findings are limited in their transferability because of small sample sizes and investigation of a phenomenon in a specific social context, with a unique group of participants in a given time period (Hansen et al. 2011). At the simplest level, these types of syntheses involve articulating a research question, defining inclusion criteria by which to select and include articles in the synthesis, conducting a systematic and comprehensive search of the published peer and gray literature, appraising the quality of each primary study, extracting the data and then, at various levels, aggregating or interpreting the collated findings. The intent is that by using a rigorous approach to integrating findings, higher level constructs and results will emerge with improved transferability to a range of contexts. This is appealing to decision-makers and health policy analysts who require a comprehensive understanding of health or social problems from multiple perspectives and who lack the time and perhaps resources and skills to independently search for, retrieve and appraise individual primary studies. Researchers however need to recognize that there is a range of methods for synthesizing qualitative methods and must be able to determine which method is most appropriate for answering their research question or addressing a policy problem. Examples of different approaches include meta-ethnography, thematic synthesis, meta-study, meta-narrative, and qualitative meta-summary. Barnett-Page and Thomas (2009) provide a valuable and detailed overview and critique of the different methods of synthesis, highlighting that the different methods can either be categorized epistemologically as idealist or realist approaches and may vary across the following dimensions: search strategy, quality assessment, problematization of the literature, question, heterogeneity of the included studies, and the final synthetic product created.

Box 31.2 The Role of Scientific Evidence on Legal and Political Decision-Making: A Case Study of Canadian Supervised Injection Facilities (Hyshka et al. 2013)

Insite is a supervised injection facility located in Vancouver, Canada that provides space, sterile injection equipment, safe syringe disposal services, health education, primary health care, and referrals to other health and social care services. Although it is illegal in Canada to possess specific controlled substances, Insite was granted a temporary legal exemption to operate by the federal government based on a plethora of scientific research evidence demonstrating the effectiveness of the intervention to reduce drug related harms. In 2006, the Conservative federal government attempted to revoke Insite's legal exemption; a 2011 ruling by the Supreme Court of Canada ordered an extension however of the initial exemption. A policy case study was conducted by sampling and reviewing jurisprudence, legislation, scientific evidence, and media texts. The objectives of the policy case study were to evaluate how scientific evidence influenced policy and legal decisions; analyze the legal ruling and explore the potential implications for other Canadian cities seeking a legal exemption for a supervised injection facility and to determine the likelihood of new sites being established. The authors conclude that it is unclear if new sites wanting to establish a supervised injection facility will be granted a similar exemption under the current ruling or if further court action will be necessary. The importance of establishing small-scale pilot sites as a strategy for influencing policy makers is identified.

31.4.4 Case Study

Qualitative case study methodology allows health policy researchers to holistically study complex phenomena within their natural contexts using a variety of data sources and types. The use of multiple triangulation strategies results in robust, credible qualitative findings. Case study is a valuable method for developing and evaluating policies and it is extensively used in HPSR and health policy analyses (Walt et al. 2008). In their review of the characteristics of published health services qualitative research, Weiner et al. (2011) determined that among the 329 studies revised, case study was the most common qualitative approached used, with 59 % of articles using a multiple-case study design and 11 % describing use of a single-case design.

Case study methodology can be selected when: (1) the research question being posed is *how* or *why*; (2) the purpose is to discover core contextual conditions that are believed to influence the policy or health problem under study; and (3) the boundaries are not clear between the context and the phenomenon (Baxter and Jack 2008; Yin 2009). Explanatory case studies are used to answer questions that attempt to understand the relationship between policy components, implementation, and end effects or consequences and that are too complex to be evaluated using experimental designs (Baxter and Jack 2008). Exploratory case studies are conducted to understand situations where the policy being evaluated has no clearly defined set of outcomes (Baxter and Jack 2008; Yin 2009). Descriptive case studies are conducted to identify the components of a policy or problem, as along with their dimensions and properties (Yin 2009). Case studies are also frequently employed to document the policy implementation process as well as analyze the implications of particular policy decisions.

Box 31.1 Single Mothers' Transition from Welfare to Work (Cook 2012)

Across the western world, welfare-to-work policies are being instituted that require low-income single mothers to reenter into the work force. Cook conducted a thematic synthesis of eight qualitative studies describing mothers' experiences of the welfare-to-work transition and the perceived impact of these programs on their health. This author summarizes that in this process, women experience multiple health and economic issues during this transitory stage, including various degrees of poor mental and physical health. For participants in the USA medical challenges were exacerbated by a loss of health benefits as they entered into low-wage jobs. The combination of reduced government subsidies with insufficient wages resulted in increased use of food banks and an inability to afford appropriate childcare. On the basis of these findings, the author concludes that welfare-to-work policies do not result in a more efficient distribution of resources, and that participation in the job market may result in fewer resources for single mothers and increased illness burden. She recommends that future welfare and employment policy examine the interactions between work incentives and disincentives and the family-care requirements for lone mothers.

31.4.5 Interpretive Description

An exceptionally practical research method for applied health policy researchers is interpretive description (Thorne 2008). While developed within the field of nursing research to describe and interpret clinical phenomena, this qualitative approach provides a practical framework for describing health issues and policy processes. What differentiates this approach from qualitative description is the analytic focus on interpretation and explanation by answering the all important question of "so what?" (Thorne p. 33). This method also fills an important void in current qualitative methodologies in that it provides a method that is flexible, suitable for addressing health policy content, process and outcome research questions, and allows for basic description but also encourages interpretation within the current social, political, and cultural context but does not require the high-level conceptual abstraction required in such approaches as grounded theory, ethnography or phenomenology. Researchers often select one of the more traditional approaches to answer an applied research question because there is a basic appreciation that grounded theory is selected to study questions related to process, phenomenology selected to describe and interpret the meaning of phenomena and that ethnography provides tools to understand the symbols, patterns and routines within a defined culture. However, many health researchers lack the disciplinary and methodological training in the fields of sociology, philosophy or anthropology to adequately and robustly conduct these types of highly abstract and theoretical studies. What is also frequently noted in the health services and policy literature are researchers who adapt or only borrow a few techniques from an established social science method, do not follow the full set of methodological rules for the method they insinuate they are using, and thus run the risk of producing results of debatable credibility, dependability, or transferability.

In interpretive description, the research question must evolve from the field and be developed to address a specific practice, or in this case, policy goal (Thorne 2008). It is imperative also that researchers engage in the project with a sound understanding of what is already known, or not known, about the topic including empirical evidence and the tacit knowledge held by stakeholders. Through the interpretive lens, the researcher can then “deconstruct the angle of vision upon which prior knowledge has been erected and to generate new insights” (Thorne p. 35). The guidelines associated with this method will support health policy researchers in their goals of understanding the context in which policy decisions are made and also document and critically analyze existing “subjective, experiential, tacit and patterned” knowledge (Thorne, p. 36).

31.4.6 Developing Stories

One of the greatest challenges in translational research is identifying strategies to transform empirical evidence into understandable and usable information that can be communicated quickly, and with effect, to key decision-makers. As identified earlier, qualitative findings when expressed as well-written narratives have an advantageous appeal in that they can be used to evoke emotional responses and be powerful tools to promote the adoption of a policy option or to explicate the implications or consequences of a policy decision. The transformation of qualitative data into stories—structured narratives that present a sequence of events to explain a process and the resulting outcomes—can be a useful way

Box 31.3 Exploration of Parent and Student Perceptions of Implementing School Nutrition Policies (MacLellan et al. 2010)

MacLellan and colleagues used an interpretive descriptive approach to describe students’, in grades 4–7, and their parents’ perceptions of the barriers and facilitating factors that influenced the implementation of a school nutrition policy in Prince Edward Island designed to promote healthy eating habits within the school environment. Parents shared that communication between decision-makers and stakeholders was strong during the policy development process but that it was inadequate during the policy implementation stage. Parents and students were also concerned that they were not consulted about planned changes to food options sold at school during the lunch hour and that student food preferences were not taken into consideration. A significant barrier was the perception that it is a parent’s, and not the school’s, responsibility to address nutrition and dietary habits. The authors interpret that poor communication during the policy implementation stage resulted in parents’ lack of understanding and awareness about the content of the policy. Additionally they explained that personal beliefs about who is responsible for children’s health behaviors may influence long-term sustainability of the policy.

to communicate essential background information on a health issue, descriptions of the target population and their experiences, and the steps taken to develop and implement a policy (Zwald et al. 2013). During a process evaluation, the development of stories can also be a short-term solution or deliverable to communicate to stakeholders about the progress being made and to share emerging results. This can be an important way of keeping stakeholders informed about progress being made even before the quantifiable impacts of a policy are known. The most significant challenge in the health field currently, however, is securing resources to develop and create the stories and supporting individuals to develop skills in writing them.

To ensure that the stories are viewed as credible sources of evidence and not just anecdotal accounts of an individual's experience, researchers can ensure that data collected to tell the story emerge from the findings of a structured research design, such as interpretive description (Thorne 2008) or narrative inquiry (Clandinin and Connelly 2000). The steps in the story development process create specific opportunities where researchers can implement certain methodological strategies to enhance the overall trustworthiness, and in particular the credibility, of the qualitative data that is embedded with the stories. For example, after conducting the primary interviews for the purpose of creating the basic story structure, there is a requirement to collect additional data to fill in any apparent gaps in the story. Researchers can therefore expand their sample to include other data sources, so that the story can be understood from the perspective of different stakeholders or about the role of different contributing levels of policy-makers. Beyond interviews with stakeholders, other data types can be collected and reviewed at this point, including media reports, observations, or policy documents. Both data type and data source triangulation will enhance the overall credibility of the data and thus the story that is narrated and disseminated. During this stage, as well as the stage of developing and refining the stories, opportunities to engage in member checking should be established as part of the protocol, or finding opportunities to share the emerging storyline back with the main participants to ensure that their story is accurately being interpreted and represented in the final product.

The Centers for Disease Control and Prevention in their work to communicate various policy, systems, and environmental approaches used to prevent obesity, developed a seven-step framework for story development (Zwald et al. 2013). In adapting the framework proposed by Zwald and colleagues for qualitative researchers working to communicate to policy actors, there are several steps they can engage in. First, identify the target audience for the story and then determine if the story will focus on policy content, process or outcomes. It is important to also articulate at this stage the purpose of the writing the story; that may include increasing awareness about a policy, documenting lessons learned or to advocate for one policy option over another. The next step involves the collection of data using a qualitative approach and rigorous strategies for sampling, data collection and analysis. At this stage, it is important to determine if the final story will emerge out of a single narrative or will be comprised of a compilation of stories and experiences. Once this decision has been made, authors will then review and select stories, collect additional data to enrich the background information about the policy to fill any gaps in the storyline and then finish by refining the story. At this stage, it is recommended (Zwald et al.) that researchers secure the assistance of a technical writer to assist in writing the story by transforming the qualitative data into a suitable narrative form. Throughout the process, one can engage participants and other policy actors in determining the title for the story, one that will engage the reader and highlight the story focus. With this lens to informing or discussing health policy, one might consider that the story content could include, but not be limited to, a description of: (a) policy or program details; (b) implementation process; (c) short- or long-term outcomes, including both intended and unintended consequences; (d) identification of all stakeholder roles and partnerships; (e) the potential impact on population health; (f) lessons learned, including identification of facilitators and barriers and recommendations for other jurisdictions; and (g) contact information. Once the story has been drafted, circulated for review and feedback from participants, then engagement of a graphic designer to select photos, design a story template and to confirm the story format (e.g., booklet, single page newsletter) is recommended (Zwald et al.). The final stage is to identify multiple communication channels through which to disseminate the stories to the various stakeholder audiences.

31.4.7 Photovoice

Upon entering the foyer of a local children's aid society, in a single instant I learned the power that a photograph can have on understanding a complex issue from a new perspective and that a photograph can act as a catalyst for change. The photograph collage observed was part of a photovoice project conducted with youth who were asked to take pictures of their experiences of being in foster care and also to share their visions for their futures. The collage consisted of a series of ten photographs of different front doors, with the title "You gave me a house when I needed a home […]. I wouldn't have built a wall around me if I wasn't in care." (FCSGW 2012, p. 8). That image portrayed to me a broken foster care system that does not provide stability or security to our most vulnerable youth and results in tremendously negative health outcomes.

Photovoice, as a qualitative approach, has its foundations in participatory-action research and may be engaged as a part of an emancipatory research project where the goal is to share stakeholders' perceptions and experiences of a problem or situation and to use those findings to engage politically in promoting the development or uptake of positive social and health promotion actions (Marshall and Rossman 2011; Wang and Burris 1997). Photovoice as a tool for knowledge creation empowers individuals to describe and share their perspective of how they experience the world, or even a specific health or social condition, through the use of photographs. Explicitly, the three overarching goals of a photovoice project are to: (1) have all participants document and reflect on an identified issue; (2) increase awareness and then to engage in a critical discourse with individuals or groups about the photographs; and (3) engage with policy and decision-makers to create an awareness of an issue and to promote for social change (Wang and Burris). There is no doubt that decision-makers at all levels are busy, inundated with information and may lack time, skills or resources to read published research reports. Photovoice however requires physical and verbal dialogue and interaction between the very people that a policy will impact and the individuals responsible for developing and implementing the policy options. Not only do photos have the power to convey messages, but the participatory nature of this approach allows for recipients of health policy to be actively engaged in defining the problem and presenting potential policy options (Wang 1999). As a participatory method, policy and decision-makers are also not just passive recipients of knowledge; instead they are invited to actively in engage in different stages of the projects, not generally as photographers, but as advocates and liaisons for supporting the consideration and implementation of policy options suggested by participants.

31.5 Utility of Qualitative Research Evidence

In HPSR evidence can be utilized for different purposes including decisively guiding decisions, developing a new perspective on about a health problem, or to politically substantiate decisions that have already been made by policy makers. Given the time and resources that are invested in conducting qualitative studies, I think that researchers must also take on a certain level of responsibility for explaining to decision-makers *how* their inductively derived findings can be useful in the policy analysis process. At minimum, this should include providing detailed

Box 31.4 Flint Photovoice: A Critical Discussion Among Youth, Adults and Policy Makers About the Strengths and Assets in Their Community of Flint, Michigan (Wang et al. 2004)

A once vibrant community, primarily dependent upon a single automotive industry, the community members of Flint, Michigan have recently struggled with the health, social and economic impacts associated with deindustrialization, disinvestment and urban decay. To document and critically discuss this transition, youth, community members and policy makers engaged in a photovoice project to take photos of what they perceived were primary concerns and assets of their community. Together, 41 individuals, representing different ages, incomes, experiences, neighborhoods of origin and levels of social power, took photos and then engaged in a process of "freewriting" about one or two photos from their roll that they identified as particularly important. In reflecting on each photo, they were asked to answer the following questions: (1) What do you see here? (2) What is really happening? (3) How does this relate to our lives? (4) Why does this problem or strength exist? and (5) What can we do about it? Following group discussions, key themes were identified. The photos and themes were presented at interactive forums with invited policy makers, community members, the general public and members of the media. As part of this process, decision makers gained a new understanding about issues of safety and violence. The authors also identify that an important outcome of this type of research is also the development of new partnerships between community members and decision makers.

descriptions of the setting or context of the study, and characteristics and demographics of the study participants. This supports a reader's ability to determine if the results are transferable and applicable to his or her own local context.

31.5.1 Instrumental Use

Instrumental use refers to the direct use of research findings to inform a policy decision (Amara et al. 2004). Qualitative data collected, often within the scope of pilot studies, to address questions of a program or policy's acceptability with different stakeholders, can be immediately used to adapt, change or refine health policies before they are implemented or targeted to a larger group of stakeholders. Within Canada, my research team has been advocating for, and working with, decision-makers within local public health agencies and across different provincial ministries to consider a policy option of offering extended maternal-child home visiting (from early pregnancy through to a child's second birthday) to vulnerable mothers. The program under consideration is the Nurse-Family Partnership, a nurse home visiting program for young, low-income pregnant women and first-time mothers. This program has been extensively evaluated in the USA over the last 35 years but its effectiveness in the context of the Canadian health care system is unknown. In 2008, a pilot study was conducted in Hamilton, Ontario to determine the feasibility and acceptability of delivering this program through a local public health agency. A qualitative case study was conducted to explore the acceptability of the program elements with a range of stakeholders including physicians, social workers, clients and their family members, public health nurses and public health mangers (Jack et al. 2012). One important finding in this study was that public health nurses in Canada are unable to sustain the same caseload level of clients compared to US nursing colleagues delivering the same program. As a result of this finding, an instrumental change was made to the program guidelines and the recommendation to reduce caseload levels from 25 clients to 20 per nurse was implemented. Within the policy arena, the instrumental use of qualitative findings can play a significant role in the policy development phase by identifying and then including recommendations and actions within the policy recommended by core stakeholders. In the evaluation phase, instrumental use also occurs by identifying barriers, facilitators, and unintended effects of the policy, or allowing decision-makers to clearly identify factors that contributed to the policy's success or failure. Once these have been identified, adaptations or changes can result.

31.5.2 Conceptual Use

Given the exploratory and descriptive nature of most qualitative findings, they will most commonly be used conceptually by decision-makers. Conceptual utilization has been referred to as an enlightenment process that provides the reader with insight about, or a novel appreciation of, contextual issues. Additionally, when studies are conducted to describe and explore stakeholders' perceptions, values, and beliefs, then this provides an opportunity for decision-makers to understand the nature of a problem from the perspective of others. Health policy issues such as homelessness, food security or wait times are complex. How an issue is defined, and the solutions proposed to address the problem, will differ by stakeholder group. Using qualitative evidence is one strategy by which decision-makers can access at least a summary of how the issue is seen by different groups, and to view the issue from a point of view that may differ considerably from the prevailing view that exists within the policy, agency, or government environment. For example, across North America, many professional health organizations and jurisdictions are advocating for the implementation of universal screening for intimate partner violence among women accessing health care services. The presumed intent of such policies is to identify abused women early and provide or refer them to appropriate supports and services to reduce their exposure to violence. Despite the lack of evidence in support of the effectiveness of screening (MacMillan et al. 2009), qualitative research also reveals to us that some abused women may choose to not disclose this information to health care providers, and that they fear losing control over how, when, and what information is shared (Catallo et al. 2013). As a health care provider, I might perceive that when a woman discloses her abuse status, that this creates an opportunity to intervene and provide supports and services. However, this qualitative data helps the decision-maker to understand the issue from the perspective of the client and to conclude that there is perceived risk associated with screening and that for women, it results in increased feelings of powerlessness and vulnerability. It has been further argued that the conceptual use of qualitative evidence not only provides an opportunity to have new insight into an issue, but that it is through this process of heightened awareness and sensitivity that the potential for developing policies that are relevant and sensitive to the needs of the population can be created and implemented (Jack 2006).

31.5.3 Symbolic Use

A decision-maker may also selectively choose specific results or research studies to justify or validate a predetermined position or policy. Whereas the process of evidence-based or evidence-influenced policy requires decision-makers to access and consider a range of research evidence *before* making a decision, when evidence is used symbolically, it is retrieved *after* the decision is made. A qualitative multiple-case study was conducted to explore how senior child welfare decision-makers utilize research evidence in the policy process (Jack et al. 2010). In exploring participants' perceptions of how provincial child welfare policy is developed, they were critical of how they believed research evidence had been used in the process. They accused policy makers of handpicking evidence to support the policy changes and by even manipulating the research evidence to legitimize the political agenda. The challenge for researchers then becomes how to ensure that high quality research evidence is easily accessible and available for decision-makers, either before, or after a decision is made.

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Generating New Health Knowledge

32

Richard A. Young, Karin Olson, and Izabela Z. Schultz

32.1 Summative Themes

Assertion 1. The chapters of this *Handbook* contribute to a better and fuller understanding of qualitative health research in several ways. They address fundamental issues about qualitative research, review and integrate qualitative heath research in specific areas, and address issues regarding its application. Thus, the *Handbook* speaks to both the misunderstanding and undervaluing of qualitative health research and how these characteristics are and can be addressed. It gives voice to qualitative evidence in health.

Assertion 2. Qualitative health research is not the same as quantitative health research. It is not simply a matter of qualitative and quantitative health research using different forms of data. While there are reasons to appreciate the continuities between qualitative and quantitative research, it has been well recognized in these chapters that the differences between qualitative and quantitative health research are fundamental, based on different ontologies, epistemologies, and axiologies. There are also important sociopolitical developments that have contributed to the rise of different research paradigms. Gergen and colleagues (2015), for example, credited the 1960s civil rights, anti-war, and feminist movements in the USA to the appreciation of the particular over the universal, which eventually led, in their view, to the reintroduction of qualitative research methods in psychology.

Assertion 3. Health and health care are on a continuum of applied human action. Although most of the chapters address health-care topics explicitly, for example, in the context of oncology, cardiology, and medication adherence, the literature reviewed and the chapter authors themselves frequently assume and emphasize the agency of the person in the process. We have also seen in these chapters that health is historically and culturally situated. An understanding of health begins with the individual and those with whom the individual interacts, a perspective that is an important driver of qualitative health research.

Assertion 4. Qualitative health research recognizes and is based on the applied nature of health and health care. It is the applied nature of questions about health and health care that led to

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qualitative research. For example, it is not simply a matter of whether a treatment or intervention works, but also for whom, under what circumstances, in what context, and in light of what clinical practice knowledge. Qualitative research often begins with the context in which people are living lives or professionals are practicing health care. It begins with the application and, as a result, shows how knowledge, in the form of both formal research findings and naïve theories, is applied in everyday life. Qualitative evidence from health research has a direct connection to social action, including policy and practice.

Assertion 5. Qualitative research speaks directly to, and supports, a biopsychosocial model for health and health care. It has helped to shift the focus from a biomedical model of health, a Cartesian approach begun in the seventeenth century, to a biopsychosocial model. This shift is increasing awareness about the contributions qualitative health research can make to solving major problems on the health agenda. Still, the work addressed in the *Handbook* raises the question about the extent to which this opportunity has made its way into the health discourse. Health and particularly health care are complex phenomena in the world. The ontological and epistemological roots of qualitative research designs make it possible for researchers using these approaches to address this complexity. The research reviewed in the *Handbook* has, for example, increased knowledge about complex behaviors and experiences by making beliefs, expectations and values of health and health-care stakeholders explicit in areas such as illness, disability, self-care, and self-efficacy. Qualitative health research contextualizes knowledge, making it possible to show how context changes knowledge. Qualitative health research also gives voice to vulnerable and marginalized populations and otherwise "invisible" people and issues. It increases knowledge about human relationships in health and health care and about the process of delivery of health-care services. One of the challenges facing researchers and research users is finding ways to use the knowledge gained about the complex phenomena to shift the health discourse.

Assertion 6. Qualitative health research contributes to reversing three developments in health care identified by Timmermans and Almeling (2009). These developments are first, objectification, which refers to considering people as objects, secondly, the standardization of clinical practice guidelines and, thirdly, the commodification of health care that portrays health care as a business in which health-care personnel provide a product that is then obtained and used by patients. Each of these is itself worthy of being addressed in research because, as Timmermans and Almeling argued, they have shifted the direction of health care. The authors of many chapters in this *Handbook* have shown that qualitative health researchers have addressed the objectification, standardization, and commodification of health care by giving voice to patients/participants through the interview process, by recognizing the person's agency both conceptually and methodologically, by basing research on paradigms that depart from standard notions of generalization, and by attending to local conditions, multi-system interactions, and cultures.

Assertion 7. Qualitative health research addresses issues of breadth and depth of health and health-care issues, as has been well illustrated in the *Handbook*. Specific health topics such as pain, trauma, and reproductive health as well as broad concerns such as the patient's experience and how to apply qualitative research to practice are included. At the same time, qualitative health research can address the important topic of interpersonal dynamics in health care, not only between the patient and care provider, but also among the complex and evolving interactions among multiple systems involved in health care across time trajectories. It has shown in various chapters in the *Handbook* and elsewhere that dimensions of patient diversity matter in health care, and how they matter. The breadth and depth capabilities of qualitative health research are evident in investigations of poorly understood clinical conditions and contexts, patient satisfaction, non-standard health outcomes, developmental trajectories, and aging.

Assertion 8. Qualitative research, as integrated in the *Handbook*, underscores the key areas of health and health-care inquiry that involve otherwise difficult to access constructs and poorly understood phenomena critical for the improved conceptualization and outcomes of health interventions. In addition to addressing the issues of individual and contextual diversity and relational dynamics in health care, qualitative research tackles other difficult to measure phenomena for which methodologies are just emerging, including transdisciplinary approaches to multi-system stakeholder interactions in health care. Such studies are called for by the increasingly popular World Health Organization's Model of Health (WHO 2001), which focuses on the dynamic interactions among individuals and systems. Moreover, qualitative research helps answer broader health-related questions rooted in social models of health, such as power relationships and their dynamics, health and health-care communications, complex decision-making, stigmatization-legitimization, and social oppression/marginalization-acceptance processes. Many chapters in the *Handbook* also focus on important but difficult to study themes in health care that are of significance to future outcomes. Such themes include contextually based coping with health issues, the role of the concepts of selfhood, identity, and insight, expectations of recovery and health services, struggle to rebuild life, development of "personal medicine," and spirituality and resiliency. One of our chapter contributors aptly called these still poorly understood issues "invisible" and "off the grid" in health-care research.

Assertion 9. Qualitative research rests upon a broad social framework of health interventions located on a continuum of primary, secondary and tertiary interventions in the context of individuals' social and occupational integration. Context-dependent social reality within which health interventions operate is challenging to study and quantitative methodologies do not have ready-made answers. Qualitative evidence helps stakeholders understand how contexts guide and inform health and social behavior, institutional norms, cultural expectations and socio-political macrosystems, including macro-regulatory environment and health policy. It helps in understanding the balance between barriers and facilitators, both systemic and individual, that would potentially best serve to develop a future roadmap for effective health interventions.

32.2 Continuing Challenges

Assertion 10. Notwithstanding the views about evidence introduced in Chap. 1, and addressed in one way or another in all of the subsequent chapters, the nature of evidence remains a critical issue in health research. Indeed, as Allen (2001) pointed out, the debate about what constitutes evidence has gone unabated since Antiquity. Much more recently, however, the evidence-based movement, with its roots in the objectification, standardization, and commodification of health care, privileges the traditional, post-positivist scientific paradigm that subordinates evidence with other ontological and epistemological roots. The randomized control trial (RCT) is the gold standard of this approach. The popularity of the evidence-based movement and the RCT is based, in the perspective of some, on their having made health care more effective and available, and at uniformly higher levels of excellence. This approach has promoted the biomedical model, had a significant influence on the health discourse, and continues to influence health policy and practice. This hegemony is evident in the values that guide national health policy and private insurance programs.

The authors of the chapters in this *Handbook* give substantial weight to an alternative view of evidence by documenting the results of qualitative studies in a variety of areas. Collectively, these studies show that the epistemological uniqueness embedded in qualitative research results in a different form of knowledge. It is not merely more of the same using a different data form. It is a different way of conceptualizing the research problems and collecting and analyzing data, and informing practice. The criteria for what counts as evidence from the perspective of qualitative research, as has been pointed out in the *Handbook*, are now broader, but still are not clear. However, it is also evident that there is not a uniform agreement of what constitutes evidence among the chapter authors nor within the literature they cite. The identification of what constitutes evidence is sufficiently broad to encompass both qualitative and quantitative health research, and will continue to challenge the field. Researchers are encouraged to be clear about how their findings provide evidence to address the research questions they pose and the research problems they conceptualize.

Assertion 11. One of the key challenges to the future of qualitative research is the reliance on the biomedical model, with its emphasis on the traditional scientific paradigm, in some areas of medicine and health care. Consider, for example, the emphasis on biomedical sciences in the training of physicians and the reliance on technology in treatment. Elliott and Richardson (2014) noted that the medical community has continued to focus on the biomedical model in the treatment of epilepsy, and the same can be said of other illnesses. The development of effective knowledge mobilization and exchange strategies for the dissemination of the evidence generated through qualitative research will help to address this challenge and should be emphasized by qualitative health researchers.

Assertion 12. Although there is substantial evidence for mixed methods studies in the *Handbook*, this type of research remains challenging because of the different epistemologies on which qualitative and quantitative research are based. One way of addressing this challenge is to conceptualize health phenomena and research questions in such a way that one can readily identify the levels of the phenomena or questions that are amenable to quantification and those that are not. Researchers must not lose sight of the fact that it is likely that the phenomena or questions have both quantifiable and *qualifiable* aspects to them. For example, Trembly and Lucie (2014) suggested complexity as a potential paradigm for health promotion in which different epistemological and methodological stances are matched with health promotion concepts.

Assertion 13. Knowledge translation is a practice in health research that has received increased attention in recent years. It implies a linear and sequential process in the generation and application of new knowledge. First, knowledge is generated, then it is applied or translated. Qualitative research, as has been so evident in the chapters of this book, has the potential of turning this linear sequence on its head. Qualitative health research begins in the field, in applied settings, with physical and psychological conditions as they are lived. It is much less a question of translating the knowledge gained in qualitative health research than it is using this knowledge to translate evidence-based manualized treatments, technological interventions, and biomedical science into actual effective clinical practice. Qualitative health research provides information critical to the translation of knowledge from research to practice. At the same time, as the amount of qualitative health research and number of researchers engaged in this research grows, it may begin to seem like an end in itself, in which case knowledge mobilization and exchange with health and health-care stakeholders will have to be addressed.

Notwithstanding the place of qualitative health research in the knowledge exchange process, the question that needs to be asked is whether and to what extent physicians, as an example of one primary health-care practitioner group, respond to the issues raised in this *Handbook*. This question is raised not to challenge the importance of physicians and other practitioners as highly competent in the use and application of technologies, but it is to ask whether in doing so, fundamental aspects of health and healing, such as agency, context, and holistic practice, are well integrated into their work.

32.3 Future Directions

Assertion 14. The *Handbook* took a generic approach to qualitative health research, that is, it did not focus on a particular methodological approach or approaches, although specific approaches are addressed within chapters. A future direction for understanding the uniqueness of particular methodologies is to focus within traditions rather than across them in order to appreciate the depth of understanding that is generated within specific traditions. We can anticipate and look forward to, for example, a *Handbook of Phenomenological Health Research* or a *Handbook of Ethnographic Health Research*.

Assertion 15. For the most part, the qualitative health research discussed in the *Handbook* has been about the Western view of health. At the same time, there are many Indigenous and alternative views of health and health-care practices throughout the world. For example, the Indian Board of Alternative Medicines (2015) lists more than 100 Indigenous, traditional, or folk medical practices. Many of these practices are based on fundamentally different ontologies and epistemologies. It is not simply that culture influences health and illness as one among several causal factors. People in various cultures who engage in health and illness as practitioners or patients often understand and experience these phenomena differently. Qualitative research has already shown itself to be useful in understanding these approaches in a variety of ways. For example, Hopkirk and Wilson (2014) were able to use a methodology based on Māori culture to investigate the Māori concept of wellness. Qualitative methods can also be used to understand Indigenous health practices. For example, Ojelade et al. (2014) examined how Orìsà priests initiated within the Yorùbá-based system of Ifá addressed mental health problems.

As has been reiterated in various ways throughout the *Handbook*, we have seen that qualitative research challenges the ways problems are conceptualized, from whom information is sought and how it is sought, and the purposes of research itself—all of which provide an inclusive framework for the study and understanding of Indigenous and other traditional health and health-care practices. Even more importantly, the question that needs to be asked is how qualitative health research can serve to draw the practices into culturally specific and well-grounded health and wellness for a variety of groups worldwide.

Assertion 16. Because of its applied focus and its close connection to practice, qualitative health research is a call to action, often framed in the social justice context. Thus, it has the potential for incorporating poststructuralist, critical, transgressive, and emancipatory action approaches. Some of our chapter contributors call for an interactionist approach to research, involving persons with health conditions and disabilities, and representatives of other health and health-care stakeholders on research teams. All these approaches increase the possibility of engaging with health research in a more ethically and politically explicit way. But the challenge of asking strong research questions and following explicit methods that address such research questions are criteria that cut across approaches. Indeed, strong research questions and explicit methods, as we have seen in the research reviewed in the *Handbook*, will themselves contribute to knowledge that is meaningful for practice as well as ethically and politically meaningful.

Assertion 17. Perhaps a step or two removed from the kinds of research reported in the *Handbook* is the recent emphasis on performance research. Although more often linked with the arts than social science, performance research incorporates forms of the creative arts and performance as part of the methodology as a means to both develop new understandings and to translate new knowledge for practice. In its own ways, it undertakes to reduce the divide between knowing and action. For example, a recent special issue of the journal *Performance Research*: *A Journal of the Performing Arts* focused on Medicine (Bouchard and O'Brien 2014). Within ethnographic and some other qualitative research approaches, a focus on performance has emerged. This was not referred to in a significant way in the chapters in the *Handbook* but remains a promising approach of bringing research and research findings to life. Performance research represents new way of communicating with audiences about health knowledge.

32.4 Conclusion

Our hope for the *Handbook* is that it serves as both a resource and a stimulus for health-care researchers and their progeny. The *Handbook* addresses a range of topics, methods, and applications on health and health-care topics but, in each of these areas, more remains to be done. The substantial size of the *Handbook* and the extensive literature reviewed in it may suggest that the qualitative health research project is finished or nearing completion. It is not. This is just the beginning, albeit an extensive one, of the dialogue that this research engenders with all health and health-care stakeholders and with the future. We hope, to paraphrase the words of the American pragmatist philosopher Richard Rorty, that the *Handbook* serves to keep the conversation about health and health care going.

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ERRATUM TO

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There was a mistake in the author's email ID and web address on the title page of Chapter 28. The author's email and the web address should read as below:

E-mail address: colleen.mchorney@ert.com
Web address: https://www.ert.com/ecoa/pro-ecoa-scientific-services

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