Carey DeMichelis
Michel Ferrari
Editors

Child and Adolescent Resilience Within Medical Contexts

Integrating Research and Practice

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Carey DeMichelis
Department of Applied Psychology
and Human Development
Joint Center for Bioethics
University of Toronto
Toronto, ON, Canada

Michel Ferrari
Department of Applied Psychology
and Human Development
University of Toronto, OISE
Toronto, ON, Canada

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Contributors

Jesmin Akter College of Social Work, University of Utah, Salt Lake City, UT, USA

Lamia P. Barakat The Children's Hospital of Philadelphia, University of Pennsylvania School of Medicine, Philadelphia, PA, USA

Ronald T. Brown Department of Psychology, University of North Texas at Dallas, Dallas, TX, USA

Tara J. Cheetham Department of Psychology, University of Bath, Bath, UK

Cindy Dell Clark Department of Anthropology, Rutgers University, New Brunswick, NJ, USA

Lynnda M. Dahlquist Department of Psychology, University of Maryland, Baltimore County, MD, USA

Carey DeMichelis Department of Applied Psychology and Human Development, Joint Centre for Bioethics, University of Toronto, Toronto, ON, Canada

Michelle M. Ernst Department of Pediatrics, Division of Behavioral Medicine and Clinical Psychology, Cincinnati Children's Hospital Medical Center, University of Cincinnati College of Medicine, Cincinnati, OH, USA

Michel Ferrari Department of Applied Psychology and Human Development, University of Toronto, OISE, Toronto, ON, Canada

Emily Foxen-Craft Department of Psychology, University of Maryland, Baltimore County, MD, USA

Richard D. Goldstein Department of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute, Boston Children's Hospital, Harvard Medical School, Boston, MA, USA

Jessica Hoehn Department of Psychology, University of Maryland, Baltimore County, MD, USA

Christina E. Holbein Department of Psychology, Loyola University, Chicago, IL, USA

Grayson N. Holmbeck Department of Psychology, Loyola University Chicago, Chicago, IL, USA

Cathy Humphreys McMaster University, Hamilton, ON, Canada

Min Ah Kim Department of Social Welfare, Myongji University, Seoul, South Korea

Mary Jo Kupst Department of Psychology, Medical College of Wisconsin, Milwaukee, WI, USA

Chantal K. LeBlanc IWK Health Center, Halifax, NS, Canada

Bandy X. Lee Law and Psychiatry Division, Yale University, New Haven, CT, USA

Center for the Study of Violence, Ames, IA, USA

World Health Organization, Geneva, Switzerland

Grace Lee Education Studies Program, Yale University, New Haven, CT, USA

Jaclyn M. Lennon Department of Psychology, Loyola University, Chicago, IL, USA

Linda Liebenberg Faculty of Graduate Studies, Dalhousie University, Halifax, NS, Canada

Cheryl Mattingly Department of Anthropology, Division of Occupational Science and Therapy, University of Southern California, Los Angeles, CA, USA

Michael W. Mellon Department of Pediatrics, Division of Behavioral Medicine and Clinical Psychology, Cincinnati Children's Hospital Medical Center, University of Cincinnati College of Medicine, Cincinnati, OH, USA

Robyn Munford School of Social Work, Massey University, Palmerston North, New Zealand

Caitlin B. Murray Department of Psychology, Loyola University, Chicago, IL, USA

Jane Noyes School of Social Sciences, Bangor University, Gwynedd, UK

Wendy Pinder Department of Psychology, University of Maryland, Baltimore County, MD, USA

Alexandra M. Psihogios Department of Psychology, Loyola University, Chicago, IL, USA

Katherine S. Salamon Nemours/Alfred I. duPont Hospital for Children, Wilmington, DE, USA

Lisa A. Schwartz The Children's Hospital of Philadelphia, University of Pennsylvania School of Medicine, Philadelphia, PA, USA

Julie M. Turner-Cobb Department of Psychology, Bournemouth University, Poole, Dorset, UK

Michael Ungar School of Social Work, Resilience Research Centre, Dalhousie University, Halifax, NS, Canada

Jaehee Yi College of Social Work, University of Utah, Salt Lake City, UT, USA

About the Editors

Carey DeMichelis Is a doctoral candidate in the Department of Applied Psychology and Human Development at the University of Toronto. Her research focuses on the way adolescent patients make medical decisions—particularly in cases where the family's cultural or religious beliefs conflict with medical recommendations. Drawing from biomedical ethics, developmental psychology, and medical anthropology, Carey's research explores the way adolescent autonomy intersects with medical authority, cultural identity, and legal precedent in these complex cases. Carey is a member of the Collaborative Program at the Joint Centre for Bioethics. She is a graduate associate at the Centre for Ethics and at the Centre for Critical Qualitative Health Research at the University of Toronto.

Michel Ferrari, Ph.D., Teaches developmental and educational psychology in the Department of Applied Psychology and Human Development at the Ontario Institute for Studies in Education (OISE), part of the University of Toronto. From 2004 to 2005, he was a visiting scholar at Harvard and at the Max Planck Institute for the History of Science and in 2013 was a visiting scholar at the University of Potsdam. He is interested in personal identity and developing wisdom throughout the life span and has studied self-understanding of identity in people diagnosed with autism. Dr. Ferrari has coauthored and coedited books on wisdom, including *Teaching for Wisdom: Cross-cultural Perspectives on Fostering Wisdom* (with Georges Potworowski, Amsterdam: Springer, 2008) and *The Scientific Study of Personal Wisdom: From Contemplative Traditions to Neuroscience* (with Nic Weststrate, Springer, 2014). Dr. Ferrari has also coedited books on child development and education, most recently, *Developmental Relations among Mind, Brain, and Education: Essays in honor of Robbie Case* (with Ljiljana Vuletic, Amsterdam: Springer, 2010) and *Handbook of Resilience in Children of War* (with Chandi Fernando, Springer, 2013).

Chapter 1
Relational Resilience: An Interdisciplinary Perspective

Carey DeMichelis

This handbook is intended to begin an interdisciplinary conversation about pediatric resilience. The chapters collected in this volume bring together scholars and practitioners from Health Psychology, Social Work, Medical Anthropology, Child Life Specialty, Palliative Care, Public Health, and Nursing, each of whom contributes something important to our understanding of the ways children and their families successfully navigate illness. Since each of the disciplines represented here approaches the idea of resilience a bit differently, we will begin by suggesting an integrative framework termed "Relational Resilience" that we feel is particularly well suited to the interdisciplinary scope and subject matter of this project. By thinking broadly about the complex topic of pediatric resilience, we hope to highlight emerging points of consensus across fields and to illuminate promising areas for future research.

Relational Resilience

The picture of resilience that emerges in this handbook is a relational one. By "relational resilience" we mean that resilience is shown to be a process of complex interpersonal, institutional, and political interactions, which together make it more or less possible for people to do well in the face of adversity. When children and families are supported through close personal relationships, through institutional partnerships, and through equitable political process, they are better able to sustain well-being. They are more resilient.

C. DeMichelis (✉)
Department of Applied Psychology and Human Development, Joint Centre for Bioethics,
University of Toronto, 252 Bloor Street West, Toronto M5S 1V6, ON, Canada
e-mail: carey.demichelis@mail.utoronto.ca

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We use the term “relational” in order to emphasize the importance of relationships—not just between persons, but also between the social institutions, local communities, and political powers that make up a family’s social reality. According to relational theory from which we borrow the term, it is a mistake to assume that the world is made up of discrete pre-given units such as “the individual” or “society.” Rather researchers should begin by viewing individuals as socially constructed and fundamentally contextual—“inseparable from the transactional contexts in which they are embedded” (Emirbayer, 1997, p. 288). Originally the province of physicists and philosophers, relational theory is now enjoying enthusiastic uptake in the social sciences where it is used to make sense of the complex and dynamic interactions that shape human development.[1]

Our use of “relational resilience” differs from the way this same term has been employed in clinical settings where it has been used to mean women and girl’s emotional “capacity for connection” (Jordan, 1992, p. 2, 2013) or the “intimate bond” of interpersonal relationships across the life-course (Walsh, 2003, p. 52). While we agree that resilience is a function of dynamic relationships, we construct “relationship” much more broadly here to include not just interpersonal relationships but also transactions within and between social political systems. Resilience is relational in the sense that it is a process of dynamic interactions. It is not, in our sense, specific to a gendered experience or particular to relationships between persons—though, of course, interpersonal relationships do matter enormously.

In our more robust construal of relational resilience we follow Collette Daiute who understands resilience as “A process of ongoing development through discursive activity in social and political milieu” (2013, p. 160). Daiute calls for an account of the social dimensions of resilience—a relational view that “zoom[s] back from the figure of self-contained capacities that flourish or fail [in order] to examine the broader system of relations among individuals, groups and institutions” (2013, p. 155). This handbook attempts to provide such an account. A picture of the individual, interpersonal, institutional, and political conditions that make it possible for families to maintain well-being when facing childhood illness.

Each chapter in this handbook is concerned with answering one small part of the question: “what can we—a community of concerned researchers, service providers, and clinicians—do to promote the resilience of children who are facing illness or disability?” Though none of the chapters included here are written explicitly from a “relational theory” perspective, the handbook as a whole puts forward a relational argument: We can support patient’s resilience by helping them to build supportive interpersonal, cultural, institutional, and political partnerships. By presenting a collection of chapters from a wide range of disciplinary perspectives, we hope to give

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[1] For a relational approach in: Psychology see Urie Bronfenbrenner’s “social ecological theory” (2006), Willis Overton’s “relational-development-systems” theory (2015), Mascolo and Fischer (2015), Ayoub and Fischer (2006); in Sociology see Mische (2011), Emirbayer (1997); in bioethics see Sherwin (1992), Mackenzie and Stoljar (2000); in medical anthropology see Panter-Brick (2014), Sharp (2006)

our readers a sense of the full range of relationships that affect a family's ability to maintain well-being in the face of illness or disability.

There are at least three important advantages of thinking relationally about pediatric resilience. First, a relational framework allows us to unite work on resilience that is being done across disciplines. Second, understanding resilience relationally allows us to keep sight of the normative dimensions of the resilience concept. Finally, a relational approach to resilience gives researchers and clinicians a fuller sense of the range of adversities that families confront when managing illness, as well as a more diverse picture of what "doing well" can look like.

The fist important advantage of viewing resilience relationally is that it provides a unifying framework for an interdisciplinary conversation. Each of the chapters collected here speaks to different relationships that support processes of pediatric resilience. For example, health psychologists like Hoehn, Foxen-Craft, Pinder, and Dahlquist (Chap. 6) focus on parent child relationships, providing detailed strategies to help parents support their children through chronic conditions such as type 1 diabetes and chronic pain. Meanwhile, social worker Michael Ungar (Chap. 12) speaks to the importance of institutional partnerships in his chapter on the challenges of coordinating integrated social services that meet the needs of families navigating illness and disability. Medical anthropologist Cindy Dell-Clark uses ethnographic material in her chapter to explore the relationships children build with the medical spaces they inhabit. She demonstrates that practices such as humor, storytelling, counterfactual play, metaphors, and rituals can be opportunities for children and families to remake meaning and build resilience. At the same time, public health researcher Jane Noyes (Chap. 14) focuses on government initiatives from the UK that were designed to target resilience at the level of social policy.

The cumulative picture of resilience that emerges from these chapters is one of complex interwoven relationships and interactions that sustain well-being. Thus, relational theory provides an engaging cross-disciplinary framework to think through complex social processes like resilience. By choosing to present these chapters side by side, we as editors are making the relational argument that it is necessary to consider a wide range of personal, social, and political interactions in order to understand a complex phenomena like pediatric resilience.

A second important benefit of taking a relational approach to studying pediatric resilience is that it allows us to keep sight of the normative dimensions of the project. In their 2013 editorial commentary on the state of resilience research, anthropologist Catherine Panter-Brick and psychiatrist James Lackman urge resilience researchers to take seriously the normative assumptions that their research makes. They write, "If we are to take seriously the notion that resilience pathways are complex and context-specific, then we need to appraise the normative, as well as the functional, dimensions of adaptation, health, and wellbeing…While a resilience framework usefully pulls away from risks and deficits, it is not useful if it remains conceptually hazy, empirically light and methodologically lame" (2013, p. 335). Resilience is normative in the sense that it requires the researcher to make (at least) two judgments about the way the world *ought to be*: first that the resilient person is "doing well," and second that the resilient person has overcome "significant adversity" (Luthar, 2006; Ungar, 2007). The chapters collected here approach these judgments in very different ways. In our view, the sheer diversity of approaches represented in this volume is enough to demonstrate that "doing well" is not an objective state that can be measured precisely or defined universally. Rather what is meant by "doing well" and "significant adversity" will depend on the foundational assumptions of the researcher and the particular circumstances of the child.

A relational view of resilience reminds us that a family's personal, institutional, and political circumstances powerfully shape their social reality. These contingent and particular factors will inform the family's understanding of what "doing well" looks like, as well as what constitutes "significant adversity." Thus a relational approach helps to guard against the tendency in some resilience research to define doing well as 'not statistically different from normal kids.' If, guided by relational theory, we see the categories of "doing well" and "normal development" as socially constructed, we can better avoid a problematic dichotomous rhetoric that juxtaposes the healthy child and the deviant/disordered child (Ungar, 2007).

For researchers who study resilience in a medical context, it is particularly important to remain open to the idea that "doing well" can take many forms in order to avoid equating resilience with recovery or a return to a previous state of health. Doing so would miss the rich variety of ways children and families demonstrate resilience when confronted with illness or disability. As contributors to this handbook beautifully illustrate, resilience can be seen even in the context of palliative care where the metaphor of "bouncing back" is no longer appropriate (Goldstein, Chap. 7). A relational approach to resilience that treats normative judgments as socially embedded and focuses on the relationships and interactions that sustain well-being allows us to recognize resilience in the experiences of children and families for whom approximating "normal" is no longer an option or a goal.

Finally, viewing resilience relationally in medical contexts allows us to recognize the full range of adversities that resilient families overcome. Whether managing an acute medical crisis or a chronic condition, illness and disability can present families with a cascade of economic, social, and cultural barriers that impact their ability to "navigate" the services they need and "negotiate" for those services to be provided in culturally meaningful terms (Ungar, 2012). For example, Chap. 5 by health psychologists Salamon, Schwartz, and Barakat illustrates the negative stereotypes that confront parents of children with Sickle-Cell Disease and the barriers that this stereotyping produces for realizing resilience. Similarly, social worker Yi writes on the social stigma associated with childhood cancer in Korean communities, and the way these stigmas shape families' views of "successful" survivorship. These chapters show that the adversities families face are plural and particular—shaped by the local interactions that constitute their social reality.

A relational understanding of resilience reminds us that people are fundamentally embedded in social systems that shape the opportunities that are available to them. It is necessary, therefore, to consider the particular constellation of biology, culture, gender, ethnicity, and social resource that shape the adversity landscape for each family. Viewing resilience relationally prompts us to seek out this broader picture and allows us to recognize the full scope of adversities that families face.

Handbook Organization

This volume is organized following a roughly micro to macro "ecological" organization (Bronfenbrenner & Morris, 2006), which we feel is in keeping with our relational approach. The first section is made up of chapters that focus on seemingly individual processes that promote pediatric resilience such as a child's physiological context, their developmental context, their disease-specific context, and their personal narrative context. Chapters in the second section focus on children's interactions with the other people that make up the illness space such as parents, peers, clinicians, and community members. The third section focuses on interventions, therapies, and techniques that are currently being used or developed to promote resilience in hospitalized children. Chapters in the fourth section focus on structural considerations such as the challenges of securing integrated social services and policy formation. Finally the fifth section provides a theoretical and methodological road map for studying resilience in the future.

The Individual in Context

The first section attempts to contextualize the "individual" processes that promote resilience. In Chap. 2, health psychology researchers Julie Turner Cobb and Tara Cheetham consider the role of stress in adjusting to immune-related conditions. They argue that "building psychosocial resilience has the capacity to build physiological resilience, their interplay enabling the promotion of both psychological and physiological health." Chapter 2 demonstrates that even the most "individual" biological processes such as a person's unique physiological response to stress cannot be understood in isolation from the relational context in which it occurs. Chapter 3 turns to the intimate stories that families tell themselves in order to see their lives as meaningful and complete while managing illness. Drawing on ethnographic materials from an 18-year longitudinal study of health trajectories among African American families in Los Angeles, medical anthropologist Cheryl Mattingly focuses on "small dramas" that families play out every day. In these dramas families and clinicians work together to "discern what story or stories they find themselves a part of" and to "emplot" themselves in a story with a hopeful ending. Though these moments may go undocumented or unnoticed in the clinical world, Mattingly shows that they are of profound significance to families—an essential part of their active practice of resilience.

In Chap. 4 pediatric psychologists Lennon, Psihogios, Murray, Holbein, and Holmbeck argue for the importance of viewing chronically ill children developmentally—that is, recognizing that they are going through the same developmental changes that other non-ill children are going through. They focus on the experiences of children with chronic illness and suggest strategies to promote resilience during the transition to adolescence. Of course, the developmental context may depend on the characteristics of the diseases in question. In Chap. 5 pediatric psychologists Katie Salamon, Lisa Schwartz, and Lamia Barakat provide a comprehensive review of disease-specific risk and resilience factors. The authors focus on Cancer and Sickle-Cell Disease, drawing poignant comparisons between the sociodemographics, disease characteristics, and treatment options available for these two conditions.

The Social Space of Illness

Chapters in the second section focus on children's interactions with the other people that make up medical space such as parents, peers, clinicians, physiotherapists, and community members. In Chap. 6, health psychologists Hoehn, Foxen-Craft, Pinder, and Dahlquist detail strategies to help parents scaffold resilience in the face of chronic conditions such as type-1 diabetes and chronic pain. Hoehn et al. argue that parents can promote resilience by supporting children through the stress of medical procedures, promoting adherence to medical regimes, and enabling participation in every-day developmental tasks. The strategies discussed by Hoehn et al. aim to help children live as normal a life as possible. For some children and families, however, approximating "normal" is not an option. For example, in Chap. 7 Richard Goldstein, MD, paints a beautiful picture of the exigencies of palliative care and the strength and resilience that can be seen there. He suggests that the way to think about resilience in this contexts is not through the metaphor of "bouncing back" but rather by focusing on processes that allow the patient to "remain whole or intact in the face of their health-related challenges." This re-framing allows us to see multiple kinds of resilience: first, clinicians can provide support to help the patient to remain intact, second signs of wholeness in the patient can bolster the resilience of palliative care workers, and finally palliative care workers help to facilitate resilience in family members through practices of "re-goaling."

Following the relational insight that "doing well" and "significant adversity" may look different depending on the individual's cultural context, in Chap. 8 social workers Jaehee Yi, Min Ah Kim, and Jesmin Akter explore different ways resilience may be seen cross-culturally. Their chapter draws on a study of cancer survivorship in South Korea, arguing that resilience must be understood within the cultural context in which the cancer survivor's beliefs and values are embedded. They explore the culturally mediated "resilience work" that is required in order to adapt to an identity of "cancer survivor" in the South Korean context.

Interventions, Therapies, Techniques

The third section focuses on interventions, therapies, and techniques that are currently being used to promote resilience in hospitalized children. The section begins by considering interventions used by child life specialists to promote resilience in children and families. Cathy Humphreys and Chantal LeBlanc present detailed case studies from their own practice which demonstrate the way individual, family, and environmental risk factors are assessed, and how complementary intervention plans are developed. Through a combination of therapeutic play, specialized preparation for medical procedures, coping strategies, and self-expression activities, child life specialists work to create spaces within the hospital that nurture resilience.

Therapeutic play is picked up in Chap. 10 by medical anthropologist Cindy Dell-Clark who uses ethnographic material to illustrate imagination and play as facets of resilience in medical contexts. She demonstrates that practices such as humor, storytelling, counterfactual play, metaphors, and rituals can be opportunities for children and families to remake meaning and build resilience. Dell-Clark's chapter prompts us to ask: "Does playfulness risk subverting the rules, hierarchy, efficiency and biomedical logic of institutionalized care? Or on the flip side of the issue, do institutional and ontological prerogatives unwittingly truncate children's resources for resilience, making their medical interactions less positive than they could be?"

The importance of metaphor and symbolic thinking for promoting resilience is central to pediatric psychologists Michelle Ernst and Michael Mellon's Chap. 11 which focuses on cognitive flexibility as an important aspect of resilience. Acceptance Commitment Therapy (ACT) interventions are intended to help to promote resilience through increased cognitive flexibility. In ACT mindfulness exercises and rich metaphors that are used to help patients observe their ongoing mental processes and chart future courses of meaningful action. The authors provide case vignettes to illustrate how attending to the social constructions of meaning, wellness, and personal values can promote resilience.

Social Structures and Policy Formation

Chapters in the fourth section focus on structural considerations such as the challenges of securing integrated social services. In Chap. 12 social worker Michael Ungar uses case studies to demonstrate the difficulty of providing coordinated and meaningful services to young people with complex medical and social care needs. He argues that we are "only as resilient as the systems that surround us" meaning that services must be more than simply "available," they must also be malleable in order to "meet the needs of children and families in ways that are contextually and culturally relevant." In Chap. 13 social worker Robyn Munford extends Ungar's discussion of the link between resilience and service provision to the context of disability. Munford argues that clinicians can build resilience by taking a strengths based approach to working with families of children with disabilities that acknowledges the local expertise care-givers have developed to provide support for their children. Her vision of a resilient family is a family that is supported to "live meaningful lives, maintain a sense of control over their lives, and assert their rights as citizens to be included and to fully participate in their communities."

Ensuring that families get the services that they need is part of a larger puzzle of public health messaging and economic development. In Chap. 14 Dr. Jane Noyes, explores the potential of social policy to target resilience. Noyes provides examples of social policies that have been implemented in the UK that are intended to facilitate pediatric resilience, arguing that such programs are part of a philosophical shift in thinking about the role of public health: from promoting institutionalization to promoting self-care. The potential economic benefits of supporting policies that promote resilience are explored.

Where We Have Been, Where We Are Going

The final section provides a theoretical and methodological road map for studying resilience in the future. In Chap. 15 health psychologists Ronald Brown and Mary Jo Kupst provide a comprehensive survey of research on stress and coping that illuminates the ways researchers have traditionally studied resilience. Brown and Kupst raise important methodological questions that accompany an ecological or relational approach to resilience, emphasizing the challenges that face resilience researchers who strive to incorporate the social complexity these perspectives entail. These concerns are picked up in Chap. 16 by methodologist Dr. Linda Liebenberg. She introduces a fresh methodological framework for studying resilience ecologically—an iterative mixed methods approach that embraces the relational complexity of resilience. The central focus of our investigations, Liebenberg argues, should not be on isolating risk variables, but rather on developing better ways to understand culturally relevant "resilience processes" that remain open to a plurality of "functional or healthy outcomes." Liebenberg provides step-by-step recommendations for data gathering and analysis that enable the reader to apply these methodological strategies to their independent research projects. This section ends on a contemplative note with a chapter by Bandy Lee, MD. entitled "towards a global perspective on resilience and creativity." Lee argues that imagination and creativity make space for resilience and calls for more human-centered global governance that will nurture the creative impulse and foster resilience. Finally, our conclusion draws connections between the chapters presented here and suggests a set of recommendations to foster the resilience children in medical contexts.

Conclusion

This handbook is devoted to unpacking and exploring the personal, institutional, and political relationships that create the conditions for pediatric resilience. A relational understanding of resilience reminds us that clinicians, patients, and researchers all use different yard sticks to measure "doing well" and "significant adversity." It prompts us to ask what does "doing well" look like here? and what does "doing well" look like for *you?* (Ungar, 2012). By presenting fieldwork from medical anthropology alongside neurophysiology, behavioral interventions alongside public health initiatives, we hope to provide an illustration of the variety of empirical strategies and disciplinary frameworks that are available to explore the relational context of pediatric resilience. Throughout the handbook, areas of consensus are highlighted, chapters are cross-referenced to demonstrate points of convergence, and future research is called for. To our knowledge, no similarly interdisciplinary engagement with pediatric resilience has been attempted.

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Part I
The Individual in Context

Chapter 2
Psychosocial Factors That Influence Children with Immune-Related Health Conditions

Julie M. Turner-Cobb and Tara J. Cheetham

In the context of this chapter, resilience is considered from the perspective of health psychology, a scientific discipline at the interface between biological and psychological factors which, amongst other things, applies psychological theory and knowledge to promote health in physical illness (see APA Division 38 http://www.health-psych.org/ and BPS DHP http://www.bps.org.uk). Within this discipline there is growing interest and attention towards child health and the importance of psychosocial factors that influence health and well-being during childhood as well as across the life span. Central to psychosocial influences are the coping resources and strategies available to deal with difficult or stressful events including illness itself. The driving force behind this approach is the notion that psychosocial factors may be harnessed in order to promote physical health and well-being and to enhance biomedical interventions. This may be via a number of avenues including (1) the promotion of coping techniques to manage the potential daily stress associated with immune-related conditions; (2) the development of supportive social relationships at an individual, family, practitioner, or community level; and (3) the encouragement of appropriate communication to reduce information-related anxiety, increase understanding and uptake of medical advice, and develop good health practices. A central tenet of this chapter is the perspective that resilience is both psychosocial and physiological in nature, that developing psychosocial resilience has the capacity to build physiological resilience, their interplay enabling the promotion of both psychological and physical health. In essence, psychological resilience has the capacity to assist physiological recovery and improve prognosis. Such resilience is therefore

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J.M. Turner-Cobb, PhD (✉)
Department of Psychology, Bournemouth University, Poole, Dorset, UK
e-mail: J.M.T.Cobb@bath.ac.uk

T.J. Cheetham, PhD
Department of Psychology, University of Bath, Bath, UK
e-mail: T.J.Cheetham@soton.ac.uk

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highly relevant to immune-related conditions, particularly in paediatric populations for whom the capacity for change has the greatest potential.

Central to this health psychology perspective is the biopsychosocial model of health and illness. Pioneered by Engel (1977) it represents a development of the biomedical model to include a more holistic interplay between psychological and social factors in medical conditions. Similarly, fields that overlap with health psychology, such as psychoneuroimmunology (PNI) and behavioural medicine, also adopt this model. Lutgendorf and Costanzo (2003) describe the integration between PNI and health psychology within a biopsychosocial framework in which interactions between psychological processes and neuroendocrine and immune mechanisms influence a number of outcomes including disease vulnerability or resistance, onset, progression, exacerbation or recovery, and even survival. Of particular importance in this integrative model is the embedding of health behaviours and psychosocial interventions to influence these outcomes (Lutgendorf & Costanzo, 2003). The way resilience is viewed as defined in this chapter is as a multidimensional or multifaceted process. We consider the application of the biopsychosocial model to both theory and practice, including interventions and outcomes in resilience in children with immune-related health conditions. Based on the scientific study of resilience and the factors that contribute to this process, it is possible to develop psychosocial interventions that harness resilience to maximise coping ability, health, and well-being, across a range of physical health conditions. The three key themes already mentioned, that of stress and coping, social relationships, and communication, in variant forms underlie much of the content of this chapter, and are relevant across different medical conditions, demographic stratification, and stress status.

Here we focus on evidence linking resilience in children living with atopic conditions including asthma and eczema; infectious diseases such as HIV/AIDS; and autoimmune conditions including diabetes, juvenile arthritis, and systemic lupus.

Defining Resilience from a Biopsychosocial Perspective

The concept of resilience certainly has intuitive appeal. It has generated some imaginative metaphorical descriptions often taken from nature and linked to evolutionary survival. For example: the “dandelion child” (those with “the capacity to survive and even thrive in whatever circumstances they encounter”) vs. the “orchid child” (the “context-sensitive individual, whose survival and flourishing is intimately tied…to the nurturant or neglectful character of the environment”) (Ellis & Boyce, 2008); the “Hawk” vs. “Dove” personality types denoting levels of aggression to explain differences in behavioural responses to stress (Korte, Koolhaas, Wingfield, & McEwen, 2005); the concept of “late bloomers” (Masten & Tellegen, 2012, p. 355) in describing different trajectories of resilience to indicate adolescents who showed adaptation and resilience only as entering adulthood rather than earlier in development; and the notion of “stress inoculation” (Meichenbaum, 2007) which implies the ability to build resilience against future adverse events. More recent and a particularly useful metaphor of resilience is of tropical palm trees capable of "bending" rather than "breaking" in the face of "violent hurricanes" (Karatsoreos & McEwen, 2013).

Yet despite apparent similarities in conceptualising resilience, defining it is far from straightforward. Resilience not only has different definitions across disciplines, but it also has changed or evolved in meaning over time. A relatively new construct, resilience emerged in the 1970s and had its origins in research which sought to understand why psychopathology was not always the outcome in children exposed to risky environments such as maltreatment, poverty, deprivation, or low socioeconomic status (for review see Curtis & Cicchetti, 2003). That some children thrived despite adversity led to the exploration of psychosocial and behavioural qualities which defined resilience (Curtis & Cicchetti, 2003). Research has distinguished between two closely related but distinct concepts, that of resiliency and resilience. Resiliency relates to a "personality trait" or personal characteristic, and resilience to a "dynamic process" involving "personal, interpersonal, and contextual protective mechanisms" (Smith-Osborne & Whitehill Bolton, 2013, p. 111). Personal qualities (e.g. self-esteem) have also been described as resiliency "assets" and available qualities of the external environment (e.g. parental support) as resiliency "resources" (Fergus and Zimmerman, 2005, in Zimmerman, 2013, p. 381). Zimmerman (2013) provides an excellent synopsis of resiliency theory as that which seeks to understand the characteristics which promote and enable positive adaptation by intercepting negative "developmental trajectories" associated with risky environments and instead redirecting towards healthy mental and physical health outcomes. Summarising three different models of resiliency as "compensatory", "protective", or "inoculation/challenge" (Zimmerman, 2013, p. 382), the third model, proposed by Rutter (2006), emphasised individual differences and the context of person–environment interaction. Rutter (2012) referred to "steeling" effects in which early exposure to adverse experience toughens or "steels" the individual to be able to cope when faced with adverse situations later in life (p. 335).

Although personality characteristics are still viewed as important in childhood risk and resiliency (for example, see Shiner & Masten, 2012), as Cicchetti (2010) describes it, the scientific study of resiliency has moved from protective "personal qualities" of the child and subsequently their family context, to "prevention and intervention strategies" in order to promote resilience in the face of adversity (p. 146). This conceptualisation of resilience research as moving away from individual protective factors towards more of a focus on dynamic multilevel adaptive systems is congruent with the four waves of resilience research suggested by Masten (2007). O'Dougherty Wright, Masten, and Narayan (2013) describe the first wave of resilience research as enabling identification of individual resilience factors (i.e. what makes a person resilient?); the second wave focused on protective factors in the context of risk using a developmental systems approach; the third wave concentrated on interventions to improve resilience particularly by targeting developmental pathways; and the fourth or current wave aims to understand resilience using multiple levels of analysis with an emphasis on neurobiological processes.

Thus recent work over the last 15 years has pointed to this "multilevel" nature of resilience (Cicchetti, 2010) and called for attention to the interplay of biological factors and brain mechanisms, including genetic, neuroendocrine, immune, and cognitive processes, in examining the concept of resilience and its meaning (Cicchetti, 2010, 2013; Cicchetti & Blender, 2006; Curtis & Cicchetti, 2003). Neuroimaging has identified areas of the brain which are particularly important in developing or providing resilience under stressful conditions, such as the hippocampus, amygdala, anterior cingulate, and prefrontal cortex (van der Werff, Pannekoek, Stein, & van der Wee, 2013; van der Werff, van den Berg, Pannekoek, Elzinga, & van der Wee, 2013) and these authors call for more work in this area to identify specific brain regions involved. Perhaps of even greater importance are biomarkers of resilience in children and adolescents, particularly those that are measurable using relatively non-intrusive methods. For example, assessment of salivary cortisol as a marker of basal stress levels or stress reactivity (for a review of cortisol assessment in children see Jessop & Turner-Cobb, 2008) provides a window on hypothalamic pituitary adrenal (HPA) axis activity. Markers such as salivary immunoglobulin A (sIgA) and other classes of antibodies produced in response to specific pathogens including bacteria or viral antigens enable an assessment of antibody-mediated or humoral immunity (for a review of endocrine and immune markers in children see Turner-Cobb, 2014). Antigen resistance via antibody production (i.e. staying well in the face of exposure to a virus) offers not only a metaphorical parallel of psychosocial resilience but also a biopsychosocial mapping of resilience to psychosocial events at the level of antibody defence. More recent developments have enabled identification of brain-derived neurotrophic factor (BDNF) which link to genes responsible for its expression (Karatsoreos & McEwen, 2013) and salivary nerve growth factor (sNGF) as an adaptive factor in stress resilience (Laurent, Laurent, & Granger, 2014). These markers provide evidence of underlying biological mechanisms driving resilience as well as offering insight into the plasticity of mechanisms and systems involved in resilience. An excellent example of the gene–environment interaction in resilience is provided by Hostinar, Cicchetti, and Rogosch (2014) in their ingenious analysis of interactions between the receptor gene for oxytocin (a social and affiliative hormone), social support, and resilience in maltreated adolescents. They found that those adolescents who had been maltreated and who also had the genetic variant in their oxytocin receptor gene were more vulnerable to the effects of their social environment (Hostinar et al., 2014). Whilst the outcome in this study is related to psychopathology (internalising symptoms) rather than physical health outcomes, the underlying rationale remains the same.

This multidimensional or multifaceted process of resilience, examined in the face of adversity, when that adversity or external stressor or stimuli is a physical health condition, is the context being considered in this chapter. Within this definition of resilience, a biopsychosocial approach incorporating both psychosocial and biological aspects and their interplay is crucial. Immune-related conditions provide the perfect backdrop to examine resilience in physical health due to known interactions between psychosocial factors and neuroendocrine and immune functioning.

Key Theories Linking Psychological Factors and Physical Health to Resilience

An important theory in this respect is that of allostasis and the concept of allostatic load (Sterling & Eyer, 1988), which has revolutionised the psychosocial stress research in the last quarter of a century. Allostasis is defined as the ability of an organism to maintain stability through change and allostatic load as an individual's accumulated lifetime stress (McEwen, 1998a, 1998b, 2012; McEwen & Stellar, 1993; McEwen & Wingfield, 2003). Maintaining stability through change is the very essence of resilience since it encapsulates an individual's dynamic ability to adapt to challenging circumstances. It involves meeting the challenge with the physiological resources available and returning to a more stable, although possibly changed state, once the event has subsided. Similarly, it may involve adapting to repeated or multiple stressors in such a way that the physiological response is not activated to the same extent in future aversive encounters. This physiological adaptation is dependent upon the psychosocial resources and factors that accompany and elicit the responses. Allostatic load is the wear and tear put on the allostatic stress response systems (including immune and neuroendocrine mechanisms) when dealing with life stressors. Three main patterns of allostatic load occur when adaptation fails, either because of a lack of adaptation to (1) repeated or multiple acute stressors; (2) chronic ongoing stressful events; or (3) increased sensitivity following severe stress exposure and each is linked to specific types of ill health conditions. A recent addition to this theory is that of "allostatic overload", a state in which stressful events are of a nature that overcomes an individual's ability to cope at both a physiological and psychological level and is associated with detrimental physical health outcomes (McEwen & Wingfield, 2003; Offidani & Ruini, 2012). A Darwinian concept of stress is centred around the notion that the ability to maximise resilience and adaptability is associated with greater chances of survival (Korte et al., 2005) or better health outcomes. The concept of vulnerability then is seen as the opposing end, or "flipside" of resilience (Karatsoreos & McEwen, 2013) where risk and vulnerability are the unstable factors at one end of the continuum and resilience is the positive outcome associated with stability at the other end of the spectrum. The importance of the age of the individual for immune-related vulnerability has also been highlighted in both animal and human work, which has emphasized particular health impacts at "critical periods" associated with both ends of the life course—in the early years of life as well as in the elderly (Coe & Lubach, 2003).

In sum, borrowing from stress theory, we know that physiological plasticity and psychosocial adaptation is vital in reducing vulnerability and maximizing resilience, that childhood is a critical period for future health effects, and that resilience can be fostered or developed.

Resilience is defined in this chapter as a process, drawing from the biopsychosocial perspective, incorporating the theory of allostasis, in which an individual's ability to thrive in a given situation or life circumstance, is determined by their adaptive capability. As applied to immune-related conditions, resilience is the ability to cope with the many challenges of the condition, whether psychosocial or physiological in nature, and the interplay of these to affect the outcome of the condition.

Coping Theory

Coping clearly underpins the concept of resilience. Two key theoretical models of relevance in considering the response to illness and associated challenges that it brings are the transactional model of stress and coping (Lazarus & Folkman, 1984) and the stress-control model (Connor-Smith, Compas, Wadsworth, Thomsen, & Saltzman, 2000).

The transactional theory of stress and coping developed by Lazarus and Folkman (1984) views stressful experiences as an interactional process between the person and their environment in which the individual makes both primary appraisals (assessing the stressor as harmful, threatening, or challenging) and secondary appraisals (assessing the resources available to cope with the stressor). Stress occurs when there is a discrepancy between the primary and secondary appraisals. The transactional theory has been applied to a variety of studies of children with immune-related health conditions, including asthma and diabetes (Hocking & Lochman, 2005; Peeters, Boersma, & Koopman, 2008). This model has provided a valuable theoretical framework for studying the influence of diabetes on children's quality of life (QOL) and research has suggested that psychosocial interventions for ill children should be based on the transactional model as it is a good predictor of resilience factors, such as coping skills, that influence health-related QOL (Peeters et al., 2008). It includes key factors such as illness parameters (e.g. type and severity of the illness), demographic parameters (e.g. age, gender, and SES), child adaptational processes (e.g. cognitive processes such as stress appraisal and methods of coping), and child adjustment. The "methods of coping" variable refers to the different coping strategies used by ill children. Disengagement and negative thinking, for example, are highlighted as being associated with poorer child adjustment (Hocking & Lochman, 2005).

However, some researchers have suggested that although the transactional model is useful in guiding interventions and practice it requires updating as the original structure of the model is over 30 years old. For example, the model was updated for use with children with chronic illnesses by Thompson, Gustafson, George, and Spock (1994) and further updated by Hocking and Lochman (2005) who suggested that the variable "maternal functioning" in the model should be replaced with "family functioning", as it is not merely one parent but the whole family who are affected by a child's illness. They also suggest the addition of a new variable, "behavioral competence", to encompass resilience characteristics such as social skills, adaptive behaviors, peer interaction, and age-appropriate activities (Hocking & Lochman,

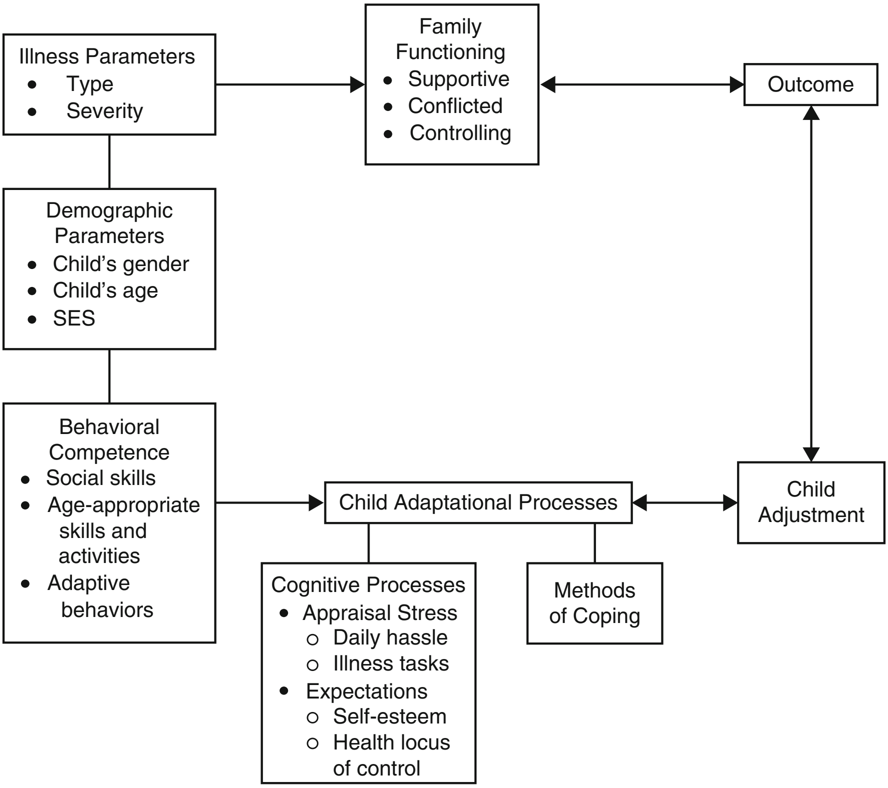

Fig. 2.1 Modified stress and coping transactional model for chronic illness in children (Hocking & Lochman, 2005). Copyright Springer

2005, p. 230). These competency features are important as they can influence the child's ability to adapt to their illness. Figure 2.1 illustrates this updated model as applied to children with a chronic illness.

The stress-control model of coping developed by Connor-Smith et al. (2000) built on the transactional model created by Lazarus and Folkman (1984). This model suggests that there are several types of coping strategies (voluntary vs. involuntary, engagement vs. disengagement, and primary vs. secondary). Findings applying the stress-control model of coping (Connor-Smith et al., 2000) indicate that when faced with uncontrollable stressors, as is frequently the case with chronic illness and medical procedures, secondary control coping styles (such as acceptance and cognitive restructuring) provide the most favorable outcomes. Hence primary coping is about changing the stressor itself, whereas secondary coping is about changes that the individual facing the stressor makes within themselves in order to deal with the stressor. Disengagement styles of coping (emotional numbing, cognitive interference) are associated with the poorest outcomes (Connor-Smith et al., 2000; Weisz, McCabe, & Dennig, 1994). Weisz et al. (1994) made recommendations for practice based on their findings that secondary control coping was associated with more positive resilience outcomes, for example, better behavioral adjustment and less self-reported distress during medical procedures, in chronically ill children. The researchers explain this finding by suggesting that for uncontrollable stressors, such as medical procedures, adjusting to the stressor is more adaptive than attempting to alter the stressor itself. Although this research was conducted with children with leukemia, some of the medical procedures used were relevant to other conditions and settings (e.g. hospital stay and medication side effects). An awareness of the different types of coping strategies children might use enables clinicians to encourage and develop those associated with the most positive outcomes in immune-related conditions, dependent on the controllability characteristics demanded by the specific situation.

The "shift and persist" strategy proposed by Chen, Miller, Lachman, Gruenewald, and Seeman (2012) combines aspects of both coping theory and allostasis and is a clear example of the need for person–environment concordance. The shift and persist coping strategy appears to promote adaptability and reduce allostatic load in a specific subset of individuals. Chen et al. (2012) introduced this notion of shift and persist in applying the concept of resilience to the physical health arena, identifying it as a protective factor specifically for adults who experienced low socioeconomic circumstances during childhood. Central to this theory of shift-and-persist is the psychological construct of control, a key component of the stress response. Taken from a life span approach, primary control is defined as being able to change the environment or circumstances to the way an individual desires it to be, whereas secondary control is the ability to change oneself to fit within the constraints of that environment or being able to shift and persist within the circumstances imposed (Chen et al., 2012). Being able to adapt via use of secondary control therefore fits better with a low SES environment where changing the circumstances is unlikely but changing oneself to fit within the circumstances is more compatible (Chen et al., 2012). For those from a high SES background, theorized to have more capacity for primary control, the shift and persist strategy was not protective in respect to lowering allostatic load. The notion of "biological embedding" (Hertzman, 1999, p. 89) explains how childhood adversity such as economic hardship can influence health in later life. Adversity can have the effect of accelerating aging and creating susceptibility to age-related illness, via changes in the nervous, endocrine, and immune systems during childhood which continue into adult life and alter the landscape of the allostatic systems (Danese & McEwen, 2012; Miller, Chen, & Parker, 2011). This might include alterations to basal physiological levels as well as to reactivity to stress throughout the life course. The influence of chronic immune-related conditions on allostatic systems in childhood is therefore important not just during the childhood years but beyond to influence subsequent health. How a child reacts to events and is able to make use of resources early in life will influence their chances of successful adaptation later on, particularly if faced with chronic stress in adult life (Eiland & McEwen, 2012) which may in turn influence subsequent potential resilience.

Developmental Considerations

Resilience has been described as a “dynamic developmental construct” which both highlights the critical period of childhood and raising other more specific questions with regard to the timing of interventions (Cicchetti, 2010, p. 152). A child’s age and developmental level are crucial to consider in this respect. A number of studies in children up to 11 years of age have found at least some support for staging models of child development as related to understanding of health and illness (e.g. Bibace & Walsh, 1980). More recent work has identified greater complexity in children’s understanding of health and illness to include influences from their everyday life experiences (Normandeau, Kalnins, Jutras, & Hanigan, 1998), as well as their own experience of illness, with children having different levels of understanding across different types of illness and variation in their understanding of cause as opposed to recovery (Myant & Williams, 2005). Most strikingly, there is growing evidence that children as young as 4 or 5 years old may have a richer understanding of illness and some concept of the link between stress and illness than developmental stage theories alone would concede (Cheetham, Turner-Cobb, & Gamble, 2015; Myant & Williams, 2005; Valentine, Buchanan, & Knibb, 2010). Children have also been found to use different coping strategies dependent upon their age and cognitive-developmental level. For example, Band and Weisz (1990) found that children with diabetes in the formal operational group (average age of 14.6 years) and pre-formal operational group (average age of 8.8 years) used different coping strategies, with the formal operational group showing more secondary control coping and also more advanced knowledge of diabetes. For more on supporting chronically ill children during the transition to adolescence, see Lennon et al. this volume.

For children that adapt well and flourish under difficult circumstances relating to ill health, there is much to be learnt about the person–environment interaction that may be developed as an intervention to promote resilience in other children for whom the match between person and environment characteristics is less compatible. Zimmerman (2013) emphasizes that resiliency theory provides a “conceptual framework” or “scaffolding” from which to understand and explore how exposure to adverse events can be overcome and interventions developed to improve outcomes (Zimmerman, 2013, p. 382). Figure 2.2 represents a diagrammatic representation of the various components of resilience from the biopsychosocial perspective outlined so far in this chapter. The top row illustrates underlying factors that may influence the outcome of the biopsychosocial interplay and bidirectional pathways are indicated between psychosocial and biological factors, and between these factors and resilience outcomes. Interventions can occur across all levels depending on the particular target for intervention and outcome required.

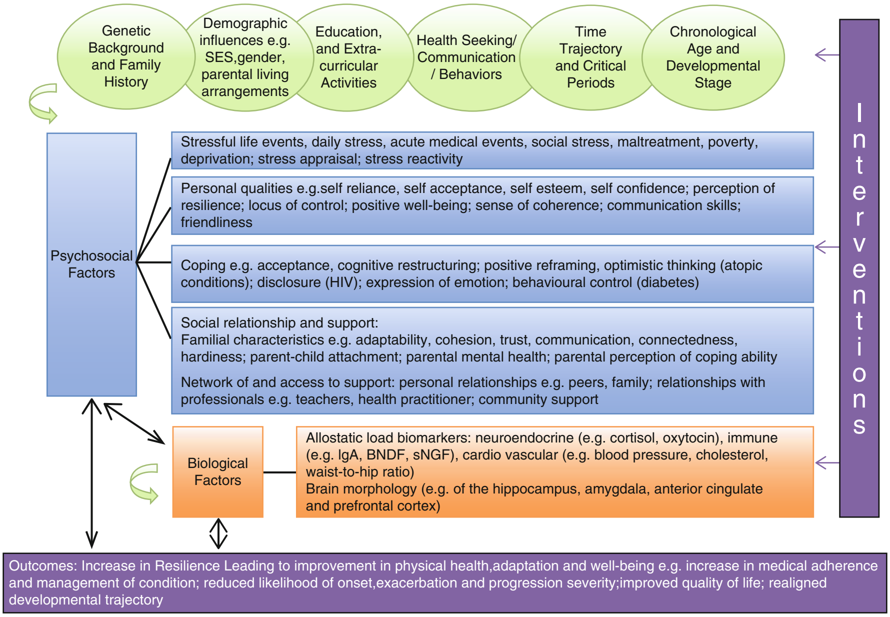

Fig. 2.2 Diagrammatic illustration of biopsychosocial factors associated with resilience in children as applied to immune-related health conditions

Theoretically Informed Practice

A variety of theories and models have been discussed which encompass key aspects of resilience in children and of important validity in respect to considering immune-related health conditions. Models and theories of resilience have much to add in respect to informing practice. A number of factors affect whether children with immune-related health conditions are resilient or vulnerable to stress. The interaction of multiple risk factors, for example, can determine resilience vs. vulnerability (Ebersohn & Ferreira, 2011). From this theoretical perspective, risk factors can be viewed as barriers to resilience. It is recommended that health professionals take into account an individual's risk factors or barriers (e.g. poverty) and protective factors (e.g. social support) when interacting with and treating children. Based on this risk vs. protective factor framework, those with a greater number of barriers and who have less protective factors are more at risk of adverse physical and psychological outcomes (Wallander & Varni, 1989). Similar risk-resistance frameworks of resilience have been used to guide practice in terms of how health professionals such as nurses interact with children with diabetes (Amer, 1999). This develops clearer communication by enhancing knowledge of the challenges experienced by children with diabetes and being better able to judge the level of support they require.

Several recommendations from theory have been made specifically regarding coping with medical stressors, most of which revolve around the topic of communication between children, their families, and health professionals. Children tend to be naturally information-seeking rather than information-avoiding, which is generally linked to better outcomes (Peterson, 1989). As research in this area greatly emphasizes the need for healthcare communication to be age-appropriate (Forsner, Jansson, & Sorlie, 2005a, 2005b; Gultekin & Baran, 2007) and this is especially relevant when trying to address children's fear of medical procedures and hospitalization (Rokach & Matalon, 2007). Health professionals' knowledge of relevant theory is also crucial in order to understand the ill child's perspective and to be able to communicate effectively. Knowledge of mediators (e.g. child characteristics) and moderators (e.g. stress, coping and adjustment) in how children cope with painful medical procedures has been highlighted as highly significant in improving resilience outcomes for children (Rudolph, Dennig, & Weisz, 1995). The role of the family is central to children with chronic illness, as highlighted by autoimmune conditions such as celiac disease and diabetes (Bacigalupe & Polcha, 2013). Illness-related stress has an impact on the whole family (Drotar, 1981). Knowledge of family history, health behavior, how parents communicate health messages, and the social support available to them is essential for health professionals in developing resilience (Bacigalupe & Polcha, 2013). This relationship between the child's illness and the family is not merely unidirectional, but can be viewed instead as a "reciprocal interaction" as the family can impact the illness as much as the illness can affect the family (Sholevar & Perkel, 1990, p. 371). Research suggests that if health professionals have a good working knowledge of the theory underlying a family-centred approach, this will enhance practice and improve outcomes for both the child and their family (Sholevar & Perkel, 1990).

Theories have been used both to inform clinical practice and as a foundation for interventions aimed to enhance children's resilience. The following sections outline some of the key recommendations for practice, drawing on the biopsychosocial model, the theory of allostasis, the transactional theory of stress and coping and the stress-control model, within the context of resilience theory and a family-centred approach.

Psychosocial Resilience Factors and Interventions in Children with Immune-Related Conditions

A range of interventions to increase resilience, as measured by a wealth of outcome variables, exist for children with immune-related health conditions. For a comprehensive review of psychoneuroimmune-related interventions for children with paediatric chronic illness see Nassau, Tien, and Fritz (2008). The interventions discussed in this section have been grouped based on three types of immune-related conditions: atopic conditions (e.g. asthma, eczema, IgE associated allergies); infectious disease (e.g. HIV/AIDS); and autoimmune conditions (e.g. type I diabetes, lupus, juvenile idiopathic arthritis).

Atopic Conditions

Atopic disorders such as asthma, eczema, and IgE associated allergies atopic are predominantly antibody-mediated T-helper 2 (Th2) driven responses associated with interleukin (IL)-4 and IL-5 production. Both onset and acute episodes of these types of chronic conditions have been linked to psychosocial factors such as stress.

Asthma

Asthma is "a disorder of breathing characterized by widespread narrowing of airways within the lung. The main symptom is shortness of breath" (Macpherson, 1999, p. 46). Although asthma can be potentially life threatening, medications can lead to symptom relief and prevention of future symptoms/asthma attacks. Due to these preventative measures the majority of research has focussed on changing children's health behaviors, such as adherence to medication. However some researchers have focussed on the importance of psychosocial factors that can impact the physical health of children with asthma. For example, Bahreinian et al. (2013) examined the association between asthma incidence/prevalence and allostatic load (AL) using a composite measure of AL composing eight biomarkers (including fasting glucose, total cholesterol, cortisol, and blood pressure) in children (7–10 years) followed until adolescence (11–14 years). Adolescent boys with high allostatic load (assessed as a biomarker of chronic stress) were more susceptible to asthma (incident onset or continued prevalence) than in boys with low allostatic load. Similarly, socioeconomic status (SES) has been cited as an important factor in determining the success of a psychosocial intervention. Chen et al. (2006) compared a sample of 37 children aged 9–18 years with asthma with 39 healthy children, and found for the asthmatic children only an association between low SES and higher production of interleukin (IL)-5, IL-13 and eosinophil counts, as well as greater chronic stress and perceived threat. Chen and Miller (2012) and Chen et al. (2012) also report the use of shift and persist strategies (e.g. use of positive reframing and optimistic thinking) to be associated with better asthma outcomes (less asthma inflammation and impairment) in low SES children compared to high SES children.

Parental and familial relationships are important psychosocial resilience factors in asthma and family hardiness has been linked with adaptation and resilience over time. Svavarsdottir and Rayens (2005) found that depression and anxiety *negatively* impacted family hardiness whilst positive well-being and sense of coherence *positively* impacted family hardiness. Equally, poor family relationships can have a negative impact on physical health. In a study of 67 children with asthma and 76 medically healthy children aged 9–18 years, which examined children's perceptions of parental support and assessed immune markers IL-5, IFN-γ and eosinophil protein levels; those who reported lower parental support were more resistant to anti-inflammatory effects on IL-5, IFN-γ and had higher eosinophil proteins (Miller, Gaudin, Zysk, & Chen, 2009). For more on the role of the family in promoting resilience, see Hoehn et al. this volume.

Extensive work by Buske-Kirschbaum and colleagues has found consistent evidence for HPA axis disregulation in children with allergic atopic conditions in response to an acute stress challenge; Th2 responses appear over-activated and exacerbated as a result of an inadequate cortisol response (Buske-Kirschbaum et al., 1997, 2003). A predisposition towards developing atopy, as evidenced by altered HPA reactivity, was also observed in 3-day-old neonates with a family history of atopy or elevated umbilical cord IgE (Buske-Kirschbaum, Fischbach, Rauh, Hanker, & Hellhammer, 2004).

Relationship difficulties such as insecure attachment during the first 2 years of life, have also been linked to attenuated cortisol in response to a laboratory stressor (lower cortisol levels 15 and 30 min post stressor) in adolescents aged 17–19 years with a genetic predisposition to asthma (Kelsay, Leung, Mrazek, & Klinnert, 2013). These authors did not find a direct relationship between cortisol and asthma status however. Similarly, in their large scale TRAILS study of over 2000 children aged 11–16 years, Vink, Boezen, Postma, and Rosmalen (2013) found no significant relationship between awakening, diurnal, or laboratory induced cortisol and development of asthma either cross-sectionally or prospectively.

Social support has been found to have a mediating as well as a direct effect on health outcomes. For example, whilst poor maternal mental health has been linked to atopic and non-atopic wheezing, positive perception of social support acts as a protective factor (Marques dos Santos, Neves dos Santos, Rodrigues, & Barreto, 2012). Family interaction and social support have also been found to be beneficial in other atopic conditions such as allergies. Family functionality, defined as adaptability and cohesion, has been linked to recovery from allergies in children aged between 18 months and 3 years (Gustafsson, Kjellman, & Bjorksten, 2002). It is evident from the studies described above that psychosocial factors such as family relationships and social support can have positive or negative effects on health outcomes in atopic conditions, and that this relationship is bidirectional (Chida, Hamer, & Steptoe, 2008). Furthermore, the combined effect of underlying chronic family stress and acute stress events have been reported to induce asthma symptoms in children aged 9–18 years (Marin, Chen, Munch, & Miller, 2009). The authors suggest that the stress response systems become activated over time, resulting in a down-regulated cortisol response that promotes a Th2 cytokine imbalance.

Several behavioral interventions have been directed at the reduction of physiological and psychological stress associated with asthma attacks. These include the use of techniques such as biofeedback (self-regulation based on monitoring physical responses such as heart rate) and relaxation (e.g. progressive muscle relaxation, meditative breathing, and the use of imagery) (Masek, Fentress, & Spirito, 1984). Often relaxation-type breathing exercises can be difficult for children with asthma due to their reduced breathing capacity. One technique that has been found to be effective in overcoming this is the assessment of precursors or triggers for an asthma attack, before attempting to remove or reduce the impact, in order to break the cycle (Creer, 1982; Kotses & Glaus, 1981).

Infectious Disease

Psychosocial factors involved in infectious disease have perhaps been best demonstrated not in immune-related conditions per se but in acute upper respiratory infectious illness which "provides one of the most useful paradigms in which to measure links between stress and illness" (Turner-Cobb, 2014, p. 82). It can provide a brief insight into immune resilience vs. vulnerability in the face of everyday stressors as well as in situations of adversity. A number of studies have reported associations between life event stress, daily hassles, perceived stress, social support, family functioning, coping, and onset and duration of the common cold in adults and in children (for example, Cohen, Doyle, Skoner, Rabin, & Gwaltney, 1997; Cohen, Tyrrell, & Smith, 1991; Meyer & Haggerty, 1962; Turner-Cobb, Rixon, & Jessop, 2011; Turner-Cobb & Steptoe, 1996, 1998; Turner-Cobb, Steptoe, Perry, & Axford, 1998). With this paradigm in mind, we turn to the chronic condition of HIV/AIDS.

HIV and AIDS

Living with the immune conditions human immunodeficiency virus (HIV) or acquired immune deficiency syndrome (AIDS) can have a significant and pervasive impact on children's physical and psychological well-being. In considering this we shift the focus from stress as a causative agent in disease onset or exacerbation to the impact of stress caused from living with the condition itself. Furthermore, some of the research in this area focuses not only on children who have AIDS or HIV themselves, but also those who are affected by AIDS, such as those who have experienced the death of a parent from AIDS. For a thorough review of the research in this area see Betancourt, Meyers-Ohki, Charrow, and Hansen (2013).

A variety of interventions have been developed to increase resilience and promote other positive outcomes in children with HIV/AIDS, many of which draw on the social support provided by friends, family, teachers/schools, and the community. One such intervention study views teachers and schools as "resources to buoy resilience in the face of adversities" (Ebersohn & Ferreira, 2011, p. 596). This research is part of a longitudinal project following the level of psychosocial support 57 teachers provided to students with HIV/AIDS after they had participated in a school-based intervention known as the "Supportive Teachers, Assets and Resilience" (STAR) project. Based on theories of resilience, the intervention involved teachers identifying available resources, barriers, and assets (e.g. protective factors) followed by designing and implementing action plans to address these barriers. Thematic analysis of interviews with these teachers highlighted that social support was a key feature of the themes that emerged, providing support for the use of social support from a range of sources outside the school to help teachers to promote resilience within it.

Other interventions have focussed on the family as a source of social support. For example, Lyon et al. (2011) investigated the impact of a family-centered care planning intervention based on the transactional stress and coping theory on outcomes such as spirituality and medical adherence in a sample of 40 HIV-positive adolescents (aged 14–21 years) and 40 legal guardians (aged 21 and over). Spirituality was found to be a protective factor for adolescents coping with HIV. Adolescents who did not believe HIV was a punishment from God showed higher spirituality and adherence scores, with "facilitated family conversations" having a particularly strong positive effect on these outcomes (Lyon et al., 2011, p. 633). Another parental intervention used in South Africa aimed to stimulate mother–child interactions based on evidence of strong relationships as a protective feature of resilience. Fifteen mothers and their children (aged 6–10 years) took part in this intervention which reported increased positive maternal mental health and strengthened mothers' capacity to care for children, increasing their self-esteem and survival skills (Visser et al., 2012). This intervention thus aimed to increase child resilience by first increasing maternal resilience.

As is often the case in HIV/AIDS in developing countries, parent mortality has necessitated the provision of care and support for children and adolescents by the wider community. Skovdal and Campbell (2010) suggest that an analytical framework is needed in order for interventions to appropriately support communities who, in turn, support orphaned children. The framework encompasses six psychosocial resources that the community require to facilitate resilience: appropriate knowledge and skills; opportunity for community discussion of barriers and solutions; recognizing local strengths and coping resources; confidence; within-community solidarity; and the ability to access other sources of support. Again, social support is seen as a key feature in enhancing children's resilience through interventions.

Resilience research in children and adolescents with HIV/AIDS is beginning to move away from a paternalistic approach (i.e. children being seen as passive victims rather than active agents) towards a more "strengths-based" family-centered approach and the idea that children often have inbuilt resilience and/or coping skills (Skovdal & Campbell, 2010; Skovdal & Daniel, 2012). Therefore interventions are recommended to target not only the children but also whole families, communities, and institutions, including schools, with the aim of enhancing self-reliance and self-acceptance (Amzel et al., 2013). This approach to resilience builds on Bronfenbrenner's (1986) social ecological theory of human development, blending an ecological resilience approach with a risk reduction paradigm. Other interventions have done just this, by designing and directing interventions at whole families rather than just the child, measuring a variety of outcomes and psychosocial resilience factors. Examples include group sessions led by a community care worker focussed on improving communication and daily living skills for 390 mother–child dyads (161 in the intervention group and 169 in the standard care control group) in which the children with HIV were aged 6–10 years (Eloff et al., 2014); a community program to educate children and parents about HIV prevention and to give long-term social and emotional support leading to decreased high risk sexual and substance abuse behavior (Pivnick & Villegas, 2000); and a family strengthening intervention used to improve family connectedness, social support, and children's

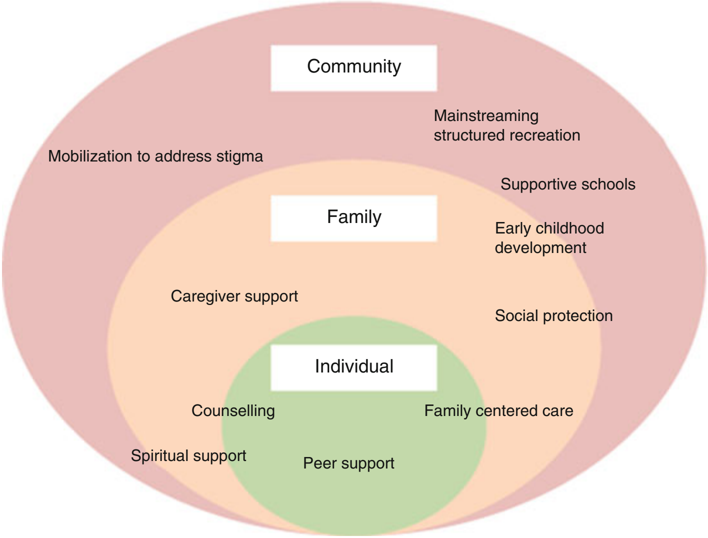

Fig. 2.3 Examples of combination interventions aimed to increase resilience in children and their families (Amzel et al., 2013). Copyright Lippincott Williams & Wilkins

pro-social behavior in 20 families with one child aged 7–17 years and at least one HIV-positive adult (Betancourt et al., 2014).

A thorough review of individual, family, health-care professional and community interventions is provided by Amzel et al. (2013). These levels of intervention are encapsulated in Fig. 2.3 below which highlights the importance of a combination intervention approach at different levels of the ecological model: individual, family, and community (Amzel et al., 2013). The researchers suggest that the interventions that are the most feasible and successful in increasing families' well-being are those which target several levels of the model, i.e. a combination approach.

Autoimmune Conditions

Lupus and Juvenile Idiopathic Arthritis

Rheumatic conditions such as lupus and Juvenile Idiopathic Arthritis (JIA) can exhibit symptoms such as joint pain and fatigue, therefore research into these conditions has frequently focused on the ability to cope with physical symptoms. Using a qualitative approach to identify how illnesses affect psychosocial resilience factors in a sample of 21 children with lupus and 16 parents, Moorthy, Peterson, Onel, Harrison, and Lehman (2005) and Moorthy et al. (2004) found that a variety of domains of QOL are affected by lupus, particularly coping and locus of control. This research highlighted a bidirectional approach, i.e. that illness can impact resilience factors as well as resilience affecting health outcomes. Although the research suggests several potential resilience factors which could be targeted using interventions, there is a scarcity of interventions reported in the literature which are specifically aimed at increasing resilience in children suffering from JIA and only one intervention for lupus. In this study, a randomized controlled trial (RCT) with three groups (a cognitive-behavioral group, an education only group, and a no contact control group) was trialled in 53 adolescent girls aged 12–18 years with systemic lupus (Brown et al., 2012). The cognitive-behavioral intervention group received a course of CBT which aimed to enhance coping skills and cognitive restructuring techniques. Although no differences were found between the groups for the primary outcomes (pain management, disease adjustment, and quality of life) there was an increase in positive coping skills, social support, and control in the CBT intervention group. Evidently there is a need for more interventions of this kind for lupus and other autoimmune conditions such as JIA.

Diabetes: Insulin-Dependent Diabetes Mellitus/Type 1 Diabetes (IDDM/T1D)

Diabetes is “a condition characterized by a raised concentration of glucose in the blood because of a deficiency in the production and/or action of insulin” and insulin-dependent, T1D “occurs as a result of autoimmune destruction of beta cells within the pancreas” (Macpherson, 1999, p. 141). Numerous interventions have been created to improve both the physical aspects (e.g. metabolic control) and the psychosocial factors relevant to children with T1D. For a review of educational and psychosocial interventions available for adolescents with diabetes, with a particular focus on RCTs, see Hampson et al. (2001).

The stress-control model of coping has been applied within the adolescent diabetic population by Jaser and White (2011). They report that coping skills can have an impact on resilience in adolescents with T1D. Primary and secondary control coping were related to higher competence scores, better QOL, and better metabolic control than disengagement coping techniques (Jaser & White, 2011). Therefore interventions which aim to enhance coping skills could lead to an increase in protective resilience factors. One such intervention was conducted by Grey, Boland, Davidson, Li, and Tamborlane (2000) who allocated adolescents with diabetes to one of two intensive diabetes management (IDM) conditions: with or without coping skills training (CST). Those who had the CST showed better medical self-efficacy and less impact of diabetes on their QOL than those who received only the IDM without the CST. This highlights the importance of children and adolescents with a chronic illness developing the appropriate coping strategies to manage their illness and its impact on their lives.

As discussed in relation to many of the other immune conditions, family can have an impact on health outcomes and resilience. In a descriptive comparative study of adolescents attending a diabetes camp several resilience factors were considered as important: self-efficacy, perception of personal resilience, and parental living situation (Winsett, Stender, Gower, & Burghen, 2010). Interestingly, living with both parents was linked to better glycosylated haemoglobin suggesting that this could be a protective factor. Another family factor which affects resilience is family cohesion and positive affect which have been found to positively correlate with increased metabolic control. Adolescents who rated themselves highly on positive qualities (e.g. honesty, friendliness, helpfulness) had “more cohesive families, better disease management, and, indirectly, better metabolic control” (Mackey et al., 2011, p. 314). Last in this chapter but certainly not least in terms of effectiveness, positive affect has also been shown to be increased by interventions utilizing animal-assisted therapy. The use of animals as a therapeutic tool has become increasingly popular in a variety of physical and psychological health conditions including for children undergoing medical treatment; for a discussion of this topic see Turner-Cobb (2014). Kaminski, Pellino, and Wish (2002) found that pet therapy led to more positive affect than play therapy in a group of chronically ill children, including children with diabetes.

Summary

In this chapter we have examined resilience in children from a biopsychosocial, health psychology perspective. The psychoneuroimmune focus has enabled a thorough investigation of the meaning of resilience, an examination of psychosocial and biological characteristics, and an exploration of psychosocial interventions to develop resilience and facilitate resilient outcomes. That resilience has both psychosocial and physiological characteristics and that an interplay exists between these factors is particularly relevant to immune-related health conditions as exemplified by atopy, infectious disease, and autoimmunity. Coping theory, highlighting the importance of secondary control coping in resilience, has been a key theme throughout this chapter. Similarly, the theory of allostasis and concept of allostatic load provides an important explanatory theory at the core of stress-based resilience as applied to physical health in children. Different perspectives of resilience have been considered throughout, including the perspectives of ecological resilience and that of a risk reduction paradigm. This chapter attempted to integrate these models to offer a more multidimensional approach. It is clear that the characteristics of resilience can be nurtured, developed, and promoted across a range of conditions in ways most effectual for those specific conditions. Resilience is important as both a predictor and an outcome in immune-related health conditions and a valuable characteristic and tool in the fields of health psychology and psychoneuroimmunology.

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Chapter 3
Resilience, Disparity, and Narrative Phenomenology: African American Families Raising Medically Vulnerable Children

Cheryl Mattingly

Introduction

In my home discipline of anthropology, studies of health among marginalized or oppressed peoples tend to emphasize the pernicious consequences of economic and political inequality. Anthropology has relied upon a host of powerful intellectual voices to give analytic depth to accounts of suffering and disparity. This important scholarly focus, while fruitful, has tended toward the unfortunate consequence of offering an overly one-sided picture of people's lives. People not only suffer, but they try to do things to ameliorate suffering and to create lives worth living. What about the aspirational aspects of life, what one might call moral striving? This chapter asks: What truths might we uncover when attending to not only suffering but also to people's attempts at realizing good lives even in unpromising circumstances? How might we look at the inventive qualities of moral striving? What kind of analytic frameworks might serve us in addressing these kinds of questions?

A focus on resilience, especially as a moral phenomenon, offers one starting place. As the title of this volume suggests, there is growing interest in resilience among medically vulnerable populations. Resilience focused studies often wed a health disparities concern with an effort to look at what allows marginalized people to thrive—or fare better than many—despite radically difficult health and social circumstances (Ager, 2013; Anderson-Fye, 2010; Panter-Brick, 2014; Panter-Brick & Leckman, 2013; Rutter, 2013; Wexler, Difluvio, & Burke, 2009). Some of this work explores crucial and subtle interplays between resilience and vulnerability (e.g., Mullings & Wali, 2001). This represents a significant paradigm shift for many disciplines (not just anthropology) since most work on health disparities has focused on risk and negative outcomes rather than the complementary phenomenon of resilience (Panter-Brick, 2014). This

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C. Mattingly, Ph.D. (✉)
Department of Anthropology, Division of Occupational Science and Therapy, University of Southern California, Los Angeles, CA, USA
e-mail: mattingl@usc.edu

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paradigm shift can help correct for an overly narrow focus on risk, vulnerability, structural violence, and social suffering. It also—at least potentially—raises essential conceptual questions about agency and about how to investigate what morally matters to people's lives. This is especially the case if "resilience" or "well-being" are not defined by predetermined functional outcomes (as they often are) and inquiry is opened up to investigation of how these, or other salient concepts, shape aspirations among the people one studies. As anthropologist Panter-Brick has contended, research on resilience must concern itself with "what really matters" (Kleinman, 2006) and this, in turn, takes us to "the moral dimensions of human experience where people live a life of great uncertainty and danger" (2014, p. 442). And as she further argues: "Agency in resilience does not mean extraordinary action; on the contrary, many scholars forcefully argue that resilience…is predicated on the competence and resourcefulness of everyday life" (2014, p. 441).

This chapter addresses resilience in this more open-ended sense. I explore how African Americans families raising children with significant disabilities and medical vulnerabilities attempt to create greater resilience in their families and communities despite barriers and vulnerabilities, and the dangers and hopes these efforts entail. As I will argue and try to show in what follows, my ethnographic material presses me to understand a term like "resilience" by connecting it to what matters in people's lives, to their deepest moral concerns and how they understand what makes life worth living.

I offer the following example.

Experimental Soccer and the Good Life: Resilience, Suffering, and Moral Striving

It could be one of any thousands of soccer fields scattered throughout America: grade school children in their uniforms running up and down the grass shouting to one another as their parents cheer them on. It is an ordinary Saturday afternoon event repeated in countless towns and cities across the United States. Except that in the center of this field, as screaming children fly by, is a boy in a wheelchair being madly propelled by another boy as, together, they too head in the direction of the ball. His father and mother stand on the sidelines watching the action. The boy's parents, Tanya and Frank, have three children—two girls and a son, Andy, who is their oldest. Andy was born with an extremely severe case of cerebral palsy that not only leaves him physically disabled but very cognitively impaired as well.

Tanya is one of those mothers determined to fight for her son's rights to good schooling and she is fierce in her determination to stand up to school board members, principals, and other public officials in order to get good care for her son. "It's my Jamaican blood," she laughs, justifying her willingness to battle authorities.

But she credits her husband, Frank, for opening her eyes to her son's capability to participate in everyday children's activities that she would have shielded him from otherwise. Her husband is an athlete, a natural at many sports, and a son—his son—should love sports as much as he does, he maintains.

Frank decided that he should get Andy involved with the local children's soccer team. Tanya, however, was terrified and absolutely refused; they fought about this for several years. But finally, Frank prevailed and Tanya let her son go out onto the field. During one of the games, just as she feared, Andy's wheelchair was accidentally knocked over and he toppled to the ground. But, to her great surprise, he was not only unhurt but he didn't even act frightened. This is a story Tanya has told more than once. It moves her every time; catching her up short, not only the delight of it but also this realization that despite her determination that others view her son as capable, she herself underestimated him and the community surrounding him. This experience created new hopes for her child and it also challenged her own self-understanding as "good mother." She has asked herself, with some anguish: How did I not see what my child, and my community, could do?

I came to know Tanya and Frank as part of *Boundary Crossing*, a long-term ethnographic study among African American families in Los Angeles. The short story I have told reveals something about the ethically nuanced character of hope. The story is an opening vignette in a recent book (Mattingly, 2014) in which I explore the moral complexities surrounding parental care of medically vulnerable children. I have repeatedly been struck by how often parents respond to the suffering of their children by trying to transform not only themselves but also the social and material spaces in which they live. Parents like Tanya struggle to cultivate more morally worthy characteristics—to become better parents—in the face of immense demands illness and suffering can bring; to "step up to the plate," as one father put it, in order to care for their medically fragile children. These practices of care are undertaken in circumstances that are always fraught and sometimes seem impossible spaces in which any "best good" worth acting upon can be found. Parents may even carry out moral experiments, such as the reinvention of a local soccer game, as part of raising their children. These small experiments also invent, or reinvent, hope.

What does this say about resilience? Certainly the story of Tanya and Frank does not offer an obvious example of a resilient family in any straightforward sense. We see the earnest struggle of these parents to create a good life for their child and their family, a life that they can endorse morally and that they find personally and socially significant. Their attempts and experiments raise hopes but are (at least for Tanya) also accompanied by new vulnerabilities. Examples like this suggest a picture of well-being or resilience less as a stable achievement or state of being—something one has or lacks—so much as an ongoing practice. This is a practice where the very criteria defining well-being can have very family-specific meanings, may not be shared among all family members, and may shift over time. I am speaking of a complex and fraught practice, yielding gifts of trouble as well as joy and satisfaction.

A Narrative Phenomenology of Resilience

In this chapter, my conceptual and empirical starting point for a consideration of resilience is a narrative one, a narrative phenomenology which is grounded in the lives of particular persons and intimate moments of family and clinical life. In previous work, I have not used the vocabulary of resilience or well-being. I have tended to associate such struggles and aspirations with quests for "hope," a term that does not cover exactly the same ground as "resilience," but bears a family resemblance. The families I have studied do not use words like "resilient" to describe themselves, but they do speak of hope, and just as often, of bitterness, anger, and despair.

What might a narrative approach offer to an investigation of resilience? Even beginning to answer this requires immediate clarification because I am not simply referring to storytelling. Ordinarily, when we speak of narrative we have in mind either a kind of artifact, a text, or a performative genre, a particular kind of speech act. For my purposes however, this framework is not large enough to encompass a narrative portrait of resilience. Storytelling and the reception of cultural texts represent one small part of what I mean by narrative. Narrative phenomenology, as have my colleagues and I have construed it, builds from a dramatistic perspective on social action that has a significant, if minor, history in social thought. More than 70 years ago, Kenneth Burke (1945) proposed "dramatism" for the study of communicative acts. He sought to offer a framework for understanding human action which would distinguish it from the leading theories of his time that were based on behaviorist models of action. Behaviorism, he declared, was "designed to study people as mere things," (1966, p. 53) as he put it, needing no strong theory of agency and intention—of the centrality of *motive* to practical life and practical understanding. In anthropology and sociology there are multiple strains of dramatism which include such key figures as Victor Turner and, very differently, Erving Goffman. Performative and phenomenological approaches to social action and experience, especially studies of ritual as social drama, have also played a contributing role (e.g., Csordas, 1996; Kapferer, 1983; Schieffelin, 1996).

I have relied upon a dramatistic image of action to argue that practical action involves both the ongoing apprehension and the co-creation of acted stories, including (at times) dramatic moments that engender significant experiences. Practical action, from this view, is highly eventful and the eventful features of everyday life are worth particular attention. The anthropologist Michael Jackson's (2005) description of an "ethnography of events" is close to what I have in mind. An ethnography of events he tells us "seeks to explore the interplay of the singular and shared, the private and the public." Everyday life presents actors with "a series of situations whose challenges and implications always ramify beyond the socio-cultural…." Thus, attention to events "illuminates what is at stake for those involved," as well as carrying "ethical and practical implications that far outrun specific individual intentions and awareness" (Jackson, 2005, p. 75).

This narrative phenomenological approach speaks to actors' attempts to discern (or, perhaps more accurately, to dream) hopeful future stories, and the vulnerable, or even tragic possibilities inherent in this project. It presumes that cultural meaning is emergent and unstable (even a matter of cultural border crossings as actors navigate their way in multiple cultural worlds), and that it is produced in specific historical contexts by particular actors who are in the business of trying to live their lives.

In narrative terms, actors are trying to discern what story or stories they find themselves a part of, which ones they ought to be trying to further and which they ought to avoid, and what their narrative possibilities are as these change over time (Mattingly, 2010).

I call upon phenomenology to enrich this narrative approach because of phenomenology's investigation of lived experience, especially the experience of human time. From a phenomenological perspective, time is not the next mechanical progression of clock time. Rather human time or lived time is experienced as a "threefold present"—that is, what we call "the present" or the "now" is configured in a temporal structure. This configuring structure includes both past and future because both memory and anticipation are brought to bear in our experience of a particular present moment (Ricoeur 1984). Phenomenologists often use the example of how we hear the note of a song—a present moment of sound. That note is not heard alone, as a singular sound, but is heard by us as something configured by the notes that have preceded it and those we anticipate (through prefiguration) that will follow it. Put in more cultural language, our memory (of the sounds we have heard) and our anticipation (of future sounds) have been shaped not only by the immediate past (the song's earlier notes) or anticipatory future notes that we expect to hear—these expectations of past and future are culturally shaped. We are familiar with a repertoire of types of songs and this cultural repertoire will shape memory and anticipation.

If we take the example of the soccer game, we can see it in narrative phenomenological terms by noting that the "now" of a particular soccer game, say the one in which her son is pushed over and does not mind after all, presents itself an experience to Tanya in light of a past (which includes the many years of arguing with her husband) and an anticipatory moment—in this case, the surprise of an experience in which her anticipatory understanding of how things would unfold (her son would be hurt, this would be a disaster) is met with an event she does not anticipate. Her son's response challenges her own expectation of his vulnerability. This is not a passive challenge. Rather, this experience affects her so profoundly that it actively shapes how she begins to see her son's future and her own. I have offered an oversimple analysis of the phenomenological depth of her experience, but I hope to have at least intimated what a narrative phenomenology of experience might bring to studies of people's aspirations for good lives and for well-being as an unfolding, effortful practice.

Resilience and Health Disparities: A Narrative Phenomenological Approach

As I discussed earlier, resilience has become an important concept in health disparities research because it can supplement an overly narrow focus on obstacles, barriers, risks, and social inequalities. It does so not by presuming that these are insignificant but rather by offering complementary attention on the circumstances and activities that permit people to thrive, despite formidable barriers. Using a narrative phenomenological approach, I offer the following example of a low-income African American mother (Andrena) who has a daughter with a severe form of brain cancer. Her situation illustrates a common issue in health disparities—access to care. Andrena's daughter had a long delay in diagnosis and the cancer had progressed far before she received any treatment.

Just as with Tanya and her family, my example of Andrena and her daughter will not offer us a straightforward picture of thriving. Rather it reveals the many efforts that Andrena makes to promote thriving—or, more accurately, living the best possible life—despite the desperate situation she and her daughter face. The situation I describe below takes us into a clinical space. It suggests how a clinical encounter can contribute significantly in helping families and patients realize good lives even when a cure is unlikely or medically impossible. And it also suggests that this clinical contribution can come in the form of small dramas rather than large medical interventions. Such small dramas go virtually unnoticed and certainly undocumented within the clinical world. And yet, they may be of profound significance to families and patients.

The Witches' Tea Party

For nearly a year, Andrena took Belinda to emergency rooms all over the city, seeking some kind of diagnosis for her increasingly ill child. Time and time again, she was told to go home, that nothing was really wrong. Finally, after Andrena's very strong protests that she would not go home until someone looked at her daughter because she knew something was very wrong, a doctor examined her and recognized that there was a serious problem. Within 2 days, Belinda was diagnosed with a brain tumor that had grown unchecked for a year and was, by the time of diagnosis, the "size of an egg." Prognosis was not good; no more than 60 % chance of recovery, the doctors told Andrena. Belinda had surgery and radiation, followed by chemotherapy.

After surgery, Andrena and her Belinda spend at least 2 days a week at the hospital for the next year and a half. Tuesdays are chemo. Thursdays are outpatient physical and occupational therapy. Her oncologist is someone Andrena gradually comes to trust, and there is a physical therapist who Belinda is particularly fond of. Andrena credits this physical therapist with teaching Belinda to walk again after surgery, a healing drama of momentous proportions when one hopes for a child to recover. And Belinda loves her therapy days because (a) she does not get a shot and (b) she gets a chance to play with some new people who, sometimes at least, know how to have fun. I describe a moment when a narrative is created in a treatment session with one of her occupational therapists—a narrative which is both hopeful, and, in a sense "ready to break."

An occupational therapist, Amy, who was not so familiar with Belinda had just taken over the case. She tried for a few sessions, very unsuccessfully, to get Belinda involved in some fine motor activities, like cutting and pasting pictures from magazines onto a page in some collage art activity. Belinda was generally bored and fretful, repeatedly jumping up from the table to wander off and see what other toys might be around. About the third frustrating session, Amy had an idea. She noticed that Belinda gravitated to some of the play clothes kept in the cupboards of the little treatment room where they had had their sessions. Also, Belinda was obsessed with the sink in the treatment room, each session heading immediately to it to wash her hands and then proceeding to take the sponge and wipe down the counters. Amy decided they should have a tea party, in fact a witches tea party. Belinda was delighted. They tried on many clothes together, Belinda attempting to tie various scarves on her bald head, preening in front of the mirror, and then settling with great delight on wearing a gigantic black witch's hat. The therapist, Amy, similarly donned a hat and Belinda even found one for me to wear, though I was trying to sit quietly in the corner and take notes. They set the table, placing their dishes just so, invited a few stuffed bears and other creatures to the tea, filled the teapot with water (Belinda's favorite part) and had some lovely plastic bagels to go with their drinks, which they sipped decorously in a ladylike way. There were, of course, many fine motor components to the party (scarve tying, buttons buttoned), which was a great hit.

How to Throw a Witch's Tea Party: The Narrative Emplotment of a Therapy Session

The interlude just recounted marks a shift from a therapy time the therapist designates as "scattered" to a focused and dramatic moment, narrative time governed by a desire, suspense, drama and a sense of the whole. Play clothes and plastic bagels transform the pair into festive witches eating and drinking with friends. Few words are spoken but this is a story all the same, and one imbued with symbolic density, a story that signifies. The depth of its signifying power is never guessed at by the therapist who so beautifully orchestrates it. Understanding why this therapeutic moment holds power for Belinda and her mother depends upon knowing more about Belinda's life than this therapist does. However, the therapist is fully aware that she and Belinda have effected a transformation in this part of the session. They have managed to shift from clinical time which is scattered, where she cannot get minimal cooperation from Belinda, and where, if she is unlucky and this persists, she may have to force Belinda to perform a set of tasks directed to discrete problems (weakness of her left side and especially her left hand, attention deficits caused either by the original tumor or brain damage from the surgery). She knows that out of an inauspicious beginning, they move into imaginative play where treatment of pathology is embedded within such merry adventures as dressing up as witches and pouring water from a teapot.

The drama relies upon their ability to move into a cultural script they share, one surrounding the everyday business of making tea and throwing parties. They make tea, they prepare snacks, they share food and drink with others. For this purpose, water becomes tea, stuffed creatures become honored party guests, and plastic bagels the tasty snacks fit for a proper witch's tea. The therapist's ability to follow the "pacing" of Belinda and to build opportunistically on what intrigues her, allow all of us—as actors or audience—to enter the "same story"—to create a healing story—for the space of a therapy session. But it is only when placed in context of Belinda's (and Andrena's) unfolding life that the real drama is revealed. This session connects Belinda to everyday life in the sense that it plays out a familiar canonical scene. (Belinda, like other children her age, loves nothing more than playing at being grown-up and cooking is a quintessential everyday activity reserved for those older than herself.) But its dramatic potency is due to the way it disconnects; it creates a breach from the life Belinda has been living since her illness. Amy and Belinda make an upside down story of her life—one which connects to Belinda's life but is powerful for Belinda because there are so many reversals of everyday life.

This little performed narrative connects clinic life to a hopeful plot Andrena is fiercely trying to live out, despite the devastating losses that have recently occurred. This story is one where Belinda has a joyful childhood, where she lives to the fullest. This hopeful plot requires such nurturing because it runs counter to the life story that has been unfolding. It is an upside down story in light of the many losses of her recent life. Here is a brief catalogue of the most important ones: (1) she leaves preschool, which she loves, and stays home all the time, away from her friends; (2) her father moves out and her parents are now divorcing; (3) she and her mother move from a small rental house to an apartment because her mother has been fired (missing too many days due to Belinda's illness) and can no longer pay the rent on the house; (4) since they are now cramped for space, her 23-year-old sister, who had been living at home, moves out, taking her son who is Belinda's age and is very close to Belinda; (5) Belinda loses her old neighborhood and now lives in a place with no yard; (6) Belinda's grandmother is diagnosed with stomach cancer and has become quite ill. She cannot visit Belinda as much as she once did; (7) Belinda eats so little, has grown so thin from the illness and the chemotherapy, that her mother now gives her a baby bottle because she will eat more that way. Belinda seems to be hurtling backward in developmental time.

Belinda cries sometimes at the loss of school playmates, father, and nephew, and is frequently mutinous at her mother's constant entreaties that she eat. Eating has become something of a battle between the two of them, and food has become a source of worry rather than fun. And in the midst of what has felt like a losing battle to get Belinda to eat, to keep enough food in her, and keep her from losing more weight, this therapy session has offered her a chance to feed others. As a witch at a tea party, she is the nurturer of other creatures as well as herself. She prepares the food and sets the table and brings everyone together. And she does so in disguise. She is Belinda but not Belinda, for she has donned a mask, a new costume, a new identity—Belinda the friendly witch. And she is not at a tea party by herself—what kind of party would that be—but with another witch, the friendly therapist who has finally thought up something fun to do. Even the outside anthropologist is invited to join, as Belinda insists that she wear a witch's hat too. So Belinda, who loves people but has been spending more and more time alone, can also orchestrate this social gathering, this social drama—thanks to the clever organization by Amy, the therapist.

Amy embeds certain activities directed to discrete disabilities (an impaired left side) within an activity which she knows the child finds absorbing. The most intense moments are dramatic in their quietude. Time slows. Within this pause, it is possible to glimpse a different child. This glimpse is intensely in the present, which takes on its own authority. But the very intensity of the present facilitates a foreshadowing gaze. This is not a predictive gaze so much as a freewheeling speculation; Belinda is transformed into a cheerful witch capable of caretaking. These are not realistic images. But their very fancifulness lends them power and intensity—even a certain seductive authority. Perhaps Belinda *will* emerge from a scary, isolated world where she is not only weighted down with a life-threatening illness, but faces the losses of friends and loved ones as well. And, perhaps the point is not only about some unlikely future but also about the possibilities within a present moment, a moment where Belinda does emerge as the lively, mischievous girl that her mother fondly remembers her to be, before she was struck with this illness.

Frail Dramas: The Invisibility of Healing Moments

Although the therapists may not realize this, their work has helped Andrena to envision a "return to life" after surgery, in which Belinda is able to laugh, walk, and play. In fact, Andrena sees these therapeutic interventions as so pivotal to Belinda's well-being that, unbeknownst to the therapists, she has built an entire home version of the rehab gym.

In this example, the therapist is well attuned to Belinda, but she is not at all aware of how her work fits into the larger life world of this child. She, and the other therapists who work with Belinda, is fully unaware of the extent to which Belinda's mother has incorporated the work of the therapists into her home life. The four therapists I interviewed about Andrena strongly concurred (in separate interviews) on several points: (a) Andrena "loved her child to death"; (b) She "popped in and out of sessions" which several therapists found troublesome since all struggled hard to hold Belinda's attention and Belinda frequently looked for her mother. Often she didn't come to the session at all but disappeared, which also disconcerted or annoyed the therapists; (c) Andrena seemed "pretty overwhelmed," a phrase repeated by all the therapists. As one put it, "I just think there's lot more going on in her life. She's just got such a full plate. I just get the impression that she's really overwhelmed"; (d) Noting Andrena's devastation at her child's illness and her life, which has become overwhelming, these therapists often mentioned that Andrena did not appear to be "absorbing" much of what the therapists were telling her. She often seemed rather "dazed" or "spacey" they said.

These remarks were made in sympathetic tones, a sympathy quite lacking when therapists describe parents *not* perceived as "loving their children to death." However, Andrena commits a breach from what, in the context of clinic culture, is approved parent behavior. She neither sits through the entire session nor waits patiently in the waiting room to be called upon by therapists as needed. Instead, she "pops in and out" and "disappears" for stretches at a time. Therapists have few means for evaluating whether parents are good "partners" or not; being available for therapists is an important (and generally unspoken) rule. The "good parent" shows up on time and cooperates with the therapist, assisting, watching from the sidelines or waiting in another room, as the therapist deems most appropriate. Andrena's violation of this cultural code requires a narrative explanation. The therapists' story about her life that explains this violation (she "needs a break," she is "overwhelmed," she "has a full plate") is quite correct, as far as it goes. They have read with unerring acuity Andrena's love for her child and guessed with equal accuracy that there are many more difficulties Andrena faces.

What they have missed, in their sympathetic reading, is Andrena's capacity to be overwhelmed, to violate the cultural code of the outpatient rehabilitation unit, and still be able to "read" their minds, to see what they are doing and why it is important for her child. They are utterly unaware of the extent to which Andrena has gone beyond anything they would dream of asking in incorporating therapy life into home life. Andrena views all the rehabilitation therapies as utterly central to her quest to, in effect, bring Belinda back to life after her surgery. When I have asked Andrena what she thinks the point of therapy is, she always returns to a moment after Belinda's initial surgery, painting a vivid picture of how therapy, as well as her family, has helped to bring Belinda back to life. Therapy's role is to get Belinda "back to where she was before she got bad." Because, she explains, "after the surgery was over, she could not even walk. She could not use her hands, well at least her left hand. She could not use her left eye. So she couldn't do anything…when she, you know, was out of surgery and they moved her downstairs, it was like she couldn't do nothing but just lay there. She wouldn't even laugh until my grandson and my father came up here to the hospital. And then, she like, my grandson was making her laugh and she was like starting laughing. She got all in good spirits… She just started laughing and she was coming, like coming back to life."

In Andrena's narrative of Belinda's "return to life" after surgery, the therapists are instrumental, even helping her to walk again, one of those recovery moments that are always dramatic for parents. At one point, in remarkable synchrony with many of the therapists' accounts of how they work with children, Andrena relies on musical metaphor to depict the skill of the therapists. Jane (Belinda's favorite physical therapist) was so good with Belinda because she tried to "fall into Belinda's mode of behavior." The therapists were good because they knew how to "slow down" and "take time" with Belinda. They push Belinda because they are able to figure her out.

What would most astonish the therapists is not only Andrena's accuracy at reading what they have been doing, and why it matters, but also how thoroughly she has built upon their work. She is, in fact, the dream parent, the one that therapists long for. She has transformed her entire living room in her small one bedroom apartment. It looks like a compressed version of the large rehabilitation room in the outpatient clinic. There is a child-sized basketball hoop, a slide, tunnels to crawl through, even a cheaper version of a "ball bath," a standard piece of pediatric rehabilitation equipment. Andrena remarked, who saw nothing extraordinary in what she'd done, explained matter of factly that she thought it would be good for Belinda to have this setup at home so that Belinda could work more on the therapeutic activities Andrena had seen the therapists do with her at the hospital. She laughingly noted that Belinda's cousins and nephew were her "home therapists" because they got her to play on all the equipment.

It is not just Andrena who tries to create experiences in which the hopeful stories born in therapy are lived out. Belinda too looks for such opportunities. And when the occupational therapist has the good sense to offer the chance for a witch's tea party, Belinda takes full advantage, laughing as she admires herself in her extravagant witch's hat. This is a particular way to consider "learning by doing" or "learning from experience," where the task to be learned is an emotion, if you want to put it that way, a whole perspective on life.

Life is complex and it would be foolish to presume these few months of occupational therapy sessions with Amy as single-handedly altering Belinda's fortunes. But at the very least, it is clear that Amy helps Belinda and her mother to realize an image which is mostly hidden by her poor physical health, her grim prognosis, and her difficult home situation. One plausible story to tell about Belinda and Amy is that Amy played a vital role in cultivating hopeful possibilities for Belinda and her family. She saw something in this child at a time when the predictions of other health care professionals were grim. Better and more important, she could use what she saw or guessed about Belinda to help create dramas in which this picture was embodied, was made evident to everyone: mother, researcher, Belinda herself.

And yet, for all of the brilliance of Amy's work with this child, there is a fragility that surrounds her interventions. While she recognizes her success in building fine motor skills, she fails to recognize the significance of these interventions in recrafting a tragic vision of Belinda's future into the hopeful possibility of a "return to life." One moral here, for health professionals, is that even when it is not clear what significance a session has, even when the parent doesn't seem to be around, it is possible, very possible, that more is going on than even meets the clinician's eye. It is possible that clinicians, more often and more powerfully than they even realize, may be contributing to the creation of life stories, offering hopeful moments with deep phenomenological impart.

Conclusion

In my narrative phenomenological approach, I have not presumed that resilience is something one can simply find but rather is a phenomenon embedded in the complexities and shifting character of people's lives and social circumstances. I have foregrounded the temporal complexity, historical situatedness and singularity of action, its ethical nature, its vulnerability in the face of an unknown future, and its imaginative character especially as revealed in the shadowy presence of futures not yet revealed.

I have also agued for the social qualities of resilience, its reliance upon communities that cannot always be predicted ahead of time but may be particular to a person's or family's situation (for example, a local soccer team, a rehabilitation therapy unit). In fact, part of the effort that parents make in trying to thrive includes searching for communities and social resources that can support their child's well-being. Furthermore, these social resources aren't simply found—they are, in part, created by the actors themselves. A soccer team becomes a different sort of team when it includes a child in a wheelchair—this social world is, in part, created by the actors involved. So, too, the rehabilitation therapists like Amy, and children like Belinda, who find their way into the kind of tea party that Belinda can especially enjoy.

Finally, I have noted the fragility of resilience-producing moments, the ways that they can be shattered because the actors who are so crucial to helping to create them are unaware of their own efforts. This bears particular significance when looking at the role of health care providers. In other work which goes beyond the purview of this chapter, I analyze some of the institutional features of health care provision that so often lead to this very unfortunate consequence (Mattingly, 2010; Mattingly & Lawlor, 2001; Mattingly 2000, 2007, 2008a, 2008b). In this chapter, I merely note this to underscore the ongoing and vulnerable work involved in creating something we might want to call "thriving" or "resilience" or "well-being."

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Chapter 4
Promoting Resilience During the Transition to Adolescence in Chronically Ill Children and Their Families

Jaclyn M. Lennon, Alexandra M. Psihogios, Caitlin B. Murray, Christina E. Holbein, and Grayson N. Holmbeck

The number of children and adolescents diagnosed with a chronic illness has steadily increased over the past two decades (Van Cleave, Gortmaker, & Perrin, 2010). Prevalence rates of childhood chronic conditions vary based on region, and based on the diverse methods used to measure prevalence in epidemiologic studies (van der Lee et al., 2007). Still, current research suggests rates have been steadily increasing, with some studies suggesting that as many as 1 out of 4 children in the United States aged 14 years and younger suffer from a chronic health problem, defined as lasting at least 12 months (e.g., Van Cleave et al., 2010). This increase is primarily attributed to higher prevalence rates of certain chronic illnesses such as obesity (Ogden, Carroll, Curtin, Lamb, & Flegal, 2010; Van Cleave et al., 2010), diabetes (Dabelea et al., 2014), and asthma (Weiss, Sullivan, & Lyttle, 2006). In addition, advancements in medical care and treatments have led to increased survival rates for certain illness groups such as those with cancer (Ward, De Santis, Robbins, Kohler, & Jemal, 2014), cystic fibrosis (CFF, 2010), kidney transplants (Smith, Martz, & Blydt-Hansen, 2013), and spina bifida (Parker et al., 2010). Conditions once seen only in young children are now being seen into adolescence and beyond, with as many as 85 % of children with congenital or chronic illnesses now surviving into adolescence (Halfon & Newacheck, 2010; Yeo & Sawyer, 2005).

As chronic illness rates in children and adolescents continue to increase, so does the associated burden. A chronic illness creates numerous challenges and stressors that can be unexpected, uncontrollable, and functionally impairing for families (Compas, Jaser, Dunn, & Rodriguez, 2012). Children and parents respond differently to chronic illness, as each family is confronted with unique challenges and possesses certain strengths. Responses to pediatric chronic illnesses are therefore

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J.M. Lennon, M.A. (✉) • A.M. Psihogios, M.A. • C.B. Murray, M.A.
C.E. Holbein, M.A. • G.N. Holmbeck, Ph.D.
Department of Psychology, Loyola University Chicago,
1032 W. Sheridan Rd., Chicago 60660, IL, USA
e-mail: jlenno2@luc.edu; gholmbe@luc.edu

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best understood from a developmental perspective that recognizes both individual experiences and the shared experiences of child and adolescent development. The transition from childhood to adolescence may be a particularly challenging time for families of children with a chronic illness, as this developmental period is marked by rapid changes related to biological, cognitive, social, and emotional functioning (Susman & Rogel, 2004). Indeed, the manner in which the transition from childhood to adolescence is managed has important implications for disease outcomes throughout the remainder of the life span (Williams, Holmbeck, & Greenly, 2002).

Managing a chronic illness, while maneuvering the developmental challenges of adolescence, can prove taxing for families. Attention is needed to how medical practitioners can assist families in responding to the challenges of this transitional period. Promoting resilience in these families can produce optimal responses to the daily stressors of chronic illness, by building upon the strengths of each family. Resilience has been defined in many ways but, in this context, it refers to the attainment of desirable social and emotional adjustment, despite adversity due to chronic illness (Rutter, 1985). A social-ecological model conceptualizes resilience as the notion that an individual or group can adapt to and overcome challenges by utilizing psychological, social, cultural, and physical resources (Ungar, Ghazinour, & Richter, 2013). This model is based on social-ecological theory insofar as human development is best studied by considering the dynamic interplay among the social and environmental contexts in which the individual is imbedded over time (Bronfenbrenner & Morris, 2006). This understanding of resilience provides a comprehensive framework for understanding how families respond to challenges presented by childhood chronic illness. Indeed, research in the area of pediatric psychology supports a disruption-resilience model, which suggests that while the presence of a child with a chronic illness may disrupt normative family functioning in certain ways, these families are able to adapt and demonstrate considerable resilience. In other words, families of children with chronic illness display both resilience and disruption, compared to families of healthy children (Costigan, Floyd, Harter, & McClintock, 1997; Lennon, Murray, Bechtel, & Holmbeck, 2015). Therefore, medical practitioners working with families of children with chronic illness may promote better outcomes if they adopt a strength-based approach that will help such families capitalize on their own strengths and resources to solve problems.

The present chapter aims to identify potential resilience factors and how medical practitioners can target these factors as a way to promote an optimal response to pediatric chronic illness during the transition to adolescence. These issues are examined from the perspective of pediatric psychology, "a multifaceted and integrated field of both scientific research and clinical practice that focuses on addressing a wide range of physical and psychological issues related to promoting the health and development of children, adolescents, and their families, with an emphasis on evidence-based methods" (Aylward, Bender, Graves, & Roberts, 2009). First, we will review the impact of pediatric chronic illness on children and families during the transition to adolescence, including its impact on children's biological, cognitive, psychological, and social functioning, as well as its impact on parenting and family functioning. Next, we will identify potential individual, family, and community resilience factors that can serve as targets for interventions. We will conclude with suggestions for medical practitioners, as well as areas for future research.

The Impact of Chronic Illness During the Transition to Adolescence

To promote resilience from a developmental perspective, it is useful to have an understanding of typical development during this period, including children's individual abilities and functioning as well as parent functioning and family processes. Adolescence is characterized by rapid biological, cognitive, and social maturation in which the adolescent begins to assume new roles within the family (Hill, Bromell, Tyson, & Flint, 2007). The biopsychosocial changes that occur as children transition into adolescence can increase youths' physical and emotional distress and risk behaviors, but it can also strengthen relationships and foster independence (Forrest, Bevans, Riley, Crespo, & Louis, 2013). Adolescents with chronic illness have the same developmental needs as their healthy peers, and attention should be paid to these developmental milestones and outcomes if optimal health outcomes are to be achieved (Yeo & Sawyer, 2005).

Biological and Physical Changes

The biological transition of adolescence is perhaps the most visible sign that adolescence has begun (Yeo & Sawyer, 2005). Most often referred to as puberty, or the process of physical maturation manifested by an acceleration of growth and appearance of secondary sexual characteristics, this transition begins with changes in brain-neuroendocrine processes, hormone concentrations, changes in physical characteristics, and concludes with reproductive maturity. Traditionally, these biological changes begin to occur at roughly 8 years of age for girls and at 9 years of age for boys, but there is considerable interindividual variability (Susman & Rogel, 2004).

Although the biological changes of puberty are universal, the timing, intensity, and impact of these changes differ across time and culture, and are likely to differ for children with medical conditions. Across many chronic illness groups, the sequelae of an illness and its treatment can impact biological changes in various ways. For example, the onset of puberty in adolescents with spina bifida often occurs earlier than in typically developing youth (McLone & Ito, 1998), whereas adolescents with cystic fibrosis are typically delayed in pubertal development (Arrigo, Rulli, Sferlazzas, & de Luca, 2003). In addition, the physical changes that occur during puberty often lead to an increase in awareness of appearance and attractiveness, as youth compare themselves to peers, often leading to a negative body image. Indeed, it has been found that physical appearance contributes to levels of overall self-esteem more than any other factor (Harter, 1999). Chronic illness and its treatment may produce visible signs of illness that can exacerbate feelings of self-consciousness. For example, in children with cancer, surgery can result in scarring or disfigurement, radiation can stunt growth and result in skin damage, and chemotherapy can result in hair loss or weight loss/gain (Wallace, Harcourt, Rumsey, & Foot, 2007).

Despite unique challenges that may arise for chronically ill children during puberty, puberty can be a difficult time for typically developing children as well. For example, adolescents affected by delayed puberty, regardless of health status, may be treated as less mature than same age peers (Michaud, Suris, & Viner, 2007). Thus, when working with such youth, it may be important to assess how the medical condition may be impacting puberty, and to respond as one would to any child going through puberty—by providing education and support (Susman & Rogel, 2004).

Cognitive and Academic Functioning

Cognitive development during the transition to adolescence is best characterized by the attainment of a more fully conscious, self-directed, and self-regulating mind. Developmental neuroscience highlights processes most salient to the adolescent period, such as the developing prefrontal cortex, increasingly rapid connectivity, increases in neocortical volume, and synaptic pruning that is central to executive functioning (Keating, 2004). Thus, adolescence is a critical developmental period for cognitive development. The presence of a chronic illness and its treatment may impact cognitive functioning in various ways, depending on the illness, age of illness onset, and treatment. For example, youth with spina bifida are often born with hydrocephalus, which is commonly treated with a shunt placement at birth. Both the presence of hydrocephalus at birth and the surgeries required for shunt placement and to treat shunt malfunctions or infections can negatively impact the cognitive abilities of these youth (Rose & Holmbeck, 2007). Other chronic illnesses are known to have long-term neuropsychological effects in adolescence as a result of the disease process (e.g., cerebrovascular accidents in sickle cell disease and hypoglycemia in diabetes; Michaud et al., 2007). Research on the impact of specific chronic illnesses on cognitive development is growing and, although attention is commonly focused on deficits in cognitive function, attention should also be paid to resilience. For example, one study found that among children with traumatic brain injury, those from families that experienced lower levels of stress demonstrated better cognitive outcomes later, compared to families that experienced higher levels of stress (Taylor et al., 2002).

The impact of chronic illness on academic performance and the need for educational services will depend on the overall impact of the condition on a child's functioning. Cognitive impairments described previously may impact a child's ability to meet academic demands. If problems in this area arise, the child will need educational support services such as an Individual Education Program (IEP).

Chronically ill children without cognitive impairment may still be less interested in school, have more school absences, or experience bullying which could result in lower academic achievement. For example, one study found that the presence of asthma impacts academic performance in children during the transition to adolescence, and this association is mediated by the number of missed days of school as compared to their peers. Despite these challenges, however, this same study found that the presence of a chronic health condition had a weak or nonsignificant association with how children feel toward their teachers or levels of school engagement (Forrest et al., 2013).

Psychological Functioning and Autonomy

Adolescence is characterized by numerous developmental changes that may result in challenges that negatively impact an adolescent's psychological functioning, including their mental and emotional well-being (Graber, 2004). Although adolescence is a time when the risk for psychological maladjustment increases for all youth (e.g., Kessler, Avenevoli, & Merikangas, 2001), the experience of having a chronic health condition can be particularly challenging during this developmental period. In general, studies across pediatric health conditions have shown that adolescents with medical conditions are at an elevated risk for a range of psychological symptoms (e.g., overall adjustment, internalizing and externalizing symptoms) compared to healthy children (e.g., Lavigne & Faier-Routman, 1992). For example, compared to their healthy counterparts, research on adolescents with diabetes suggest they have higher rates of depression (e.g., Hood et al., 2006), anxiety (Kovacs, Goldston, Obrosky, & Bonar, 1997), and eating disorders (e.g., Jones, Lawson, Daneman, Olmsted, & Rodin, 2000). Other salient stressors, such as concerns about death and dying, are thought to develop during adolescence in youth with cystic fibrosis (Quittner, Barker, Marciel, & Grimley, 2009) and sickle cell disease (Lemanek & Ranalli, 2009). Furthermore, chronically ill children tend to have lower self-esteem than typically developing children (Grey, Cameron, & Thurber, 1991). Despite these results, there is evidence that some pediatric populations show positive adjustment, similar to that of healthy peers. Stam, Grootenhuis, and Last (2001) found evidence for the following predictors of positive adjustment in adolescent survivors of childhood cancer: demographic factors, illness- and treatment-related factors, coping, and family and parental functioning. For example, they found that adolescents were more positively adjusted if they had been diagnosed earlier in childhood, or if they had parents who were less psychologically distressed immediately after diagnosis (Stam et al., 2001).

In North America, the transition to adolescence is also characterized by a striving for individuality, which is often accomplished through an increase in autonomy (Steinberg & Morris, 2001). While previous research has proposed a dichotomy in which parents from individualistic societies encourage autonomy while parents from collectivist societies encourage relatedness, recently, scholars have suggested that these developmental goals can coexist in families from all cultures (Tamis-LeMonda, Hughes, Yoshikawa, Kalman, & Niwa, 2008). The development of autonomy is considered a major task of adolescence for all youth, and is understood as the interpersonal process by which adolescents begin to develop a greater capacity for independent behavior in the context of continued family connections (Steinberg & Morris, 2001). The construct of autonomy is often deconstructed into the construct of behavioral autonomy, which includes self-reliant behavior and intrinsically motivated behavior, and emotional autonomy, which has been described as part of the process by which adolescents relinquish dependencies on their parents (Friedman, Holmbeck, DeLucia, Jandasek, & Zebracki, 2009). Autonomy development has been identified as one of the most important relational changes to occur within the family during adolescence (Hill & Holmbeck, 1986). The task of autonomy development may be challenging for an adolescent with a chronic illness, especially considering that some dependency on adults is often necessary for an adolescent who is chronically ill. However, some pediatric populations develop independence in ways similar to their healthy counterparts. For example, children with spina bifida and their same-age peers show similar increases in independent behavior and emotional autonomy from their parents over time, suggesting children with spina bifida appear to demonstrate considerable developmental resilience in the face of significant challenges (Friedman et al., 2009).

For many youth with chronic health conditions, the transition to adolescence is also characterized by increased autonomy with medical care. For instance, it has been found that parents of children with diabetes (Anderson, Ho, Brackett, Finkelstein, & Laffel, 1997), cystic fibrosis (Modi, Marciel, Slater, Drotar, & Quittner, 2008), and spina bifida (Stepansky, Roache, Holmbeck, & Schultz, 2010) begin to transfer medical responsibilities to children during early adolescence, or around the age of 13. For more on the role of parents in promoting adjustment to chronic conditions see Hoehn et al., this volume. Medical care regimens provide youth with an opportunity for developing responsibility and confidence. However, despite these gains in autonomy, rates of adherence amongst adolescents are generally lower than adherence rates in younger children and adults (i.e., a 50 % adherence rate is often found among adolescents with various chronic health conditions; La Greca & Mackey, 2009). This may be because certain developmental events (e.g., increased peer socialization) interfere with the scheduling and completion of medical management tasks, such as taking medication as prescribed, adhering to a specific diet, adhering to a bowel/bladder program, or completing physical therapy exercises. Also, the severe and/or permanent nature of a disease may become more evident and discouraging during adolescence. An adolescent may realize that his or her illness will persist, even if he or she is fully compliant with medical regimens, and this thought process may negatively affect the adolescent's level of adherence and psychological well-being. Thus, the changes that an adolescent is experiencing (in terms of increased responsibility for disease management and salient developmental events) may make it difficult for an adolescent to be successful at caring for their health without additional support.

Social Functioning

Social functioning in youth with chronic health conditions may be especially important to consider during the transition to adolescence, as this is a time when typically developing youth begin spending more time with friends (Larson & Richards, 1991). Many youth with chronic health conditions are at risk for challenges in social contexts. Social difficulties in pediatric populations are likely related to multiple factors. Children with chronic health conditions may feel they do not "fit in" with their healthy peers because their lives include unique experiences (La Greca, 1990), such as painful medical treatments and complex self-care regimens, fears of future health challenges, and coping with stigma associated with visible physical disabilities (Perlman & Routh, 1980). The increased risk of both internalizing and externalizing symptoms in youth with chronic health conditions (Lavigne & Faier-Routman, 1992) puts them at a further disadvantage in social contexts. Cognitive impairments associated with some health conditions and treatments (e.g., neurocognitive late effects among childhood brain tumor survivors) may also interfere with successful peer relations due to diminished capacity to engage with peers (Wallander & Varni, 1998).

Various social difficulties have been studied in pediatric populations. Such youth may lack the foundation of social skills necessary for successful social interactions (Nassau & Drotar, 1997). They may also have fewer opportunities to socialize with peers outside of school (Wiegerink, Roebroeck, Donkervoort, Stam, & Cohen-Kettenis, 2006). Children with chronic health problems may have fewer close friendships (Barrera, Shaw, Speechley, Maunsell, & Pogany, 2005; Holmbeck et al., 2010), with these friendships often lower in quality and emotional support (Devine, Gayes, Purnell, & Holmbeck, 2012; Helms, Dellon, & Prinstein, 2015). In addition, many youth with chronic health conditions encounter bullying and victimization by peers (Nadeau & Tessier, 2009; Petteway, Valerio, & Patel, 2011).

Two recent meta-analyses revealed that youth with chronic health conditions are less socially competent than their healthy peers (Martinez, Carter, & Legato, 2011; Pinquart & Teubert, 2012). Although these studies and others (e.g., McCarroll, Lindsey, MacKinnon-Lewis, Chambers, & Frabutt, 2009) provide evidence for social deficits in pediatric population in general, meta-analytic techniques suggest varying levels of social impairment across health conditions (Martinez et al., 2011; Pinquart & Teubert, 2012). In fact, children with disorders of the central nervous system (CNS; e.g., epilepsy, spina bifida) tend to exhibit greater social difficulties as compared to those with other health conditions (e.g., blood disorders, diabetes, obesity). Social difficulties have also been found for children with diabetes (Helgeson, Reynolds, Shestak, & Wei, 2006), sickle cell disease (Noll et al., 1996), Tourette's disorder (Stokes, Bawden, Camfield, Backman, & Dooley, 1991), juvenile rheumatoid arthritis (Feldmann, Weglage, Roth, Foell, & Frosch, 2005), and inflammatory bowel disease (Mackner & Crandall, 2006), among others.

Despite evidence for social difficulties in pediatric populations, research has also demonstrated considerable resilience in these youth in the social domain. For instance, and contrary to the findings just noted, some studies have found no significant social differences were apparent between healthy peers and children with sickle cell disease (Lemanek, Horwitz, & Ohene-Frempong, 1994) and juvenile rheumatoid arthritis (Reiter-Purtill, Gerhardt, Vannatta, Passo, & Noll, 2003). Further, childhood cancer survivors exhibited greater social competence than healthy comparisons in one study (Reiter-Purtill, Vannatta, Gerhardt, Correll, & Noll, 2003). In another study, adolescents with diabetes reported higher numbers of close friends and emotional support from friends than their healthy peers (Helgeson et al., 2006). These findings are consistent with the disruption-resilience model presented earlier (Costigan et al., 1997), in that youth with chronic illness may experience social difficulties due to their medical condition, but other aspects of their social functioning may remain unaffected.

Parent Functioning and Parenting

Being a parent can be challenging, especially when parenting an adolescent. However, being a parent of a child with a chronic illness may be particularly daunting. Parenting quality and parent–child relationships may be dramatically altered in families with a chronically ill child (e.g., higher levels of parental overprotection and neglect; Pinquart, 2013). Childhood chronic medical conditions may produce significant social, relational, emotional, and financial stress for parents (Barlow & Ellard, 2006; Drotar, 1997; Klassen et al., 2007; Palermo & Eccleston, 2009). Common stressors experienced by parents include increased child-rearing responsibilities (e.g., implementation of therapeutic or medical procedures), changes in daily activities, disruption/shifting of social and family roles, and the burden associated with adherence to complex medical regimens (Drotar, 1997). Parents may also experience increased stress from managing their jobs and careers in response to increased time demands and greater financial burden (Case-Smith, 2007). Further, both mothers and fathers of youth with chronic conditions are at risk for psychological health difficulties (e.g., depression, distress, negative affectivity; Pai et al., 2007), which may impair a parent's ability to provide quality care for their child (Drotar, 1997). Reductions in distress in parents of chronically ill children should therefore be an important treatment goal for medical practitioners.

Family Functioning

Researchers have proposed that an adolescent's ability to effectively manage and cope with his or her chronic health condition is best examined within a family context (Kazak, Rourke, & Navsaria, 2009). The social-ecological model proposed previously in this chapter is especially useful for understanding the manner in which children and their families (and other relevant systems) interact to shape adjustment to chronic illness (Ungar et al., 2013). As most families with chronically ill children appear to be otherwise healthy families faced with difficult circumstances, understanding the transactional process in which the presence of a pediatric illness changes the family system is essential (Kazak, 1997).

Within pediatric populations, much of the existing body of literature on family adjustment has focused on particular family-centered variables, including family adaptability, social support, the ability to balance the demands of the illness with other family needs and responsibilities, effective communication, adaptive coping strategies, and the effective balance of autonomy-granting in the context of ongoing parental support (Kazak et al., 2009). Understanding these family-centered variables can help to clarify the complex, dynamic relationship between family functioning and child adjustment across salient developmental periods, including the transition to adolescence. For example, lower levels of cohesion were observed in families of preadolescents with spina bifida than in a matched typically developing comparison sample, although differences in family conflict were nonsignificant (Holmbeck, Coakley, Hommeyer, Shapera, & Westhoven, 2002). Notably, this study also found that families of preadolescents with spina bifida who were of low socioeconomic status were most at-risk for low family cohesion, suggesting that the combined experience of having a child with spina bifida and low socioeconomic places families at the highest risk for maladjustment.

The relationship between family functioning and treatment adherence has been studied extensively across childhood chronic illnesses, particularly type 1 diabetes. A number of studies of family functioning found that relationship factors (e.g., communication, problem-solving skills, conflict resolution) significantly predicted adaptive adherence behaviors for children and adolescents with diabetes (Wysocki et al., 1999). This finding has been supported in a spina bifida population, with studies finding that high levels of family conflict predict a decrease in concurrent (Psihogios & Holmbeck, 2013) and later adherence (Stepansky et al., 2010). According to Stepansky et al. (2010), the longitudinal association between family conflict and medical adherence suggests that family conflict and medical adherence become increasingly intertwined during adolescence.

It has also been suggested that siblings of chronically ill children are at greater risk of adjustment difficulties, as they may feel neglected due to decreased time with parents and involvement in family discussions (Yeo & Sawyer, 2005). Indeed, a meta-analysis conducted by Sharpe and Rossiter (2002) found that psychological functioning (i.e., depression and anxiety), peer activities, and cognitive development were lower for siblings of children with chronic illnesses compared to matched controls.

Promoting Resilience

As the previous section has highlighted, there is wide variation in the functioning of youth with chronic illnesses and their families; while some of these youth and families may function quite well, others may be confronted with significant challenges.

Despite the negative impact that the presence of a chronic illness may have on a child and his/her family during the transition to adolescence, there are multiple individual, family, social, community, and cultural resilience factors that are found in families of youth with chronic illnesses. For medical practitioners to assist in promoting and building upon this resilience, it is important to identify and have an understanding of *what* makes a family resilient, and *how* such resilience emerges in the face of adversity.

Individual Resilience

Investigations of individual resilience factors facilitate a clinician's understanding of important within-child protective processes that may contribute to positive functioning, despite difficult life circumstances (Betancourt, Meyers-Ohki, Charrow, & Hansen, 2013). Moreover, knowledge of individual-level protective processes is needed to design effective interventions that capitalize on or promote children's natural sources of resilience. Several studies have investigated individual-level strengths and sources of resilience, identifying specific coping strategies children may use to manage illness-related stressors (Betancourt et al., 2013; Jaser & White, 2011; Wu, Sheen, Shu, Chang, & Hsiao, 2013). Research has also found self-esteem and positive future expectations to be important individual-level resilience factors (Betancourt et al., 2013; Grey et al., 1991).

Coping. Youth with chronic illnesses may face a number of stressful events; these populations are typically exposed to a large number of disease-related stressors (e.g., invasive medical procedures) in addition to common, developmentally congruent stressors experienced by all children and adolescents (Spirito, Stark, Gil, & Tyc, 1995). Adjustment to these stressors is affected by youth's coping strategies, or the cognitive and/or behavioral processes that reduce or help to manage stressful events (Lazarus & Folkman, 1987). Although multiple conceptualizations of coping exist, the most recent pediatric literature supports making the following three distinctions among coping strategies: *primary control coping* includes strategies intended to directly change the source of stress (e.g., problem-solving) or one's emotional reaction to it (e.g., emotional expression); *secondary control coping* includes efforts to adapt to stress (e.g., acceptance, positive thinking); *disengagement coping* includes efforts to orient away from the source of stress or one's reaction to it (e.g., avoidance, wishful thinking; Compas et al., 2014). Among pediatric populations, primary and secondary control coping have been associated with better adjustment and medical outcomes, while disengagement coping has been associated with poorer outcomes (Compas et al., 2014). For example, among adolescents with type 1 diabetes, primary and secondary control coping were associated with better quality of life and better metabolic control, while disengagement coping was associated with lower social competence and lower metabolic control (Jaser & White, 2011). Others studies have found the use of secondary control coping to be particularly predictive of adjustment. Specifically, secondary control coping was predictive of fewer anxiety symptoms in youth with functional abdominal pain (Hocking et al., 2011), and it was predictive of fewer anxiety and depressive symptoms in youth with cancer (Compas et al., 2014).

Self-esteem and Hope for the Future. Previous research indicates that higher levels of self-esteem are linked to resilience among children with chronic illnesses (Grey et al., 1991). A recent qualitative study found that self-esteem and hope (e.g., "Thinks about her future"; "Feels she must survive"; "Feels strong") were important contributors to resilience in Rwandan children affected by HIV/AIDS (Betancourt et al., 2011). Increased hope for the future has also been linked to better psychosocial outcomes in children with chronic illnesses (e.g., pediatric burn injury, sickle cell disease; Barnum, Snyder, Rapoff, Mani, & Thompson, 1998; Lewis & Kliewer, 1996).

Understanding individual cognitive and behavioral characteristics that help chronically ill children cope with stressful aspects of illness and treatment is important for clinical intervention. Medical practitioners may find it useful to incorporate routine screening of coping strategies, self-esteem, and future expectations into their evaluations of children with chronic illness for prevention purposes (Spirito et al., 1995).

Family Resilience

As noted earlier, while the impact of chronic illness on the child should not be underestimated, the family may also experience a number of stressors that are a direct result of having an ill child. Nevertheless, there is both research and clinical evidence that many families successfully adapt, demonstrating positive functioning despite increased strains and demands. Similar to individual resilience, family resilience is not only characterized by overcoming adverse or stressful events; an important component of such resilience also includes the influence of relationships between family members (Patterson, 2002), and how positive relational bonds and parent–child interactions can promote family adaptation (McCubbin, McCubbin, Thompson, Han, & Allen, 1997). Historically, research on families of children with chronic illness has not emphasized resilience, but rather, the negative aspects of having a child with a health problem (Tinsley, Castro, Ericksen, Kwasman, & Ortiz, 2002). However, researchers and clinicians have begun to delineate aspects of parenting and family functioning that can be considered optimal in relation to a child's adjustment to illness.

Parenting. Parenting styles and the quality of the child–parent relationship play a critical role in a child's development (Steinberg, 2010) and in the adaptation of a child with a chronic illness in particular (e.g., adherence to a medical regimen; Ellis et al., 2007). Research on mostly European American samples suggests that authoritative parenting styles, characterized by the combination of both high demandingness and high responsiveness, contribute to positive health behaviors (Tinsley et al., 2002). That is, parenting behaviors characterized by higher levels of behavioral control (i.e., parenting involving age-appropriate supervision and setting of rules and regulations) and parental acceptance (i.e., emotionally supportive, approving, and involved parenting) have been linked to positive outcomes in youth with chronic illnesses (e.g., preadolescents with spina bifida; Holmbeck, Shapera, & Hommeyer, 2002). Adaptive outcomes may be due to the presence of a warm parent–child relationship in combination with appropriate levels of autonomy and restrictiveness that promote independence skills (Pinquart, 2013). In addition, there is reason to believe that authoritarian parenting styles, characterized by high demandingness and low responsiveness, may lead to better outcomes in families who are not of European descent, such as Asian American families (Van Campen & Russell, 2010). For more on the importance of cultural contexts in resilience processes, see Yi, this volume.

Family Functioning. "Family functioning" encompasses several conceptual dimensions, including cohesion, expressiveness, organization, independence, and control (Moos & Moos, 1994). In families of children with chronic illnesses, there is a growing body of evidence that both more cohesion and less conflict are linked to better child adjustment (Knafl & Gilliss, 2002). Associations between family cohesion, or the emotional bond that family members communicate to each other (e.g., expressing belonging and acceptance within the family), and positive adjustment is a consistent finding, with similar results found in studies of pediatric cancer (Kim & Yoo, 2010), diabetes (Pereira, Berg-Cross, Almeida, & Machado, 2008), sickle cell disease (Kliewer & Lewis, 1995), and mixed samples of children with chronic illnesses and physical disabilities (Wallander, Varni, Babani, Banis, & Wilcox, 1989). Greater levels of family expressiveness (e.g., encouragement to express emotions directly) has also been linked to better outcomes (Soliday, Kool, & Lande, 2000).

Identification of the attributes of a resilient family is the first step towards providing interventions to ameliorate stress in families of chronically ill children. Clinic screenings could help identify families that may benefit from interventions aimed to decrease family conflict and increase family cohesion and expressiveness. Facilitation of communication and parenting skills to strengthen the bond between the parent and child (e.g., through parent training interventions; Johnson, Kent, & Leather, 2004) may also be useful.

Social, Community, and Cultural Resilience

Social Support. Peer relationships play a substantial role in the development of resilience in youth with chronic health conditions. First, *friendships* can protect against some of the challenges faced by these youth. Although recent research has been less conclusive (Palladino & Helgeson, 2012), it has generally been found that youth who experience more social support and engage in less peer conflict are better able to manage health-related self-care tasks (Helgeson, Lopez, & Kamarck, 2009; La Greca, Bearman, & Moore, 2002). For instance, the friends of a child with diabetes may encourage healthier food choices and provide emotional support for diabetes-related challenges. Children are more likely to complete health-related self-care tasks when they perceive that their efforts are supported by their peers (La Greca et al., 2002). Peer support has also been associated with fewer emotional and behavior problems (e.g., in youth with cancer; Feragen, Kvalem, Rumsey, & Borge, 2010).

Second, inclusion of peers in interventions aimed at increasing medical adherence and promoting adjustment to chronic illness has also yielded promising results. Peer-involved group therapy intervention programs, aimed at improving disease knowledge and management and increasing social support, have been studied among youth ages 10–18 with asthma (Shah et al., 2001) and type 1 diabetes (Greco, Pendley, McDonell, & Reeves, 2001). These studies found that youth who participated in group interventions with their friends reported increased quality of life, greater proportion of peer support relative to family support, lower school absenteeism, fewer illness exacerbations, and increased illness-related knowledge (Greco et al., 2001; Shah et al., 2001).

There is also evidence to suggest that youth may benefit from interactions with other children and adolescents with shared health conditions (e.g., HIV; Funck-Brentano et al., 2005) or chronic illnesses in general (Olsson, Boyce, Toumbourou, & Sawyer, 2005). For example, pediatric health-related camps allow children and adolescents to communicate about shared experiences, practice independence skills, increase health-related knowledge, and make supportive friendships with similar peers (Holbein et al., 2013; Odar, Canter, & Roberts, 2013). Social media platforms and online support groups are additional outlets that may foster peer support for youth living with chronic health conditions (Letourneau et al., 2012; Quittner et al., 2012).

Community Support. Community factors also contribute to resilience in pediatric populations. Participation in adaptive sports and organized activities provides numerous benefits for the emotional, social, and physical well-being of youth with chronic health conditions (Murphy & Carbone, 2008). Further, access to specialty medical care also has clear implications for resilience in pediatric populations (Newacheck, Hung, & Wright, 2002). Unfortunately, availability of appropriate services is often impacted by sociocultural vulnerability factors, including low socioeconomic status, rural living environment, single-parent households, and ethnic minority status (Bauman, Silver, & Stein, 2006; Murphy & Carbone, 2008; Newacheck et al., 2002; Seid, Opipari-Arrigan, & Sobo, 2009). Although access to health insurance has previously been identified as an obstacle for many youth in the United States (Newacheck et al., 2002), the Children's Health Insurance Program Reauthorization Act of 2009 (CHIPRA; Pub L No. 111-3) and the Patient Protection and Affordable Care Act of 2010 (ACA; Pub L No. 111-148) have succeeded in improving access to insurance, enhancing insurance benefits, and allowing for receipt of appropriate medical services for millions of children with special health care needs (Committee on Child Health Financing, 2014).

Culture and Spirituality. Youth with chronic health conditions and their families can derive additional benefits from cultural and spiritual practices. Prayer, meditation, and healing rituals can provide comfort and strength when a child is experiencing significant health-related stress (Rolland & Walsh, 2006). In fact, recent research suggests that adolescents' utilization of positive spiritual coping techniques may protect against development of depressive symptoms (Reynolds, Mrug, Hensler, Guion, & Madan-Swain, 2014). Building on cultural strengths and diversity allows for the establishment of rapport and collaboration between medical practitioners and pediatric patients, resulting in a more specialized, empowering treatment plan (Hilliard, Ernst, Gray, Saeed, & Cortina, 2012). Within the medical setting, positive outcomes can be attained when the medical team aims to establish a collaborative relationship with families that respects unique cultural beliefs and practices (Rolland & Walsh, 2006). For practice-relevant suggestions to help medical practitioners to build these collaborative partnerships see Munford, this volume.

Intervening to Promote Resilience

Medical practitioners play an important role in facilitating understanding of how a child's chronic illness may, or may not, be impacting a child's development. Clinical interventions can help build resilience by creating a therapeutic collaboration that is designed to utilize and build upon families' existing strengths and abilities across multiple systems (Luther, 1991; Masten, Best, & Garmezy, 1990; Shapiro, 2002). These interventions can teach children and their families how to manage the demands of a chronic illness while also navigating the dynamic transition to adolescence.

A *first step* in identifying what intervention will be most appropriate for a family is to accurately identify their resilience factors as well as barriers. Assessment of resilience involves conceptualizing individual families with a strengths-based approach to the assessment of developmental challenges (Shapiro, 2002). This can be achieved by interviewing families and asking questions to assess the areas of resilience previously mentioned. There are also screeners and measures that have been developed to quickly identify areas of resilience. For example, the Adolescent Resilience Questionnaire (ARQ; Gartland, Bond, Olsson, Buzwell, & Sawyer, 2011) assesses the strengths within the adolescent, family, peer group, school, and community, and was developed with adolescents with chronic illnesses. Example items from the ARQ include "I feel confident that I can handle whatever comes my way" and "There is someone in my family I can talk to about anything" (Gartland et al., 2011). The Haase Adolescent Resilience in Illness Scale (HARS; Haase, 2004) is a single factor scale consisting of 13 items that measure how children with cancer feel or think about managing their health since diagnosis. Family measures are also important, such as the CHIP (McCubbin et al., 1983), a parent self-report inventory that includes 45 behaviors that one might use to cope with a child's chronic illness. Although more research is needed on the psychometric properties of resilience measures, there are multiple reviews on current existing measures (e.g., Alderfer et al., 2008; Blount et al., 2008; Hall, 2010; Windle, Bennet, & Noyes, 2011).

In addition to developing and building upon resilience, clinical interventions can identify barriers that may be disrupting the path to healthy development. Barriers can vary in their nature and seriousness, are multifaceted, and can be related to pragmatics, health beliefs, expectations, skills and knowledge, and/or marginalization. Examples include high costs, misunderstanding the course of a disease, negative expectations of encounters with the health care system, lack of knowledge about care availability, or feeling that a previous bad experience was a personal affront (Seid, Sobo, Zivkovic, Nelson, & Davodi-Far, 2003). As with resilience, most barriers can be identified through an interview with families. There is a pressing need for the development of a validated measure of barriers to care (Seid, 2008). More importantly, there is a need for validated measures that can assess both barriers and resilience factors, in order to aid clinicians in conceptualizing families.

Interventions aimed at promoting resilience and positive child and family outcomes may strive to help families identify positive coping skills, enhance family functioning, and access resources. Interventions may also target parent mental health, parenting behaviors, and/or sibling adjustment as a means to improve the well-being of families and improve child health outcomes. For example, the Child Illness and Resilience Program (CHiRP), based in Australia, is a stepped-care mental health promotion intervention guided by a family resilience framework and designed to support families with a chronically ill child (Harnall, Heard, Inder, McGill, & Kay-Lambkin, 2014). CHiRP aims to help families identify existing strengths and provide strategies to target protective factors and processes that enhance family resilience, such as coping skills, family functioning, and social support. Specific components include providing families with literature on psychoeducation and practical resilience building strategies, facilitating the completion of family-based cognitive-behavioral exercises, and offering parent support groups (Harnall et al., 2014).

In addition to CHiRP, there are other interventions designed for families of youth with chronic illnesses that aim to positively impact parent behavior, mental health outcomes, and child symptoms and behavior (Law, Fisher, Fales, Noel, & Eccleston, 2014). Although these interventions may not be labeled as "resilience" interventions, many utilize a strengths-based approach and aim to improve child, parent, and family outcomes. For example, a recent systematic review and meta-analysis of such interventions found that those that incorporated Problem-solving Therapy demonstrated the greatest positive effects on parental mental health and behavior (Law et al., 2014). In addition, because siblings of chronically ill children are at a greater risk of adjustment difficulties for reasons mentioned previously, it is recommended that siblings be included in family interventions and provided with opportunities for special support, such as through participation in sibling support groups.

Successful interventions are those that focus on the family's view of the problem, validate their adaptive strategies for managing developmental stress, and provide perspective on and alternatives for their maladaptive strategies. To increase the opportunity for success, clinicians should work with families to set intervention goals that are realistic and attainable. Emphasizing families' strengths will increase feelings of self-efficacy, which will also aid in helping families to meet their goals

(Shapiro, 2002). The most successful interventions will also be those that promote effective communication. Miscommunication and misunderstanding of an individual's needs and perspectives is common within families during the transition to adolescence. Interventions focused on communication improvement will facilitate increased mutual understanding and support among family members. Miscommunication is also common between families and the health care system. Working with both providers and families on communication will encourage optimal outcomes (Seid et al., 2009).

The Role of Medical Practitioners

The emphasis on interdisciplinary and integrated health care teams is accelerating (Stancin & Perrin, 2014). The family of a child with a chronic illness will interact with multiple health care providers that are involved in their care, including general and specialist physicians, surgeons, nurses, psychiatrists, psychologists, social workers, physical therapists, occupational therapists, and other behavioral medicine specialists. This interdisciplinary approach requires that these medical practitioners collaborate in care conceptualization, treatment planning, and decision-making. For more on the importance of coordinated multisystemic service-provision, see Ungar, this volume. The family's interaction with each of these practitioners is an opportunity to build resilience through educating and empowering families (Seid et al., 2009). It is important that medical practitioners working with families of chronically ill children remain mindful of the culture of the health care system and be aware that each family faces unique challenges when navigating the system (Seid et al., 2009). The culture of the health-care system includes its social structure, economic implications, and belief systems (Shapiro, 2002). Furthermore, a large responsibility of medical practitioners working with chronically ill children is to assist families with the transition to adult health care. This responsibility currently tends to fall on pediatric specialists; however, for a smooth transition, collaboration with adult providers is critical (Pai & Schwartz, 2011).

Conclusion

The present chapter has identified multiple areas in need of additional research. One such area is measurement development and validation. Although resilience measures exist, their psychometric properties need to be examined within various pediatric populations and among children at different developmental stages. In addition, there is a need for measures that can assess both resilience factors and barriers, as evaluating both of these areas is important when working with families. Importantly, more research needs to be done on how medical practitioners of various disciplines can each contribute to promoting resilience in families of youth with chronic illnesses. As stated previously, these families interact with numerous practitioners in the health care setting. It is critical to better understand how particular practitioners can play unique and important roles in building resilience. For example, a pediatric mental health professional may be the practitioner directly implementing a family resilience-promoting intervention, but there may be ways in which physicians and/or nurses can help reinforce learning and behavior change. Research is needed on what practitioners are currently doing to promote resilience, and what new strategies they can implement.

Pediatric chronic illness presents families with numerous challenges and stressors, and each family responds to these challenges with a unique set of strengths (Compas et al., 2012). Understanding these strengths and challenges from a developmental perspective allows for the recognition of both individual and shared experiences of the development of a chronically ill child or adolescent. The transition from childhood to adolescence may be a particularly challenging time for families of children with a chronic illness, as this developmental period is marked by rapid changes related to biological, cognitive, social, and emotional functioning (Susman & Rogel, 2004). Thus, it is important that medical practitioners working with such families have an understanding of the impact of chronic illness on children's transition to adolescence. Through identifying and problem-solving challenges, and building upon existing strengths, medical practitioners can help families promote resilience and reach optimal child and family outcomes.

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Chapter 5
Resilience in Pediatric Sickle Cell Disease and Cancer: Social Ecology Indicators of Health-Related Quality of Life

Katherine S. Salamon, Lisa A. Schwartz, and Lamia P. Barakat

Introduction

Promoting resilience for children and adolescents with chronic health conditions is the current focus of clinical practice and research for pediatric psychology. For decades, a deficit model dominated, in which the expectation was that youth and families would experience negative short- and long-term physical and psychosocial consequences of chronic health conditions. However, studies document variability in adaptation, and resilience is common. Recent research aims to identify the specific risk and resource factors that contribute to particular psychosocial outcomes and to develop and implement targeted and effective interventions to improve resilience. Resilience has been defined as an individual's ability to persevere in the face of a challenge, including a physical illness (Stewart & Yuen, 2011). For this chapter, we use health-related quality of life (HRQL) as the indicator of resilience. HRQL is the youth's and/or caregiver's perception of functioning/adaptation across multiple domains (e.g., physical, social, emotional, and school) and is an indicator of resilience. Research has supported HRQL as a factor linked to resilience in the context of physical well-being (Stewart & Yuen, 2011). For example, a youth with cancer who is able to manage treatment and side effects with the help of family which facilitates continued engagement in school and peer activities. Pediatric cancer and pediatric sickle cell disease (SCD) have strong literature bases in pediatric psychology and serve as excellent examples of risk and resource factors associated with HRQL for children and adolescents with chronic health conditions.

K.S. Salamon, Ph.D. (✉)
Nemours/Alfred I. duPont Hospital for Children, Wilmington, DE, USA
e-mail: Katherine.Salamon@nemours.org

L.A. Schwartz, Ph.D. • L.P. Barakat, Ph.D.
The Children's Hospital of Philadelphia, University of Pennsylvania School of Medicine, Philadelphia, PA, USA
e-mail: schwartzl@email.chop.edu; barakat@email.chop.edu

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Cancer and sickle cell disease as exemplar pediatric diagnoses. According to the National Cancer Institute (2014), over 15,000 children and adolescents are diagnosed with cancer each year. Acute lymphoblastic leukemia is the most common form of pediatric cancer, with brain tumors following as the second most common form. Although survival rates are approximately 80 %, youth diagnosed with and surviving pediatric oncology are often faced with short- and long-term physical, cognitive, social, and psychological consequences of diagnosis and treatment—treatment that includes intensive chemotherapy, surgical resection, and radiation. Risk for physical side effects (e.g., pain, fatigue, nausea) and functional disability are high while children are on active treatment. Although decreased HRQL may be observed during active treatment, HRQL tends to improve throughout treatment (Vannatta, Salley, & Gerhardt, 2009); late effects that emerge after treatment (e.g., cardiac toxicity, neurocognitive deficits, short stature) may affect development and HRQL into adulthood (Vannatta et al., 2009), however, survivors experience relatively positive outcomes (Barakat, Pulgaron, & Daniel, 2009).

SCD is a chronic, inherited disorder that affects the ability of the red blood cells to properly oxygenate the body. Although it affects multiple ethnic groups worldwide, SCD is most prevalent in the United States among people of African descent. Approximately 1 in every 400–500 African American infants is diagnosed with SCD (National Heart, Lung, and Blood Institute NHLBI, 2002). Complications include anemia, vaso-occlusive episodes, stroke, gallstones, jaundice, and acute chest syndrome. Treatments for SCD, such as hydroxyurea or blood transfusions, target pain management, infection reduction, increased functionality, and reducing risk of further complications. There is no known cure for SCD, aside from a bone marrow transplant, for which a limited subgroup is eligible (NHLBI, 2002). The irregular, unpredictable pattern of the pain episodes and complications is one important aspect that place children and adolescents with SCD at risk for poor psychosocial adaptation and decreased HRQL (Barlow & Ellard, 2006). HRQL of children with SCD is consistent with levels reported by youth with other chronic health conditions and lower than HRQL reported by their siblings and healthy peers (Palermo, Schwartz, Drotar, & McGowan, 2002).

In most pediatric medical settings, children with cancer and children with SCD are treated within the same department. Physicians, nurses, and other health care providers are trained in pediatric hematology/oncology as part of their specialty training. Moreover, the preponderance of childhood cancer diagnoses, such as leukemias, are hematological in nature (American Cancer Society, 2014). Thus, these diseases share characteristics and treatments. Yet, differences include known genetic bases, approaches to treatment (with the exception of blood transfusions and transplant), and sociodemographic factors (e.g., socioeconomic status, ethnicity, racial identity, health care access, culture). While both cancer and SCD are life-threatening, there is typically a greater sense of urgency to cancer treatment given the immediate life-threat. Similarities and differences allow for generalizations to other chronic health conditions.

Theoretical Frameworks. Wallander and Varni (1998) developed the Risk and Resistance Model to provide a theoretical framework for understanding how various

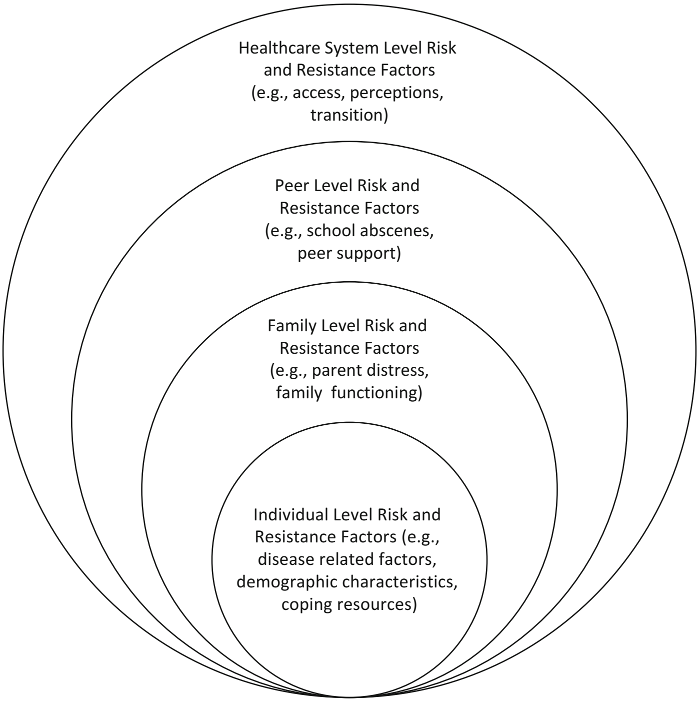

Fig. 5.1 Social-ecological model applied to pediatric cancer and pediatric sickle cell disease

risk and resistance factors interact to account for the variation in adaptation. Risk factors include characteristics of the illness (e.g., severity and complications) and psychosocial stressors (e.g., socioeconomic status and other major life events). Resistance factors are comprised of stress processing variables with coping strategies, intrapersonal characteristics and social-ecological components or the family and social environment. The Social-Ecological Model (Bronfenbrenner, 1979) applied to pediatrics (Kazak, Segal Andrews, & Johnson, 1995) takes into account multiple systems including culture and developmental change over time in exploring and promoting HRQL. At the core of the social ecology model is the child surrounded by the microsystem (family, peers, school), mesosystem (relationships and interconnections), exosystem (neighborhood, parent's workplace), and macrosystem (health care system, laws, culture). Risks and resources proposed in the Risk and Resistance Model can be mapped onto the child's social ecology (Fig. 5.1).

In this chapter, we describe risk and resource factors associated with HRQL and associated interventions within the social-ecological framework for both pediatric cancer and pediatric SCD. At the individual level, risk and resource factors associated with the chronic health condition, demographic factors, coping strategies, and disease knowledge are explored as factors that influence perceptions of physical and psychosocial HRQL. Within the family system, factors and interventions targeting caregiver resources/support and family functioning are presented. Peer functioning, social support, and school attendance are investigated within the risk and resistance framework to understand for both cancer and SCD. On the social level, HRQL surrounds resources, policies, and practices that influence perception of health (CDC, 2011). Health care access, clinician perceptions, and transition are reviewed at the health care systems level.

Individual Level Risk and Resistance Factors and Interventions

Cancer. Historically, a diagnosis of cancer was expected to lead to psychopathology (e.g., depression and anxiety) and significant deficits in functioning, but few studies show psychopathology as a common outcome. As such, there has been a shift in research focusing on resilience in adaption and HRQL, and characterizing the minority of patients and families at risk for long-term adverse adjustment (Patenaude & Kupst, 2005). Specific risk and resource factors have been identified as cumulative risk factors related to worsening outcomes, including individual level disease/treatment factors (diagnosis, type/intensity of treatment), demographic factors (age), and psychological characteristics (e.g., temperament, behavior, coping; pre-existing psychiatric diagnoses) (Kazak et al., 2012). However, the research is not yet definitive about the most harmful or disadvantageous risk factors and the optimal resources (see Table 5.1 for summary).

Disease/treatment factors confer risk for patient adaptation. Children with bone cancers and cancers with central nervous system involvement, especially brain tumors, often lead to worse HRQL than other diagnoses and children who are treated with a hematopoietic stem cell transplant (Langeveld, Stam, Grootenhuis, & Last, 2002; Maunsell, Pogany, Barrera, Shaw, & Speechley, 2006) are at risk for more limitations in HRQL because these diagnoses and treatments are most intense and can lead to functional disability due to cognitive deficits (e.g., brain tumors) and/or significant restrictions in immunosuppression. Adolescents with cancer typically have worse HRQL relative to norms and younger patients because their treatment is often more intense than younger patients, they experience more toxicity and morbidity, and they are less able to engage in typical adolescent developmental tasks such as building autonomy and forging social relationships (National Institutes of Health, National Cancer, & Young Adult Alliance, 2006; Smith et al., 2013). Diagnosis in adolescence relates to worse long-term psychosocial outcomes in survivors relative to those diagnosed at younger ages (Kazak et al., 2010).

Socioeconomic status and culture may impact the family's adjustment, especially that of the parents. Family socioeconomic status has been shown to impact adjustment (Kazak et al., 2012) but this, too, is complex. For example, single mothers have been shown to adapt worse, but this may be confounded by education (Iobst et al., 2009) or income (Mullins et al., 2011). Broader sociocultural factors may influence communication style, discussion of diagnosis/prognosis, coping styles, support, and prioritization of health-related and other goals (Schwartz &

Table 5.1 Summary of risk/resilience factors and interventions for individual level

Risk and resilience factors	Intervention
Cancer	
Demographic	
Kazak et al. (2012)	
Vrijmoet-Wiersma, et al. (2008)	
Coping strategies/appraisals	Osborn et al. (2006): *CBT*
Kazak et al. (2012)	
Vrijmoet-Wiersma et al. (2008)	
Adherence	*Survivor recommendations*
Hullman, Brumley, & Schwartz (2015)	
	Tercyak et al. (2006)
Disease process(es)/knowledge	Bakitas et al. (2009): *Problem-solving intervention*
Penn et al. (2010)	
Kazak et al. (2010)	Stuber et al. (2006)
	Kazak et al. (2005): *SCCIP*
Sickle cell disease	
Risk and resistance factors	*Intervention*
SCD complications	
Dampier et al. (2010)	
Panepinto and Bonner (2012)	
Demographic characteristics	
Palermo et al. (2002)	
Panepinto and Bonner (2012)	
Robinson et al. (2014)	
Coping strategies/appraisals	*CBT pain coping*
Ziadni et al. (2011)	Barakat, Schwartz, et al. (2010)
	Gil et al. (2001)
	Masuda et al. (2011)
	Powers et al. (2002)
Self-esteem/racial identity	
Lim et al. (2012)	
Simon et al. (2009)	
Adherence	Crosby et al. (2012)
Ziadni et al. (2011)	Modi et al. (2012) (web-based assessment for adherence)
Internalizing symptoms	
Brown et al. (1993)	
Hijmans et al. (2009)	
Midence et al., 1996	
SCD knowledge	*Family psychoeducational intervention*
Logan et al. (2002)	Hazzard et al. (2002)
	Kaslow et al. (2000)

Drotar, 2006; Thibodeaux & Deatrick, 2007). Language barriers and coming from another country also likely contribute to adaption and resilience in the face of cancer by limiting understanding of the diagnosis and treatment, undermining the ability to access resources and support in the hospital and in the community, and increasing stress related to disruptions in daily life, their social networks, and the ability to care for other children who remain in their home country (Crom, 1995; Martinson et al., 1999). Stigma is another factor related to culture that may result in misperceptions of the pediatric patient or family and create challenges to communication in the health care system (Jenerette & Brewer, 2010). For more on cultural stigma and resilience see Yi et al., 2016.

Results are mixed on the role of coping in adaptation to pediatric cancer. Research in earlier decades, including a longitudinal cohort study, found no consistent patterns of coping to predict adaptation (Patenaude & Kupst, 2005), and a recent study found that disease status is not associated with coping (Mullins et al., 2011). However, a more recent study found that coping was clearly related to outcomes in adolescents; in particular, worry was related to defensive coping and problem-focused and cognitive coping related to resilience (Wu, Sheen, Shu, Chang, & Hsiao, 2013). An example of a more complex relationship between coping and outcomes is highlighted by a study of mothers reporting on their children with cancer in which primary control coping moderated and mediated the relationship between negative affect and depression (Miller et al., 2009). Others have hypothesized that the general resilience of youth with cancer is partially due to adoption of a repressive coping style (Patenaude & Kupst, 2005). Similarly, optimism (Williams, Davis, Hancock, & Phipps, 2010) and ability to bounce back after adversity (Harper et al., 2014) have been shown to relate to resilience.

Research has shown the potential for enhanced coping abilities, motivation, and posttraumatic growth (PTG), or the process of applying positive interpretations and finding meaning in a traumatic event, among patients and family members (Barakat, Alderfer, & Kazak, 2006; Zebrack et al., 2012). Barakat et al. (2006) found that adolescent survivors identified positive consequences of their cancer in the domains of self, relationships, and future plans. Another study found that survivors were more likely to report perceived positive impact (PPI) of cancer than siblings (Zebrack et al., 2012). Thus, interventions to enhance perceived positive meaning and reduce the negative impact are indicated.

Universal psychosocial care for patients and their families may promote strengths and resources and reduce the distress, ultimately preventing the need for more intensive services. This generally includes screening at diagnosis and ongoing assessment to identify general psychosocial factors (e.g., coping and adjustment, emotional and financial resources) that may influence adaptation of the patient and family at diagnosis and throughout the course of treatment (Noll et al., 2013). The Psychosocial Assessment Tool (PAT), assessing sociodemographic, child behavior, and family risks and resources, may be helpful in identifying families that need more intensive behavioral interventions (Pai et al., 2008). Universal care includes educational materials and access to resources in the hospital such as child life specialists, teachers, and chaplains, along with programs consistent with family centered care.

The Medical Traumatic Stress Toolkit is an example of an evidence-based resource intended for use by health care providers to deliver care in a way that promotes adaptive psychosocial outcomes by reducing the likelihood of ongoing traumatic stress responses (Stuber, Schneider, Kassam-Adams, Kazak, & Saxe, 2006). The toolkit includes guidelines on providing trauma-informed care for health care providers, training materials including examples of trauma-informed care, and educational handouts for children and their parents on medical traumatic stress in both English and Spanish.

About a quarter of families of newly diagnosed children require more intensive psychosocial interventions at diagnosis and/or during treatment (Schwartz, Kazak, & Mougianis, 2009). Most evidence-based treatments to date include interventions for traumatic stress and procedural distress. Of note is an intervention targeting procedure-related anxiety and fear (Shockey et al., 2013) that utilized biofeedback and a sense of perceived control to increase solution-focused coping. Virtual reality has been utilized as a distraction technique during procedures to reduce pain and overall distress (Nilsson, Finnstrom, Kokinsky, & Enskar, 2009) by allowing youth to engage in a virtual reality scene that engages multiple sensory modalities and diverts attention away from the procedure. In general, cognitive behavioral (Kendall, 2006) and family therapy (Diamond & Josephson, 2005) approaches can be adapted for use in cancer to target beliefs associated with control, worry, and illness uncertainty.

SCD. Parallel with previous research on cancer, early reports of the association of SCD factors in the adaptation of children and adolescents with SCD focused on the link between stressors associated with having a chronic health condition and internalizing and externalizing behavior problems (Hurtig & White, 1986); although research has now broadened to evaluate individual, social, and family risk factors as well as resiliencies, subsequent studies have shown that SCD complications or disease severity (particularly pain, fatigue, and stroke) is consistently associated with individual risk factors (i.e., internalizing symptoms) and HRQL outcomes (Palermo et al., 2002; Panepinto & Bonner, 2012; see Table 5.1 for summary). For example, a youth with a previous history of stroke as well as more frequent vaso-occlusive (or pain) episodes tend to report more symptoms of depression and anxiety and lower perceived adaptation to the illness.

Beyond SCD complications, identified individual (or micro level) risk and resource factors for children and adolescents with SCD can be conceptualized as demographic characteristics (e.g., age [older], gender [female]), environmental characteristics (e.g., socioeconomic status, neighborhood distress) (Palermo et al., 2002), and (potentially modifiable) psychological characteristics (e.g., SCD knowledge, self-esteem/racial identity, pain coping strategies). Challenges to HRQL related to demographic and socioeconomic risk factors have been a particular focus of inquiry given that most youth with SCD in United States are of ethnic minority status. It is well established that demographic and socioeconomic factors place children and adolescents with SCD at risk for poorer HRQL (Karlson et al., 2012; Panepinto & Bonner, 2012). Mechanisms for this effect have received less attention, but recent studies suggest that reduced access to health care, insurance status (private/public), and health literacy limitations likely play a role (Robinson, Daniel, O'Hara, Szabo, & Barakat, 2014; Shook, Crosby, & Atweh, 2013).

Specific psychological factors associated with HRQL have been evaluated but with less consistent findings. Most frequently, internalizing symptoms (anxiety, depression) are hypothesized as risk factors, and SCD knowledge, active pain coping, and optimism/positive attributional style are considered resources (Brown et al., 1993; Simon, Barakat, Patterson, & Dampier, 2009; Ziadni, Patterson, Pulgaròn, Robinson, & Barakat, 2011). Regarding internalizing symptoms, some studies suggest higher levels of anxiety and depression for children and adolescents with SCD compared to siblings (Brown et al., 1993; Hijmans et al., 2009) or norms (Benton, Boyd, Ifeagwu, Feldtmose, & Smith-Whitley, 2011) while others report no differences or normative functioning (Gold, Mahrer, Treadwell, Weissman, & Vichinsky, 2008; Midence, McManus, Fuggle, & Davies, 1996; Simon et al., 2009). Regarding SCD knowledge, Logan, Radcliffe, and Smith-Whitley (2002) found that parent SCD knowledge served as a resource factor that was associated with routine health care utilization. Studies suggest that self-esteem and active coping for children and adolescents with SCD are consistent with levels reported by their peers (Gold et al., 2008; Midence et al., 1996); in turn, self-esteem, positive attributional style, and optimism are associated with reduced risk for internalizing symptoms (Brown et al., 1993; Simon et al., 2009; Ziadni et al., 2011). For example, Ziadni et al. (2011) demonstrated that HRQL was associated with higher adaptive behavior in the context of hopeful appraisals for adolescents with SCD. Similar to findings supporting positive self-esteem as a resource (Simon et al., 2009), recent research notes that high regard for racial identity (i.e., more positive views of self in terms of race) moderated the association of pain with physical HRQL and was directly correlated with better social HRQL (Lim, Welkom, Cohen, & Osunkwo, 2012).

As in pediatric cancer, psychosocial screening of family risks and resources can be a useful first step to providing targeted interventions. There is evidence for the reliability of the Psychosocial Assessment Tool (PAT) in an initial study with a pediatric sickle cell sample (Karlson et al., 2012). Importantly, Karlson et al. (2012) indicated that most families reported low risk and high resources; caregivers also endorsed low distress, high confidence in their ability to manage SCD, and high confidence in their child's health care teams. Areas of risk included older child age, lower family socioeconomic status, and single parent household.

The primary target of interventions at the individual level for SCD is pain coping either individually (Gil et al., 2001; Masuda, Cohen, Wicksell, Kemani, & Johnson, 2011; Powers, Mitchell, Graumlich, Byars, & Kalinyak, 2002) or in a family context (Barakat, Schwartz, Salamon, & Radcliffe, 2010). Although results of these studies are inconsistent, overall, cognitive behavioral interventions for pain in pediatric SCD are considered promising and potentially effective (Chen, Cole, & Kato, 2004). Core components of cognitive behavioral pain interventions include training in relaxation, guided imagery, and positive coping self-statements. In a single case design, Masuda et al. (2011) failed to show effects on pain using acceptance and commitment therapy for an adolescent with SCD. Barakat, Schwartz et al. (2010)

were unable to identify significant effects of a cognitive behavioral pain intervention delivered to adolescents with SCD and a caregiver when compared to a control group that received disease education. In contrast, Gil et al. (2001) cognitive behavioral intervention was associated with lower health care utilization, fewer missed days of schools, and higher functional ability when pain coping skills were practiced on a daily basis. Others have replicated the effectiveness of cognitive behavioral pain interventions for managing SCD pain and improving daily functioning (Powers et al., 2002). For more on the use of Acceptance and Commitment Therapy in fostering resilience, see Ernst and Mellon, this volume. Additionally, studies have reported increased SCD knowledge when the intervention includes SCD education, through an interactive game (Hazzard, Celano, Collins, & Markov, 2002) and through a family intervention (Kaslow et al., 2000).

Family Level Risk and Resource Factors and Interventions

Cancer. Evidence supports parenting styles, parent functioning, and family functioning—including open and supportive communication—as resources (Kazak et al., 2012); parental distress, including acute stress, depression, anxiety, and poor parent HRQL, at diagnosis are well established as risk factors for poor outcomes for youth and families (Eiser, Eiser, & Stride, 2005; Sloper, 2000; see Table 5.2 for summary). Families with higher cumulative psychosocial risk at diagnosis tend to have higher distress 4 months after diagnosis and to use more services (Alderfer et al., 2009). However, most studies show that within 6–12 months after diagnosis, distress tapers off for most families (Pai et al., 2008), and reducing parent distress has been shown to improve the well-being of the child (Fedele et al., 2013).

Building on the established link between parent and child outcomes, recent research has focused on more discrete parent, family, and environmental variables and their interaction with child outcomes (Hullmann, Wolfe-Christensen, Meyer, McNall-Knapp, & Mullins, 2010). One study found that parent–child relationship quality, and role functioning within the family, was more related to HRQL in adolescents on treatment than demographic and treatment variables (Barakat, Marmer, & Schwartz, 2010). Another study reported that the association between father and child distress was dependent on the family environment, but the same finding was not true for mothers, highlighting the importance of assessing fathers and considering different interactions that relate to resilience (Robinson, Gerhardt, Vannatta, & Noll, 2007). Perceived child vulnerability from the mother’s perspective has also been shown to relate to worse child outcomes (Colletti et al., 2008) and to mediate the relationship between parental overprotection and child HRQL (Hullmann et al., 2010). Parenting stress, parental overprotection, and perceived child vulnerability relate to different child outcomes across these studies indicating the need for prospective research to untangle these important family risk factors. For more on the role of parents for promoting children’s adjustment to chronic illness see Hohen et al., this volume.

In pediatric cancer, intervention research at the family level is limited. The Surviving Cancer Competently Intervention Program (SCCIP) is an intervention that combines cognitive behavioral and family therapy approaches to reduce ongoing traumatic stress symptoms in cancer survivors and their families. SCCIP was tested in a randomized controlled trial of 150 families in which family members in SCCIP showed reductions in traumatic stress symptoms (Kazak et al., 2004). SCCIP was adapted for newly diagnosed parents with some promising results (Kazak et al., 2005); however, recruiting and adhering to protocol proved to be difficult at the time of cancer diagnosis (Hocking et al., 2014; Stehl et al., 2009). Also, a small study testing cognitive behavior therapy for parent distress was found to be effective (Warner et al., 2011).

SCD. Among family risks and resources in pediatric SCD, parent social support, parent problem-solving skills, and parent/family functioning are resources (Barakat, Daniel, Smith, Robinson, & Patterson, 2014; Midence et al., 1996; Raphael et al., 2013) and disease-related parenting stress is consistently identified as a risk factor (Cousino & Hazen, 2013; see Table 5.2 for summary). Parents of children with

Table 5.2 Summary of risk/resilience factors and interventions for family level

Risk and resistance factors	Intervention
Cancer	
Resources	*Recommended tailoring to cultural and family risks and resources*
	Schwartz et al. (2007)
Family distress/support	Kazak et al. (2005): *Parents of newly diagnosed*
Eiser et al. (2005)	Waldron et al. (2013): *Problem-solving and communication*
Sloper (2000)	Docherty et al. (2013) *Parental meaningfulness*
Hullmann et al. (2010)	
Sickle cell disease	
Risk and resistance factors	*Intervention*
Parent perceived social support	*Recommended tailoring to cultural and family risks and resources*
Raphael et al. (2013)	Schwartz et al. (2007)
Disease-related parenting stress	
Barakat et al. (2008)	
Beyer and Simmons (2004)	
Panepinto and Bonner (2012)	
Raphael et al. (2013)	
Parent problem-solving abilities	*Family-problem-solving skills intervention*
Barakat et al. (2014)	Daniel et al. (2015)
Family functioning	*Family functioning*
Brown et al. (1993)	Barakat, Marmer, et al. (2010)
Kell et al. (1998)	Chernoff et al. (2002)
Midence et al. (1996)	Kaslow et al. (2000)

chronic health conditions, including SCD, report higher disease-related parenting stress than stress reported by parents of healthy children (Cousino & Hazen, 2013). Higher disease-related parenting stress may be associated with the nature of management of SCD complications (Barakat, Patterson, Tarazi, & Ely, 2007), in which most pain is managed at home (Shapiro et al., 1995). Although parents in Karlson et al.'s (2012) study were confident in their ability to manage SCD, Beyer and Simmons (2004) reported in their qualitative study that parents of children with SCD are strained by efforts to manage pain at home, and parents perceive most home management techniques to be inadequate. Panepinto and Bonner (2012) noted an association of disease-related parenting stress with poorer HRQL. For example, Barakat, Patterson, Daniel, and Dampier (2008) documented a direct association of disease-related parenting stress with HRQL and an indirect effect in that disease-related parenting stress mediated the association of pain with HRQL for adolescents with SCD. Raphael et al. (2013) evaluated the roles of SCD knowledge, health literacy, health care motivation, and disease-related parenting stress in health care utilization for children with SCD. Findings of this cross-sectional survey indicated that parents with higher satisfaction with social support were more likely to use routine health care services for their child with SCD, while parents with higher disease-related parenting stress had higher health care utilization rates. Additional evidence of the importance of parent factors for HRQL among children with SCD comes from a study finding positive parent problem-solving abilities served as a moderator of the association of SCD complications with HRQL (Barakat et al., 2014). Problem-solving represent parent confidence in their ability to solve problems, active engagement in seeking and implementing solutions, and willingness to reevaluate and try new strategies to bring problem resolution. Further, Kell, Kliewer, Erickson, and Ohene-Frempong (1998) reported that adolescents with SCD with higher family functioning had lower levels of anxiety and depression.

Intervention researchers have noted that considering key cultural and family factors is critical to tailoring interventions for children and adolescents with SCD and their families by reducing barriers to access, addressing multiple parent and family stressors that may reduce engagement, and tailoring content to recognize the strength of the African-American family and to reflect their cultural contexts (Schwartz, Radcliffe, & Barakat, 2007). For a strengths-based perspective on culturally competent service provision see Munford, this volume. Demonstrating the importance of tailoring, Chernoff, Ireys, DeVet, and Kim (2002) tested a community-based family intervention for children with chronic health conditions including SCD (delivered in homes or in community with an "expert parent" plus a child life specialist); compared to a group who received only telephone access to an "experienced parent," the intervention group endorsed higher child adjustment post-intervention. Similarly, in a randomized controlled trial delivered in family homes, Barakat, Schwartz, et al. (2010) documented improved family functioning in both the family-based, the cognitive behavior pain intervention group and the disease education control group. In contrast, in their pilot study, Kaslow et al. (2000) found that a family psychoeducational intervention resulted in improved SCD knowledge, but not improved family functioning. Further underscoring the challenges of testing family level interventions in pediatric SCD, a randomized trial of a family-based problem-solving intervention to improve HRQL and school functioning among school-age children with SCD found no effects for the intervention in comparison to a delayed intervention control (Daniel et al., 2015) (The intervention was delivered in a multiple group, one-day workshop format; parents and children rated positively in terms of interest and helpfulness, but low participation rate reduced power to test the intervention).

Social Level Risk and Resistance Factors and Interventions

Cancer. High levels of school absenteeism, lower school attainment, and poor social functioning have been reported for children with chronic health conditions generally and for youth with cancer (Kearney, 2008; Noll, Reiter-Purtill, Vannatta, & Gerhardt, 2007, 2010; see Table 5.3 for summary). Presence of a chronic health condition (independent of ethnicity, socioeconomic status, attendance, and grade level) was associated with lower language and math performances (Crump et al., 2013); school attendance was associated with improved grades, increased likelihood to graduate, and decreased criminal activity (Kearney & Graczyk, 2014). Survivors of pediatric cancer miss significantly more school than peers, and although school attendance does increase over time for youth, even while on treatment, lower

Table 5.3 Summary of risk/resilience factors and interventions for social level

Risk and resistance factors	Intervention
Cancer	
Peer support	*Peer support*
Kim and Yoo (2010)	Ellis et al. (2013): “connectivity project”
Zebrack and Isaacson (2012)	Rosenberg et al. (2013)
Williamson et al. (2010)	Gillard and Watts (2013)
School attendance	*School attendance*
Crump et al. (2013)	Kearney and Graczyk (2014)
Sickle cell disease	
Risk and resistance factors	*Intervention*
Social functioning	*Electronic game system with peer interaction*
Hensler et al. (2014)	Hazzard et al. (2002)
Noll et al. (2007, 2009)	
School absences/academic attainment	*Teacher and peer education in schools increases SCD knowledge and reduces absenteeism*
Schatz (2004)	Koontz et al. (2004)
Schwartz, Radcliffe, & Barakat, (2009)	*Pain coping skills/decreased school absences*
Shapiro et al. (1995)	Gil et al. (2001)

HRQL is a risk factor for increased school absenteeism (French et al., 2013; Sandeberg, Johansson, Björk, & Wettergren, 2008). While internalizing symptoms are a risk factor for school absenteeism in the general population (Kearney & Graczyk, 2014), research in pediatric cancer indicates that internalizing symptoms and other emotional functioning is not a predictor (French et al., 2013). Thus, a youth diagnosed with cancer perceived HRQOL is more associated with school attendance as compared to symptoms of depression and anxiety. In addition, youth who perceived more positive relationships with friends also self-report higher scores on a measure of resilience (Kim & Yoo, 2010). However, maintaining and promoting connection may be difficult for youth with cancer-related morbidity (Zebrack & Isaacson, 2012) and treatment-related changes in physical appearance (Williamson, Harcourt, Halliwell, Frith, & Wallace, 2010).

Kearney and Graczyk (2014) emphasized the importance of early identification of those at risk for absenteeism, conducting functional behavioral assessments to determine the core elements related to absenteeism, utilizing empirically supported interventions to address concerns, and monitoring progress throughout the school year. The proposed approach, a response to intervention system to promote attendance, could be beneficial for youth diagnosed with cancer: Targeted intervention to improve the school reentry process may include assistance in maintaining friendships during treatment as well as development and implementation of educational programs for teachers and classmates to provide developmentally appropriate knowledge about cancer, cancer treatment, and how peers can support the youth. One such intervention in Australia, coined the “connectivity project” (Ellis et al., 2013), sought to improve the social connection among youth hospitalized for pediatric cancer treatment via video connections to the classroom. Parents, teachers, and patients reported anecdotal improvements in perceived peer support, peer empathy, and HRQL. Zebrack and Isaacson (2012) indicated that peer support underlies different intervention domains for AYA with cancer, offering youth diagnosed with cancer the opportunity to decrease social isolation associated with treatment, processes emotional concerns related to the diagnosis, gain developmentally appropriate interpersonal interactions, and engage in activities that promote a feeling of normalcy.

SCD. Concerns regarding school absenteeism, lower school performance, and poor social functioning have been identified for children with SCD (Hijmans et al., 2009; Schatz, 2004; Schwartz, Radcliffe, & Barakat, 2009; see Table 5.3 for summary). Using pain diary data, Shapiro et al. (1995) noted pain on 30 % of diary days and school absences on 21 % of school days. Similarly, Schwartz and colleagues reported that adolescents with SCD missed on average 12 % of school days based on pain diary data. Pain, SCD knowledge, and adaptive behavior are associates of school absenteeism in pediatric SCD (Schwartz et al., 2009). Children with SCD have lower academic attainment (defined as children receiving special services and retained in at least one grade) than their demographically matched peers, and pain-related school absences are associated with lower attainment (Schatz, 2004). Importantly, school absenteeism and cognitive dysfunction are linked to problems with social functioning (Hensler et al., 2014). Noll et al. (2007), using peer nomination methods, found that children with SCD were more socially isolated than their peers; these differences were not noted at 2-year follow-up (Noll, Kiska, Reiter-Purtill, Gerhardt, & Vannatta, 2010).

Few school level interventions are reported for children with SCD, and none directly address school absenteeism. Of those in the literature, findings are exploratory with mixed findings. Koontz, Short, Kalinyak, and Noll (2004) reported results of a pilot trial of a school intervention in which routine services were compared with a 1-hour in-service for teachers and staff and a 1-hour in-service for classroom peers. Findings suggested that teachers and peers who participated in the school intervention had greater SCD knowledge than those in the routine services group, and they reported the in-services to be highly satisfactory. Students with SCD who received the school intervention had lower absenteeism. Also, school absenteeism was reduced via an individual level intervention, a cognitive behavioral pain intervention targeting pain coping skills for children with SCD (Gil et al., 2001). In the community, as noted above, Hazzard et al. (2002) reported on a trial of STARBRIGHT World system to help children interact with each other while hospitalized using a game system. Compared to a control group with traditional, face-to-face, verbal education, children with SCD who engaged in the STARBRIGHT World system reported an increase in perceived social support.

Health Care Systems Level Risk and Resistance Factors and Interventions

Cancer. A health care system is the organization of people, facilities, and resources that provide health care services to meet health needs. The majority of recent research in the United States has focused on the affordable health care act and how to promote access to preventative services as well as create medical homes, for safe, collaborative patient-centered care. Diagnosis and treatment of cancer in adolescents and young adults (AYAs) has emerged as a significant area of risk, and intervention, due to the high rate of cancer diagnosis and the lack of infrastructure in community oncology practices (Parsons, Harlan, Seibel, Stevens, & Keegan, 2011). The identified risk factors for delayed treatment and disengagement with clinical trials, thus potentially missed opportunities for more effective treatments, have included older age, lack of health insurance, and treatment by adult (i.e., non-pediatric) oncologists (Martin et al., 2007; Parsons et al., 2011). A task force on improving health care access and delivery for AYA cancer patients and survivors in Canada recommended more effective supportive care that addresses the unique psychosocial needs of AYA and improves symptom management, psychoeducation, research, and advocacy (Fernandez et al., 2011). While the changes in the health care system in the United States has resulted in improvements, improved access may only be one piece of the puzzle to improve diagnosis and treatment of AYA cancer patients and survivors (Kirchhoff, Lyles, Fluchel, Wright, & Leisenring, 2012). For more on promoting resilience during the transition to adolescence in chronically ill children and families see Lennon et al., this volume.

Efforts to address health systems level risks often target individual resources in knowledge, engagement in routine health behaviors, and self-advocacy (see Table 5.4 for summary). One such intervention aimed to provide first year medical residents with the tools and confidence to screen for substance use, sexually transmitted infections, and depression in an AYA sample (Gooding, Blood, & Sharma, 2012). While the residents reported increased confidence, those residents in the intervention group were no more likely to screen and provide preventative health services as compared to the control group. Despite these results, increasing education regarding the importance of preventative screening may be an area of intervention to improve the time to diagnosis and treatment among AYA subsequently diagnosed with cancer. The use of e-health may be one emerging area of research and intervention to aid in the dissemination of information on required routine, preventative care. Strecher (2007) noted that the use of the internet and phones may provide an effective, low cost mode of relaying health-related information. However, much more research is needed due to the potential limits of confidentiality when utilizing technology-based approaches.

SCD. Similar to pediatric cancer, youth diagnosed with SCD experience health care system barriers to long-term psychosocial functioning. Access to care secondary to inadequate health insurance remains a common theme for both these populations (see Table 5.4 for summary). However, youth with SCD experience an additional risk factor associated with providers' negative perceptions such as beliefs that patients are exaggerating pain, medication seeking, and/or over-utilizing the health care system (Haywood et al., 2011). Low health literacy (i.e., patient's ability

Table 5.4 Summary of risk/resilience factors and interventions for health care system level

Risk and resistance factors	Intervention
Cancer	
Access/clinician perceptions	*Access*
Parsons et al. (2011)	Gooding, Blood, and Sharma (2012)
Martin et al. (2007)	Strecher (2007)
McGylnn et al. (2003)	Fernandez et al. (2011)
Transition	
Kirchhoff et al. (2012)	
Sickle cell disease	
Risk and resistance factors	*Intervention*
Access/clinician perceptions	*Video to improve clinician perception*
Jordan et al. (2010)	Haywood et al. (2011)
Wilson (2003)	*Access*
Sanders et al. (2009)	Huang, Tobin, & Tompane (2012)
Transition	*Transition*
Porter et al. (2014)	Porter et al. (2014)

to know when and where to seek health information, retain this health information, and subsequently apply the health advice) has been associated with poorer health outcomes (Jordan, Buchbinder, & Osborne, 2010; Wilson, 2003). Despite this apparent connection, the health care system may not be addressing low health literacy as a barrier to care.

There are few health services level interventions for SCD. Haywood et al. (2011) created an 8-min video of adults discussing SCD and challenges in seeking treatment for pain episodes to educate nurses. While nurses' negative perceptions of the patients decreased, future research needs to determine if such a change in perception (less stigma/more positive attitudes) leads to improved short- and long-term health outcomes through safer, more effective care. Furthermore, as these youth are seen within a pediatric setting, the role of the parent/guardian and potential negative perceptions of the parent or guardian's role should be considered. Additionally, exploration of this type of intervention in pediatric SCD populations is needed. Given the complications associated with SCD, health literacy may be an important area of risk and possible intervention for youth with SCD and their family, especially as these youth transition into adult health care. In a qualitative study, youth with SCD identified the need for more opportunities to practice transitioning, open communication about transition planning, and the development of family-focused transition interventions (Porter, Graff, Lopez, & Hankins, 2014).

Conclusions

This chapter sought to highlight risk and resource factors within a social-ecological framework. At each level, individual, family, social, and health care systems, specific risk and resource factors emerged as important targets for clinical intervention to improve HRQL. At the individual level, sociodemographics, disease characteristics and treatment-related complications, and coping strategies are identified areas of risks and resources associated with HRQL for both youth diagnosed with cancer and youth with SCD. While some of these risk factors are not amenable to intervention, providers can utilize evidence-based techniques to potentially decrease risks and capitalize on resources. The PAT and The Medical Traumatic Stress Toolkit are starting points for early identification through screening of areas of challenge and prevention of medical trauma. Efforts to promote adaptive coping through the use of coping interventions, such as the Cellie Cancer Coping Kit (and a newly developed SCD version) (Marsac et al., 2012) which promotes coping with coping cards for patients and a parent guidebook, are encouraging.

Individual level interventions have focused on coping, particularly pain management, while family interventions target knowledge, parent distress, and family-based disease management. The evidence base for individual and family interventions is promising but still emerging. A major limitation to intervention research in pediatric SCD is limited participation and engagement in treatment trials. Treatment demands and family stressors present barriers to participation in intervention research for children newly diagnosed with cancer. Recommendations for improving participation have been made: reduce participation demands (i.e., providing the intervention during clinic visits and electronically), ensure the cultural sensitivity of the intervention design and content (in part through the use of community input to recruitment and retention protocols), and use navigators to address attitudinal barriers to research participation (Barakat et al., 2013; Daniel et al., 2015; Schwartz et al., 2007).

A potential strategy to overcome participation barriers is the use of technology, which is used increasingly across the child's social ecology in individual, family, social, and health systems interventions. For example, Re-Mission is a video game developed to enhance cancer and treatment knowledge and adherence for AYA with cancer (Beale, Kato, Marin-Bowling, Guthrie, & Cole, 2007). Another study used a psychoeducational interactive website for parents of children receiving a hematopoietic transplant, showing improvements in parent outcomes (Parsons et al., 2013). Video conferencing with school has also been used to help inpatients stay connected and maintain normalcy, demonstrating positive benefits on mood and relationships (Ellis et al., 2013) and making a therapeutic music video has been found to enhance resilience of adolescents and young adults on treatment for cancer (Docherty et al., 2013). Importantly, use of electronic interfaces seems to improve engagement in cognitive behavioral pain (McClellan et al., 2009).

Because daily school attendance is linked to academic attainment and school functioning, a response to intervention model (RTI) for both youth with cancer and youth with SCD may prove valuable in increasing days in school (Kearney & Graczyk, 2014). RTI is a method of academic intervention in which at risk youth are identified early, provided accommodations, and receive frequent reassessment in order to determine if the accommodations are meeting the needs of the youth and resulting in improved school functioning. However, interventions targeting school attendance, school functioning, and peer support for youth with chronic health conditions are just at the beginning stages. The paucity of school level interventions, particularly those targeting school absenteeism, is concerning given the critical issue of missed school and more limited school attainment among children with SCD. More research is needed to determine the most effective approach, as well as further exploration of, technology to aid in strengthening the bond between those youth hospitalized for treatment and peers within the classroom to improve transition back to school and perceived peer support.

For youth diagnosed with cancer and youth with SCD, risk factors within the health care system remain barriers to effective health care delivery and long-term outcomes. At the health care systems level, interventions to enhance resilience in youth with cancer and their families has been endorsed by many organizations (Schwartz, Radcliffe, & Barakat, 2009), but psychosocial care at pediatric oncology centers is variable and sometimes infrequent (Selove, 2007). The Pediatric Psychosocial Preventative Health Model (PPPHM), applicable to both pediatric cancer and pediatric SCD, was developed to help guide allocation of services (and scarce resources) based on three levels of family psychosocial risk and universal, targeted, and clinical needs (Kazak et al., 2007). The PPPHM is intended to aid screening, such that all families receive a basic assessment of psychosocial needs; however, higher and more intensive levels of care can be provided for families identified as the most "at risk" for lower functioning and/or higher likelihood of psychological and emotional distress. Knowledge of preventative care, comfort and confidence of providers to screen during routine exams, and health care literacy also emerge as potential risk factors within the health care system. Despite the interventions targeting health provider perceptions, more research is needed to determine ways in which researchers and clinician can alter these attitudes to improve the long-term outcomes. Furthermore, dissemination of education to youth and their families through e-health and other technology may serve as a useful medium. Transition to adult care may prove to be a unique and convenient point of intervention to address concerns related to the risk factors associated with the health care system.

Resilience is the result of a complex interaction of disease, patient, family, social, and environmental characteristics. We aimed, in this chapter, to provide a framework examining risks and resources within a social-ecological model and discussed individual, family, peer, and health care system risk and resistance factors as well as associated interventions. Overall, the literature suggests the importance of early assessment to determine the confluence of risk and resource factors to target appropriate, tailored, multimodal treatments to improve HRQL in pediatric cancer and pediatric SCD, thus promoting resilience.

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Part II
The Social Space of Illness

Chapter 6
The Role of Parents in Promoting Children's Adjustment to Chronic Illness

Jessica Hoehn, Emily Foxen-Craft, Wendy Pinder, and Lynnda M. Dahlquist

In this chapter, we highlight specific parenting behaviors that can foster resilience in the face of medical challenges. We discuss resilience from the perspective of pediatric psychology, the scientific and applied field which aims to promote the health and well-being of children, adolescents, and their families in a medical context. Our approach to resilience is informed by Walsh's family resilience framework (2003), which emphasizes key processes in families' adaptation in response to serious threats or challenges. We define resilience based on Walsh's (2003) use of the term as multiple interacting processes in which an individual or family "withstands and rebounds from disruptive life challenges" (p. 26). Pediatric chronic illness functions as a "disruptive life challenge" that threatens health and typical developmental processes. A child effectively "rebounds" from the disruptive life challenge of chronic illness by: maintaining the best possible health in the context of their illness (with optimal physical functioning and lowest possible impairment of daily functioning), displaying optimal emotional adaptation to the challenges of chronic illness, and proceeding with the tasks of development.

Walsh's family resilience perspective focuses on the family unit as a system and emphasizes parents' (and other kin members') strengths and potential for adaptation. Walsh outlines several key processes in family resilience; we emphasize here processes that are especially relevant to parents of children with chronic illness, such as developing adaptive parental beliefs and a positive outlook (conceptualizing obstacles as challenges that can be mastered), and emphasizing flexible organizational patterns. While our review is not meant to be exhaustive, we underscore parental behaviors that fit into certain areas of these processes.

We are also informed by Masten's (2001) argument that resilience arises from common, ordinary adaptive processes in development, and that promotion of resilience involves encouraging and protecting these processes. According to Masten,

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J. Hoehn, M.A. (✉) • E. Foxen-Craft, M.A. • W. Pinder, B.A. • L.M. Dahlquist, Ph.D.
Department of Psychology, University of Maryland, Baltimore County, MD, USA
e-mail: jhoehn1@umbc.edu; dahlquis@umbc.edu

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goals for interventions to promote resilience and prevent maladaptation should include promoting competence, preventing or ameliorating further problems, and facilitating already-occurring or "normal" protective processes. We emphasize how parents can promote resilience in their children by reducing further risks or stressors and fostering developmental competence through scaffolding—i.e., by exposing children to tasks that allow the development of new skills while providing the minimum amount of structure and help so that they can learn to solve problems independently (Wood, Bruner, & Ross, 1976).

Thus, parents can promote their child's competence in managing the challenges of chronic illness in various ways. By reducing further risks to physical health, promoting emotional adjustment, and facilitating the resumption of tasks of living, parents can help promote resilient processes. Specifically, parents can promote adjustment to medical procedures, maximize their child's competence to successfully manage and adhere to medical treatment, and foster tasks of "normal" living, including development of autonomy and social competence.

Promoting Adjustment to Stressful Medical Procedures

One crucial domain in which parents can promote resilience is through encouraging adjustment to medical procedures. Many aspects of medical care, such as injections, blood draws, bone marrow aspirations, and lumbar punctures are painful and anxiety-provoking for children (Slifer, Tucker, & Dahlquist, 2002). Even procedures that are not necessarily painful, such as MRI scans, can be unfamiliar and frightening (Slifer, 2014). Anxiety and distress can exacerbate pain, prolong recovery from surgery, and contribute to future negative reactions to medical care (MacLaren & Kain, 2008; Slifer et al., 2002). Thus, parents' behaviors during stressful medical procedures can significantly reduce future negative impacts from the chronic illness. Although it may not be possible to completely avoid discomfort and apprehension during medical procedures, parents can help to minimize the psychological impact of medical procedures as well as enhance the child's capacity to tolerate or master the stressful situation.

Developmentally appropriate preparation. In general, individuals are better able to tolerate a predictable stressor than an unpredictable one (Shankman, Robison-Andrew, Nelson, Altman, & Campbell, 2011). Therefore, if parents prepare children for a difficult medical procedure ahead of time, it can reduce their fears of the unknown, make the aversive aspects of the procedure more predictable, and hasten their adaptation to the procedure (Dahlquist, 1999). Research suggests that preparation is most effective if it is presented in a developmentally appropriate manner, using simple language and concrete stimuli the child can easily understand, and if it contains information about the sensations the child will experience in addition to the actual details of the medical procedure (Dahlquist, 1999).

Reducing children's distress during uncomfortable medical procedures. Parental behavior during the waiting period before the medical procedure, as well as during the procedure itself, is a major contributor to children's behavioral distress (Martin, Chorney, Cohen, & Kain, 2013). In general, when parents provide distracting activities and prompt their children to use them, children typically demonstrate less crying, verbal distress, and protest during medical procedures and recover more quickly from the event (Blount et al., 2009; Dahlquist, Pendley, Landthrip, Jones, & Steuber, 2002). Praising (rather than criticizing) children's cooperation and coping efforts, and setting limits that prevent the child from delaying or escaping the procedure have also been shown to help children cooperate with medical procedures (Slifer, 2014).

To effectively assist their children during medical procedures, parents must also control their own emotional reactions. When parents are highly anxious or catastrophize about their children's reaction to the medical procedure, their children tend to demonstrate greater distress (Caes et al., 2014). Parental anxiety has also has been shown to predict the success or failure of parental efforts to distract children during medical procedures (Dahlquist & Pendley, 2005).

Although direct links between adjustment to medical procedures and long-term adaptation to childhood disease have not yet been the focus of study, it seems likely that successful mastery of the repeated stress associated with medical procedures would afford children the opportunity to learn important emotion-regulation skills. Such skills should not only increase their self-perceptions of competence in terms of their medical condition, but also impact their future resilience in the face of other types of stress.

Maximizing Adherence to Medical Recommendations

Adherence typically refers to the extent to which a person's behavior coincides with medical or health advice or to an ideal regimen (Hayes, 1979). Poor adherence to medical regimens and difficulty fitting medical treatment into a child's life are associated with poor physical health, and as a result, poor psychological and quality of life outcomes (Brownbridge & Fielding, 1994). In contrast, when parents are able to foster their children's adherence to medical regimens, they can promote their children's physical and mental health, as well as competence in surmounting challenges posed by their illness. Therefore, in accordance with Masten's (2001) model of resilience constituting "prevention or amelioration of symptoms and problems" (p. 234), parents can promote their children's resilience by maximizing their children's adherence to medical regimens and by protecting against the stress of their child's poor health. Further, parents can model resilience-promoting processes such as flexibility, problem-solving, and a positive outlook to successfully fit their children's medical regimens into their children's daily lives according to their developmental capacities.

Complex regimens that require multifaceted behaviors, such as diabetes, have poorer adherence rates than regimens that require medication adherence alone (Quittner, Espelage, Ievers-Landis, & Drotar, 2000). Parental assistance in adherence to pediatric medical regimens can promote both physical and psychological well-being. To do so, parents must not only recognize the benefits of adherence, but also promote adherence by emphasizing the benefits of adherence to the child, and assisting with task completion, monitoring and organization. Moreover, parents must also help their child fit their medical care into everyday life and foster the child's development of autonomous self-care skills.

Parents' beliefs about health can influence their promotion of their child's adherence. The Health Belief Model, developed by Bond, Aiken and Somerville (1992), predicts adherence based on the individual's perceptions of susceptibility to illness complications as well as the benefits of adherence to the regimen. For instance, parental health beliefs regarding their child's asthma, including trust in the physician and the belief that inhaled corticosteroid treatment is beneficial, have been linked with adherence to an inhaled corticosteroid regimen (Drotar & Bonner, 2009). Further, parental plans to implement physician recommendations have been linked to adherence. Parental beliefs foster resilience if they promote problem-solving, flexibility, and optimism (Walsh, 2003). Thus, if parents trust medical recommendations and believe that regimens are actually helpful, they then are more likely to promote adherence.

Fostering competence in the management of the illness by the developmentally appropriate transfer of illness care. Parents can also improve their child's competence in managing their illness by transmitting knowledge to the child. Children who demonstrate better understanding of how to administer medications and better problem-solving skills are more adherent to oral medications (Tebbi et al., 1986). However, it is crucial that parents match their expectations to the child's developmental capacity. An appropriate fit between the child's responsibilities and developmental capacity can maximize the children's success in caring for themselves. As the impact of medical challenges changes over the developmental life span, families must adapt their responses to promote adherence (Walsh, 2003). For more on promoting resilience during the transition to adolescence, see Lennon et al., this volume.

The parents' role in matching promotion of adherence to the child's capacity is especially important in illnesses with complex medical regimens, such as type 1 diabetes. Management of type 1 diabetes requires constant care and monitoring of symptoms, including insulin administration, carbohydrate counting, and blood glucose monitoring (Diabetes Care and Control Trial Research Group (DCCT), 1994). Furthermore, adherence in type 1 diabetes has a consistently strong impact on medical outcomes, including glycemic control, such that as adherence increases, average blood glucose decreases (Hood, Peterson, Rohan, & Drotar, 2009). Because management is multifaceted, a child may be developmentally ready to manage some elements of the regimen before others. Thus, parents of children with type 1 diabetes are required to carefully monitor their child's involvement in diabetes management, and promote increased involvement from the child only when developmentally appropriate. Parents often assume responsibility for completing tasks related to management of diabetes and other pediatric conditions, but a gradual shift often occurs throughout development (La Greca, 1998). Parents of young children, for example, likely complete most tasks, but gradually shift from completing to monitoring.

Transferring responsibility. Generally, increased shared parental and adolescent responsibility in pediatric type 1 diabetes care predicts better adherence, glycemic control, and psychological outcomes (Helgeson, Reynolds, Siminerio, Escobar, & Becker, 2008). The best outcomes are associated with transfer of responsibility of care to adolescents when adolescents have the skills to manage diabetes and to be successful in caring for themselves. Transfer of responsibility for diabetes care before adolescents are ready predicts poor adherence as well as poor medical and psychological outcomes (Palmer et al., 2004). Though autonomy is a developmental goal of adolescence and in diabetes care (Anderson & Coyne, 1991), adolescents with more responsibility relative to their maturity have worse adherence rates and more hospitalizations from diabetes-related complications. Thus, parents can promote resilience by sharing responsibility with their child, and transferring responsibilities when their child is ready to be autonomous. Greater perceived autonomy, when developmentally appropriate, can lead to increased adherence; for instance, adolescents with type 2 diabetes who perceived more autonomy in diabetes-related tasks were more adherent to treatment regimens (Saletsky, Trief, Anderson, Rosenbaum, & Weinstock, 2014).

Reducing family conflict. Parents can also promote adherence (and thus, better adjustment) by minimizing family conflict while transferring more responsibilities to adolescents. Adolescents with type 1 diabetes who reported higher rates of family conflict and who were given more responsibility in diabetes management had lower rates of blood glucose monitoring (Ingerski, Anderson, Dolan, & Hood, 2010). Interventions targeting family conflict and division of responsibility can promote children's adherence and resilience in the face of chronic illness. Overall, multicomponent interventions that target family involvement have had stronger effects on adherence among children with type 1 diabetes than interventions targeting behavioral processes alone (Hood, Rohan, Peterson, & Drotar, 2010). Furthermore, interventions that provide explicit recommendations about increasing caregiver involvement and reducing family conflict may also be helpful, particularly among adolescents who are vulnerable to poor adherence (Ingerski et al., 2010; Vesco et al., 2010).

In sum, parents strengthen their children's resilience by fostering adaptation to their children's illness through promotion of adherence to the medical regimen. These resilient processes include recognizing the importance of medical regimens, increasing their involvement in necessary components of their child's medical care, placing developmentally appropriate expectations on their child, and reducing their child's exposure to family conflict. As parents gradually promote autonomy and scaffold the child toward independence and competence in managing the medical regimen, children are also likely to generalize these skills of self-regulation, organization, and executive function toward resilience in day-to-day functioning, beyond the context of their medical condition.

Facilitating the Development of Autonomy Outside the Medical Context

In addition to its importance in medical self-management, the development of autonomy is also a crucial aspect of children's more general social and emotional development (Sroufe, Egeland, Carlson, & Collins, 2005). Disruptions in autonomy development have been shown to increase the risk of internalizing symptoms (LaFreniere, Provost, & Dubeau, 1992), externalizing behavior problems (Holmbeck et al., 2002), and problems in peer relations (LaFreniere et al., 1992). Parents play a crucial role in facilitating autonomy development by structuring the child's or adolescent's activities in ways that help them learn to independently solve problems, regulate their emotional reactions, and develop social competence (Power, 2004).

Chronic childhood illness makes this autonomy-facilitating process particularly challenging because, as noted above, illness management often necessitates a greater level of parental involvement in children's lives than would otherwise be needed (Anderson & Coyne, 1991). For example, parents may realistically need to be more involved and monitor daily activities more closely in order to make sure appropriate medical care occurs and to protect their children from adverse outcomes, such as exposure to potentially harmful food allergens (Anderson & Coyne, 1991; Bollinger et al., 2006; Dahlquist et al., 2015). However, these important health-maintaining parental responsibilities can conflict with the parent's responsibility to also facilitate the development of the child's ability to function independently (Anderson & Coyne, 1991). Moreover, the illness experience may heighten parental anxiety and perceptions of their children as vulnerable and in need of assistance—both of which have been shown to relate to overprotective or overly involved parenting (Hullmann, Wolfe-Christensen, Meyer, McNall-Knapp, & Mullins, 2010; Kiel & Buss, 2009; Thomasgard & Metz, 1997).

As a result, emerging research findings suggest that parental over involvement may carry over into activities that are unrelated to medical care. For example, Power, Dahlquist, Thompson, and Warren (2003) found that parents of children with severe juvenile rheumatoid arthritis were more likely to unnecessarily structure and prompt their children during a visual memory task than were parents of healthy children or children with milder disease. Similarly, Dahlquist et al. (2015) observed that mothers of 3–4-year-old children with food allergy were more likely to provide unnecessary help during a puzzle task than mothers of healthy children.

Minimizing over-involvement. Parents can protect against over involvement by actively promoting their child's involvement in independent tasks. Similar to the ways in which parents can foster independent disease management, parents can foster the development of autonomy in academic, social, and emotional contexts by providing opportunities for children to solve problems on their own. This requires parents to distinguish between settings where their involvement may be necessary (e.g., monitoring adherence) vs. unnecessary (solving homework problems), be alert to signs of overly involved or protective parenting in themselves, and be willing to allow their children to develop competence by facing problems or conflicts, trying out different problem solutions, and experiencing both success and failures.

Promoting the Development of Social Competence and the Perception of Normalcy

Parents can also play a positive role in promoting their child's social competence. Research shows that some chronic medical conditions put an additional strain on children in terms of developing social competence equal to their peers (Martinez, Carter, & Legato, 2011; Pinquart & Teubert, 2012). Social competence refers to the degree to which an individual effectively interacts with others (Rose-Krasnor, 1997). Research shows that being socially competent is important for accomplishing many academic, occupational, and social tasks throughout life (Frankel & Myatt, 1994; Parker & Asher, 1987). Parents of children with chronic medical conditions can encourage their child's development of social competence through: (1) creating and supporting social opportunities, (2) minimizing school absences, and (3) minimizing overprotection/control of their child's social activities.

Creating social opportunities. Parents play a major role in creating social opportunities for their children from early childhood through adolescence (Hartup, 1979). Providing access to social experiences can be challenging for parents of children with chronic medical conditions, as medical regimens can make it difficult for parents to promote social contact while simultaneously ensuring their children's safety and well-being. However, access to peers is critical. Research consistently demonstrates that peer interaction is positively associated with social competence (Ladd, 1999). Evidence from the chronic illness literature further suggests that children who miss opportunities to interact with peers on a regular basis due to doctor's appointments or hospitalizations have poorer social outcomes (Pinquart & Teubert, 2012; Reiter-Purtill & Noll, 2003). Parents largely have the task of creating these important opportunities in a way that does not interfere with their child's medical needs.

To illustrate, camp-based programs have become increasingly common and accessible for children and youth with chronic illnesses. Camp-based programs for chronically ill populations are often designed to provide a safe, normative, and fun experience with peers for children who may otherwise not be able to attend camp due to their medical needs (Warady, Carr, Hellerstein, & Alon, 1992). Participation in the ordinary experiences of camp promotes competence and resilience as a result of the interaction between the child's own positive adaptive skills and the support that the environment provides (Masten, 2001). Various research groups have found positive outcomes associated with these camps; a meta-analysis of 31 studies by Odar, Canter, and Roberts (2013) found that camp improved self-perceptions for some children with chronic illness. These effects continued to be detected at follow-up (studies ranged between 1- and 6-month follow-ups), suggesting that camp may have lasting impact on self-perception for some children. Similarly, youth and young adults with spina bifida who participated in a weeklong camp with a curriculum on goal setting improved in health-related self-care, independence, and goal attainment (Holbein et al., 2013). As such, parents should encourage their children to attend these, and other social opportunities, that can have an impact on their social development, as well as their health-related well-being.

Minimizing school absences. Parents can also play a significant role in their child's perceptions of normalcy, as well as improving their child's prospects of positive academic and social outcomes by minimizing school absences. School provides children with opportunities to practice social skills with their peers (Hanish, Martin, Fabes, & Barcelo, 2008), and thus frequent absence from school places children at risk for poorer academic, occupational, and social functioning (Sexson & Madan-Swain, 1995). Parents also contribute to their child's resilience by promoting normalization of daily activities despite the chronic medical condition. Qualitative research shows that parents who emphasize the importance of balancing their child's medical regimen with maintaining normal family routines feel less overwhelmed and more competent overall in caring for their chronically ill child (Knafl, Darney, Gallo, & Angst, 2010; Peck & Lillibridge, 2005). These efforts to promote normalcy also reduce children's feelings of isolation, which according to one study with children with food allergy, can be one of the most difficult part of having a chronic disease (Lebovidge, Strauch, Kalish, & Schneider, 2009).

Finally, parents can promote children's social competence by minimizing their directiveness or control of their children's social activities. Excessive involvement in children's social experiences has been shown to interfere with the development of key social skills such as negotiation and cooperative play (Ladd & Golter, 1988).

An Illustrative Example: Fostering Resilience in Chronic Pain Conditions

To summarize, parents can promote resilience via multiple processes as highlighted by Walsh (2003) and Masten (2001), including beliefs and positive outlook (promoting medical conditions as manageable, meaningful, and important), flexibility to their child's developmental capacity, and the reduction of further risks or stressors. Parents utilize these processes to promote emotional adjustment, reduce further risks to physical health, and facilitate the resumption of "normal" tasks of living. However, certain kinds of health conditions can make it particularly challenging to accomplish these tasks. Pediatric chronic pain provides an illustrative example of the multiple roles that parents can play in promoting resilience and adaptive adjustment in their children.

Chronic or recurrent pain is defined as pain that lasts beyond the expected healing time from tissue damage, which is arbitrarily defined as 3–6 months (American Pain Society Task Force on Pediatric Chronic Pain Management, 2012). Pediatric chronic pain is quite prevalent; it is estimated that 20–35 % of children and adolescents experience chronic pain (King et al., 2011; Stanford, Chambers, Biesanz, & Chen, 2008). Families of children with chronic or recurrent pain conditions face particular difficulties in terms of maintaining normal developmental processes. Pediatric chronic pain conditions are particularly challenging because they are often associated with greater functional disability and impairment, avoidance of daily activities, depression and other negative affect (Compas, 1999), and maladaptive coping strategies (Compas et al., 2006).

Parents can play a particularly important role in fostering resilience among children with chronic pain conditions. As outlined by Masten (2001), parents can foster resilience by continuing to promote competence across developmental domains while preventing and/or addressing further problems. Thus, they can facilitate protective processes (such as teaching positive adaptive coping strategies, promoting peer relationships and other protective activities, and promoting exposure to developmentally appropriate stressors), while reducing harmful processes (such as avoiding reinforcement of the child's "sick role" and minimizing family stressors).

Promoting emotional adjustment via adaptive coping skills. The role of stress and negative coping styles in pediatric chronic pain conditions is well documented. Children with chronic pain are exposed to multiple stressors including stress from repeated pain exposures, increased negative affect, repeated medical procedures, repeated hospital stays, and physician visits (Dahlquist & Switkin-Nagel, 2009). Functional disability in children and adolescents with chronic pain has been linked to psychosocial factors such as negative coping style (Gil, Williams, Thompson, & Kinney, 1991).

Parents can counteract the potential negative impact of multiple stressors via the fostering of adaptive coping approaches. One way that parents can foster adaptive coping strategies is through modeling low levels of negative affect. Children are more likely to report disability and negative affect surrounding pain when they have parents who report experiencing more disability when they experience illness or pain (Palermo & Eccleston, 2009). However, parents who minimize the impact of their own pain on their daily functioning are more likely to have children who show less functional disability in the face of pain (Palermo & Eccleston, 2009). Parents can also model a positive outlook towards their child's pain; as Walsh (2003) describes, hope, confidence, and encouragement can all work to promote resilience in the family.

Parents can also impact their child's appraisals of the severity and impact of their pain. Research on parental influences on child coping emphasizes the importance of parents in children's appraisals of stressful situations (Power, 2004). Parents can influence children's appraisals of potential stressors through providing specific instructions on how to interpret stressors, and through modeling (Kliewer, Sandler, & Wolchik, 1994). Parents who assess stressors as manageable or as a "challenge" have better levels of personal adjustment, and could potentially model these adaptive appraisals for their children (Power, 2004; Walsh, 2003). Their children can then use them to cope more effectively with recurrent pain and other stressors.

Reducing risk of further harm and disability. Parental influence (along with other psychosocial factors) can also play a particular role in the amount of functional disability in children with chronic pain. Children with chronic pain frequently experience some level of functional disability or physical impairment, although the amount of disability varies greatly from child to child, even within the same chronic pain condition (Palermo & Holley, 2013). Children with chronic pain conditions often come to avoid certain activities (such as physical activity and school attendance) due to the short-term reinforcement of decrease in pain (Dahlquist, 1999). Avoidance of activities, however, can lead to exacerbation of pain symptoms, due to reduced distraction from pain perception and increased negative affect regarding limitation due to painful activities. Lack of activity can also exacerbate some pain conditions (such as complex regional pain syndrome) through disuse, which can lead to further impairment (Asmundson, Norton, & Norton, 1999; Bruehl & Chung, 2006).

Thus, parents can help foster resilience to chronic pain conditions by encouraging engagement in normal activities as much as possible, even when their child reports pain. Parents may have to be skilled at encouraging their children to attempt participation in activities. An understanding that movement and activities often helps, rather than hinders, long-term pain symptoms and disability is crucial for parents, and they can reinforce this concept with their children. By promoting engagement in activities, parents can also help counteract any social isolation experienced by their children due to their chronic pain condition, which can further help children to develop supportive peer relationships, increasing the child's resilience.

Parents can also promote resilience in their children by reducing harmful processes (Masten, 2001). In chronic pain, a common harmful process occurs when parents inadvertently reinforce their child's "sick role" by providing increased attention and support during pain episodes, and allowing their child to avoid demanding situations or responsibilities (such as school or chores) (Dahlquist, 1999). This adoption of the sick role is particularly problematic because it can further isolate children from important social opportunities and opportunities for autonomy development. Thus, while it is important that parents continue to support their child and validate their experiences, they must be careful to do so in a way that promotes continued engagement in activities and minimization of the impact of their child's pain. Parents can discourage adoption of the sick role via several operant strategies that minimize (without discounting) the impact of chronic pain experiences on a child's daily functioning (Palermo & Chambers, 2005; Palermo, Eccleston, Lewandowski, Williams, & Morley, 2010).

Facilitating "normal" tasks of living. Parents can also foster resilience to chronic pain by ensuring that their children are exposed to manageable, age-appropriate stressors. Parents should be aware of challenges or expectations that their children would typically face if healthy, and should be careful to make sure that their children are still exposed to these challenges in spite of their illnesses. Because adaptive coping skills require practice, frequent exposure to manageable stressors is essential in order for children to develop appropriate coping strategies (Power, 2004), which can then be used to help manage more severe stressors independently. Thus, it is crucial that children are not protected from developmentally appropriate stressors, such as academic challenges (a difficult exam or course), new social situations (extracurricular activities, sports teams), or other challenges.

Parents also play an important role in minimizing stressors related to family functioning. As in type 1 diabetes adherence, problems in family functioning (such as communication problems and high conflict) have been associated with higher disability in children with chronic pain (Lewandowski, Palermo, Stinson, Handley, & Chambers, 2010). However, positive communication between family members, high levels of support, and low conflict has been associated with less pain-related disability (Lewandowski et al., 2010). Thus, parents can promote more positive adjustment in their children by promoting adaptive communication among family members.

Conclusion

Although we have chosen to separate out the different roles that parents play in fostering resilience in the face of childhood chronic illness, in actuality, these parental roles interact with each other and with their child's behavior. Children who adhere to medical care are likely to be healthier and better able to engage in school and social activities. Children who are active socially and successful academically will have greater access to positive reinforcement for maintaining their activities and their health and will be less likely to be seen by parents or others as vulnerable or needing protection. Ultimately, the goal is to foster the development of skills needed to take care of the health condition and lead optimally productive, satisfying lives.

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Chapter 7
Resilience in the Care of Children with Palliative Care Needs

Richard D. Goldstein

In this chapter, resilience is considered from the perspective of pediatric palliative care, an interdisciplinary medical specialty attending to the particular needs of children, and their families, with life-threatening illnesses or complex medical issues significantly altering life expectancy and quality of life. As defined by the World Health Organization (1998), palliative care for children aims to improve the quality of life of patients facing life-threatening illnesses through the prevention and relief of suffering, by early identification and treatment of pain and other problems, whether physical, psychosocial, or spiritual. Palliative care is the active total care of the child's body, mind, and spirit, while also providing support to the family. It best begins early in life-limiting illness, and continues whether a child receives treatment directed at the disease or not. Involvement with the child's family lasts into bereavement. The character of the palliative care provided in each specific case is influenced by changes in the blending of goals oriented toward cure, life extension or miracles, and hope for comfort and meaning.

Children receiving palliative care generally are facing four categories of disease (Himelstein, Hilden, Boldt, & Weissman, 2004). Some children have conditions for which curative treatment is possible but may fail, e.g., those with severe or complex heart disease or advanced or progressive cancer with poor prognosis. There are children with conditions requiring intensive, long-term treatment aimed at maintaining the quality of life, e.g., children with cystic fibrosis, severe immunodeficiency, or muscular dystrophy. There are children with progressive conditions in which treatment is exclusively palliative after diagnosis, e.g., progressive metabolic disorders, severe chromosomal disorders, or severe osteogenesis imperfecta (Brittle Bone Disease). There are conditions involving severe, non-progressive disability causing extreme vulnerability to health complications, e.g., severe cerebral palsy,

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R.D. Goldstein, M.D. (✉)
Department of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute,
Boston Children's Hospital, Harvard Medical School, Boston, MA, USA
e-mail: Richard_goldstein@dfci.harvard.edu

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severe neurologic sequelae of infectious disease, or anoxic brain injury. While the particular trajectories of these illnesses and their complications may differ, they have in common the seriousness of the disease process. These children and their families live with an awareness of the threat of death, and are challenged to find different expectations and goals in comparison to the more typical aspirations parents have for a healthy child.

As pediatric palliative care programs have become integrated into broader systems of care, its patient population has become better defined (Feudtner et al., 2011). There is not a close correspondence between pediatric palliative care patients and overall child mortality trends, although the diagnoses these children carry do reflect present trends in hospital bed utilization and healthcare expenditures for children (Berry et al., 2013). A survey of leading pediatric palliative care programs in the United States and Canada found that they provide care for children of all ages, with 17 % under the age of 1 year, 38 % from the ages 1 through 9 years, and 30 % between 10 and 18 years of age. In contrast, about half of child mortality affects children under the age of 1 year. The patient population is 69.5 % white, 9 % black, and 7 % Hispanic, with minorities and impoverished patient families underrepresented relative to broader mortality trends. The children receive palliative care consultations in varied settings, including home (33 %), hospital ward (28 %), intensive care unit (18 %), hospice (11 %), and outpatient clinic (7 %). Their leading diagnoses are genetic or congenital disorders (41 %), neuromuscular disorders (39 %), and cancer (20 %). On average, children receiving palliative care take nine medications. Sixty percent have some sort of a feeding tube and 10.1 % have a tracheostomy. The median survival from the time of initial palliative care consultation is 107 days, although 69.7 % of the children are alive after 1 year of involvement. Most of the children die in the hospital (62 %).

Generally speaking, medical research in resilience is mechanistic in its focus, and tends to emphasize resilience as an ability to manage the adversities and challenges of illness (Folkman & Greer, 2000). Nonetheless, there is ample evidence supporting a transactional, ecological model of the concept when the practices and foci of the field are considered. Three areas of concern in pediatric palliative care, presented below, offer an important perspective on resilience. First, resilience is reflected in the importance of "regoaling," a process in which treatment and life goals are reframed in light of clinical developments while affirming the child and the family's identity and values. Secondly, it can be seen in the importance of addressing suffering and the efforts to support a patient's sense of personal intactness. Finally, it demonstrates itself in the recognized worth of palliative care treatment, when evidence of resilience itself becomes an indication of the positive impact of a palliative care team.

As stated in other chapters, there are definitional difficulties involved in any presentation of resilience research. The intent of this review is to address relevant research as it applies to this particular population of children and their families. Research directly examining resilience in children receiving palliative care is rare. While research efforts have certainly been hampered by methodological difficulties related to the conceptualization of resilience (Molina et al., 2014; Rosenberg, Starks, & Jones, 2014), there are also practical limitations related to communication abilities and the intensity of illness. The medicalized nature of the children's lives can lead to a reluctance on the part of patients, families, and their healthcare providers for the child to be a "subject" on the days when they are feeling well. Fundamentally, the nature of "high risk" in these patients extends beyond the psychosocial threat that makes up risk in much of the literature. The risks for these patients are mortal threat and incapacity, making them a subpopulation with a distinct experience. Many psychological or performance characteristics investigated in other populations would not appropriately apply here.

Certainly, the notion of "bouncing back" is complicated in this area. A child's inability to do so, as their disease progresses, is often taken as a sign by parents and guardians of the burdens of disease. As a matter of course, there are times, however, when an invested sense of value in a new normal is more difficult to find, even among the most resilient child/family systems. Research examining greater levels disability or disease shows the critical significance of evolving cognitive impairments, language impairments, and pathological fatigue, which are the leading reasons that palliative care consultations are initiated (Feudtner et al., 2013). These issues also challenge families about the goals and burdens of treatment for their children moving forward. As an example, parents of children dying from brain tumors observed that the loss of communication is a turning point in the child's disease trajectory (Zelcer, Cataudella, Cairney, & Bannister, 2010). This loss of function and capacity can be interpreted as removing the child, and evidence of their resilience, in important ways from their illness process. Strengths may be appreciated in the child but the redefinition at this point of the illness trajectory may be driven largely by interpretations from the family and others involved.

In everyday language, resilience is spoken of as a heroic patient narrative or as an inherent trait of invulnerability made clear by the extraordinary challenges that are faced. Indeed, it is a marvel to see how some children show a largeness of spirit despite their terrible burdens. However, it is impossible to separate the child's features from the environment in which he or she must navigate through their illness. The core conceptualization of resilience used here follows Rutter and Garmezy's notion of stress resistant individuals in high risk settings as exhibited by elements of a positive personality disposition, aided by a supportive and nurturing family milieu, and with advantages coming from a thriving social support system (Rutter, 2012). In this regard, we see resilience as a transactional feature of a child and family coping with serious illness. This transactional nature can lead to vagaries as to whether resilience is a trait (Connor, 2006), an interactively revealed trait (Mancini & Bonanno, 2009; Rutter, 2006) or a cultivated feature of an individual child within a family system. In pediatric palliative care, there is significant overlap between resilience research and outcomes research exploring quality of life, psychological adaptation, and coping in the broader support systems. Attempts to reduce resilience into a mechanistic model, often the goal in biomedical research but sometimes beyond the precision a subject matter allows, creates further difficulties with the existing resilience literature in palliative care.

Some resilience research focuses on the influence of individual characteristics as children experience serious illness. Individual attributes of a child and their psychology of coping affect their outcomes. Ego resiliency is associated with quality of life in pediatric cancer patients (Harper et al., 2014) and is indirectly associated with "effortful control," the ability to voluntarily focus and shift attention, inhibit or initiate behaviors, and develop and modify planful behavior. In hospitalized adults facing end of life, lower risks of emotional distress are associated with higher resilience (Min et al., 2013). As described by parents of children with advanced cardiac disease (Balkin et al., 2014), quality of life and healthy adaptation is better when conditions are understood to be irreversible than when there is a similar disease burden but some potential for improvement, reflecting a kind of strength that can be undermined by doubt that more effort or different decisions might be made.

On the patient level, resilience is an appealing concept to consider in the context of pediatric palliative care. The orientation of pediatric palliative care toward enhancing quality of life, maintaining self-definition in the face of serious illness, and the promotion of family-centered care puts the field's priorities in line with recognizing and promoting resilience. In the clinical setting, there is a general recognition and cultivation of resilience as a positive characteristic of survival and coping. Moreover, evidence of its presence is seen as contributing to a "good death." Experience suggests that evidence of a child's resilience can be an important motivation to those taking care of him or her. Its presence can serve as a benchmark for a palliative care team, and, although its vitality relies importantly on the child's and family's strengths, witnessing it in a patient, regardless of outcome, can lead to feelings of relative success during a child's treatment course among interdisciplinary providers involved in their care. There are many cases where the process ultimately leading to a child's death also reveals venerable, enduring aspects of the child. Typically, that legacy of resilience is carried forward into bereavement and regarded as a gift from the child to their family, community, or the world.

Most of the palliative care research related to resilience examines how the child is affected as they go through their illness process, and how they manage or emerge from acute illness. Most children with disabilities generally find their quality of life to be acceptable despite significant biomedical risk (Payot & Barrington, 2011). A striking example can be found in young adults who survived difficult neonatal treatment courses as very low birthweight infants. They survive with disabilities and symptoms that are "objectively" considered a reduced quality of life, yet nonetheless exist with a positive "subjective" quality of life and self-concept (Dinesen & Greisen, 2001). Jamieson et al. (2014) in a systemic review of qualitative studies on children living with cystic fibrosis, describes the general theme of "gaining resilience" where, the "steeling" from their health challenges includes a redefined sense of normal that includes participation in activities endorsed by their support network. There is considerable evidence for generally positive, resilient adaptation in response to living with the burdens of complex chronic illness in children.

Research also examines "balance," the way a family, as a whole, adapts to illness and its impact while striving to regain a sense of normal (Patterson, Holm, & Gurney, 2004). The impact of a child with serious illness on a family system is an appreciated stressor, although it does not preclude coping and healthy adaptation (Gayton, Friedman, Tavormina, & Tucker, 1977). Studies by pediatric oncologists have demonstrated the influence of this stress on adjustment (Barrera, Boyd-Pringle, Sumbler, & Saunders, 2000), quality of life (Kazak & Barakat, 1997), and social functioning (Vannatta, Zeller, Noll, & Koontz, 1998) in bereaved families. With regard to the patients themselves, levels of family stress were shown to predict adjustment in adolescents with Duchenne muscular dystrophy (Fee & Hinton, 2011; Reid & Renwick, 2001). There is a complex interplay between the specifics of coping in families having a child receiving palliative care and the increased family stress of having to cope with it at all. Family adaptation to serious illness, though not to be underestimated as a stressor, may be a distal risk and the way a family lives with and manages the stresses may be more proximal.

Rutter (2012) and others have shown the importance of the management of stressors in the process rather than stressor per se. Resilience research in areas of psychosocial adaptations shows, for example, that it is not separation or divorce that undermines or exposes resilience, but the way that families manage the process. Discord, conflict or poor parenting appear to lead to risk more proximal than that arising from the general circumstances (Harris, Brown, & Bifulco, 1986). Thus, some effort has been given to determine "mutable" family factors identified in parents who go on to experience a relatively uncomplicated bereavement. Elements involved include the perceived ability to overcome adversity, the inability to manage emotional distress, the tendency toward post-traumatic growth and demographic or resource related aspects of a family. Although these factors have not been found to predict resilience (Rosenberg et al., 2014), there is nonetheless interest in affecting the subjective experience of parenting a child with serious illness or mitigating negative outcomes like parental psychological distress (Rosenberg, Baker, Syrjala, Back, & Wolfe, 2013). Research in this area, however, is not conclusive. The standard of practice on pediatric palliative care, nonetheless, is to bolster family supports and foster the meaningful inclusion of family values and goals into the care plan of children.

Pediatric palliative care explicitly addresses family adaptation and coping. Children do not exist in isolation, and their treatment courses and outcomes are influenced by the family's capacities to remain vitally engaged during the child's course. Some themes in the family experience have become clear through research on the impact of living with a child with serious illness. Parents cope with emotional and financial aspects related to the child's illness (Dussel et al., 2011; Kazak & Barakat, 1997). They also cope with social disruption (Montagnino & Mauricio, 2004), social isolation, fears of abandonment, fatigue, and a sense of their lives as devalued (Carnevale, Alexander, Davis, Rennick, & Troini, 2006; Knapp, Madden, Curtis, Sloyer, & Shenkman, 2010; Stevens, Jones, & O'Riordan, 1996). Yet, despite these threats or "stressors" in the child's environment, families are driven to achieve or regain a tolerable semblance of normal, and to avoid situations where uncomfortable differences are exposed. "Regoaling" is the important capacity to redefine prior existing goals in a process involving disengagement from prior goals, reengagement in new goals, flexibility of affect, and hopeful thinking (Hill et al., 2014).

It becomes a focus in the care of seriously ill children because it has an important influence on the course of illness. The child's lived environment, the themes of their struggle, the understanding of the burdens of treatment, and the primacy of assuring for the child's lack of pain and discomfort, are all significantly affected by these changing goals. Regoaling often operates on the family level, but it exists in service of resilience.

It can be hard at times to understand whether the term resilience is measuring psychological adjustment, quality of life, or other concepts that have their own developed literature. The notion of resilience in the "disease ecology" of pediatric palliative care has important differences from that in subjects in other areas of resilience research. Because the illness outcomes in pediatric palliative care involve death or substantial loss of function, longer term outcomes or measured features cannot be measured. There are conceptual limitations to the notion of "bouncing back" implied in the term resilience itself. It may be that some of a child's strengths and excellences find their footing in these circumstances and, when supported and held by the family, the care team and the surrounding community, lead to a sense of overcoming and transforming the character of fate. In pediatric palliative care, however, the concerns relevant to resilience are more generally understood within the framework of remaining whole or intact in the face of their health related challenges.

Intactness is different than "bouncing back" or "biopsychospiritual homeostasis" (Richardson, 2002), even though disruption must occur to activate its components. The approach of a palliative care team has, as its foundation, the idea that disease, pain, and suffering may threaten the intactness of a person. This is not to say that the phenomenon of resilience is not appreciated and it is true that the multidimensional aspects of that intactness approximate resilience. Resilience is not, however, part of the dominant framework. The clinical realities in pediatric palliative care have led to an appreciation of the ability of a child within a family system, confronting serious illness, to maintain a sense of personal intactness, a way to continue engaging and living in a manner consistent with which they are recognized to be. Because of the amount of distress in patients due to physical pain and symptoms, difficult choices and trade-offs, or compromising the meanings and values of life, the "steeling" effect of risk is not trusted but ameliorated. Suffering and its minimization is the central concern in palliative care. Palliative care aims to improve the quality of life of patients facing life-threatening illnesses, and their families, through the prevention and relief of suffering.

Much of the how suffering is conceptualized comes out of the work of Eric Cassell (2013). Suffering is understood as an affliction of the person, not the body. Organs or body parts, the focus of biomedicine, do not suffer, but people with related lives filled with meaning and aspirations do. This becomes especially true with children having extraordinary disabilities or life-threatening diseases. According to Cassell (1991) understanding suffering implies learning to recognize the "particular purposes, values, and aesthetic responses that shape the sense of self whose integrity is threatened by pain, disease, and the mischances of life." Symptoms may provoke suffering, but that suffering is importantly related to the meaning or attribution given to the symptom. For example, some people may endure substantial pain without great suffering, as in childbirth, while some suffer greatly without a great amount of pain, as can be seen when the throbbing in an osteosarcoma patient's bone is seen as a sign of disease worsening and the heralding of death. Because of the complexities of speaking with children of varying ages when they face profound difficulties, this may be worsened by unstated fears, mutual pretence, where neither parent nor child discuss their fears out of an obligation not to upset the other, or the ultimate burden of the symptom. Pain intensity, fear of pain and catastrophizing predict function and reflect suffering, yet those with the remaining capacity for "dispositional optimism" are more likely to find their lives tolerable (Cousins, Cohen, & Venable, 2014). Suffering can be reduced when preexisting expectations and goals are withdrawn from one anticipated future and finds meaningful hold in another determined fate. Suffering involves a sense of the future and identity.

Through this attention to suffering, pediatric palliative care has transformed the understanding of the patient experience. Palliative care has a developed literature that supports efforts to address suffering by addressing symptoms, understanding them, showing their relationship to suffering, and supporting a family process. Research on the symptom burden of children and the accompanying suffering (Wolfe et al., 2000), characterization of those aspects of symptoms that are of greatest concern to parents and family (Pritchard et al., 2010), the promotion of disclosure by clinicians through careful discussions with parents about prognosis and its support of hopefulness (Mack et al., 2007, 2009) and the impact of parents failing to speak frankly with their children and later regret (Kreicbergs, Valdimarsdottir, Onelov, Henter, & Steineck, 2004), to name some work, contribute to a general, honest, and supportive approach in the care of children with life-limiting and life-threatening diseases. In this area of research, suffering and intactness have face validity and an entrenched conceptualization that the resilience paradigm may have difficulty displacing.

There are material, psychological, and spiritual complications that occur when the lives of children, and their families, become medicalized when facing serious illness. Palliative care clinical practice extrapolates from that the implications for suffering, wholeness and intactness and the multidimensional aspects of illness affecting both the child and the family. Palliative care treatment plans attend to the global concept of suffering while addressing specific symptoms and processes of communication. Among children with serious illness, palliative care involvement is associated with improved communication outcomes and decreased physical and psychological suffering in children (Wolfe et al., 2008).

Palliative care has a focus on minimizing suffering and promoting deliberate, meaningful self-determination in the face of serious illness. Addressing symptoms, supporting the role of parental goals and preferences and, when possible, supporting the child's voice through the process of care, have important implications for the child's resilience even as they support their intactness and respond to their suffering. While there remain important questions about whether the paradigm of resilience has unique and persuasive offerings to make to the field, the motivations in palliative care may be understood as promoting and sustaining resilience, as the child's sense of intactness is supported and protected. There are shared insights from the attention to the developing child, to the influence of life events, and to the drive toward meaningful adaptation, that make resilience a crucial issue in pediatric palliative care.

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Chapter 8
Resilience and Pediatric Cancer Survivorship in Cultural Context

Jaehee Yi, Min Ah Kim, and Jesmin Akter

Having cancer is officially recognized as a potential trauma threat in the *Diagnostic Statistical Manual of Mental Disorders* (5th ed.; *DSM–5*; American Psychiatric Association, 2013). However, there are countless triumphant individuals, including children, who have survived, and even thrived, after cancer. An estimated 175,000 children under the age of 15 are diagnosed with cancer each year worldwide. The overall 5-year survival rate for pediatric cancer is around 5–10 % in Bangladesh, the Philippines, Senegal, Tanzania, and Vietnam; 30 % in Morocco; 40–60 % in Egypt, Honduras, and Venezuela; and 81 % in the USA (American Cancer Society, 2014). As of 2010, approximately 380,000 survivors affected by childhood and adolescent cancer live in the USA.

Despite the increasing global childhood cancer survivor population, there are surprisingly few cross-cultural studies on resilience and childhood cancer survivorship. Although studies of cancer survivors have been conducted in different countries, truly cross-cultural comparisons, encompassing values, ideas, and norms (Gunnestad, 2006), have not adequately been attempted (Gray, Szulczewski, Regan, Williams, & Pai, 2014). Considering that illness experiences are socially and culturally affected and constructed (Kleinman, Eisenberg, & Good, 1978), the cultural aspects of cancer survivorship warrant research and practice attention. Although cultural discourses surrounding “strength,” “resilience,” and “survivorship” are becoming increasingly developed, much global research in pediatric psycho-oncology is still based on biomedical models of disease—a deficit model that primarily documents the negative psychosocial aspects of cancer (Parry & Chesler, 2005). With globalization occurring at a dramatic speed and scope, research must

J. Yi, Ph.D. (✉) • J. Akter, M.Sc. (✉)
College of Social Work, University of Utah, Salt Lake City, UT, USA
e-mail: jaehee.yi@utah.edu; jesminakter2007@gmail.com

M.A. Kim, Ph.D.
Department of Social Welfare, Myongji University, Seoul, South Korea
e-mail: minahkim@mju.ac.kr

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anticipate and accommodate the realities of diverse populations of survivors from different cultural backgrounds living together. Understanding resilience in pediatric populations in multicultural contexts is essential for promoting research and developing adequate and appropriate services and psychosocial interventions.

Fostering resilience is an important part of enabling children with cancer to overcome traumatic illness, adjust to life after cancer, and thrive into adulthood (Wu et al., 2015). As we will review in this chapter, strategies to promote resilience vary across different cultural contexts, especially because illness and disease is perceived and interpreted differently across cultures. In the field of social work, it is essential to understand and help people in their own environment, at the individual, family, community, and cultural levels (Mattaini, 1995). Social workers provide services by using the "person-in-environment" paradigm and assessing the patient and family's particular resources, strengths, and limitations (Glajchen, Blum, & Calder, 1995). We will review the findings of our recent cross-cultural cancer survivorship study in order to identify potential cultural factors that affect resilience in pediatric cancer survivorship.

The Korean Childhood Cancer Survivorship Study

The Korean Childhood Cancer Survivorship Study (KCCSS) was one of the first to examine the positive and negative psychosocial impacts of childhood cancer on adolescent and young adult survivors in Korea. Participants were childhood cancer survivors between 15 and 39 years old who had completed all cancer treatment (e.g., chemotherapy, radiation therapy, and bone marrow transplants) at the time of the study. Participants were recruited through online and off-line announcements of the study at advocacy foundations and support groups for childhood cancer survivors and their families throughout Korea. Because this population can be difficult to reach once medical treatment is complete, due to stigma attached to cancer in Korean culture, snowballing method was additionally used to recruit participants.

A combination of qualitative and quantitative methods was employed in the study. Qualitative hour-long interviews with 31 individual survivors were conducted in Korean by phone or in person by two researchers knowledgeable about pediatric cancer survivorship. The interview included discussion of the survivors' past and present cancer-related experiences, the positive and negative impacts of cancer on their quality of life, the roles of their families, their health beliefs, and suggestions for services.

Structured questionnaires were also mailed or emailed to potential participants, and 225 childhood cancer survivors who met our study criteria responded. The survey questionnaires included questions on psychological distress, post-traumatic stress disorder (PTSD), posttraumatic growth (PTG), stigma towards cancer survivors, spirituality, social support availability, self-esteem, coping strategies, optimism, communication about cancer experiences, perceived functioning, sociodemographic variables (e.g., age, gender, marital status, education, and employment), and cancer-related variables (type of cancer, cancer recurrence, age at diagnosis, and time since diagnosis). Most of the variables were measured using existing scales, including the Brief Symptom Inventory–18 (BSI-18; Derogatis, 2000) for psychological distress; the Medical Outcomes Study Social Support Survey (MOS-SSS) (Sherbourne & Stewart, 1991) for perceived availability of social support; the Posttraumatic Stress Diagnostic Scale (PDS; Foa, Cashman, Jaycox, & Perry, 1997) for PTSD; the Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996) for PTG; the Life Orientation Test (LOT; Scheier, Carver, & Bridges, 1994) for optimism; the Medical Outcomes Study Short Form-8 (SF-8; Ware, Kosinski, Dewey, & Gandek, 2001) for perceived functioning; the Global Self-Esteem Scale (Rosenberg, 1965) for self-esteem; and the Daily Spiritual Experiences Scale (Underwood & Teresi, 2002) for spirituality. Some measurements were tailored from the original version for use with childhood cancer survivors. For example, communication was measured by using a single item of talking about stressful events derived from a previous study (e.g., Murray, Lamnin, & Carver, 1989); perceived public stigma was measured using a combination of subscales from the Social Impact Scale (Fife & Wright, 2000) and the Devaluation-Discrimination Scale (Link, Cullen, Struening, Shorout, & Dohrenwend, 1989); and coping strategies were measured using items modified from the Brief COPE (Carver, 1997). As described in Kim and Yi (2013) and Yi and Kim (2014), the English version of the questionnaire was translated following rigorous translation procedures, and modified based on cultural considerations by the authors who are bilingual and bicultural in English and Korean.

Findings from the qualitative and quantitative data were used to develop psychosocial programs and inform future research with this population. Several manuscripts on the study findings have published in the fields of social work (Kim, Yi, & Kim, 2014), nursing (Kim & Yi, 2012, 2013; Yi, Kim, & Sang, 2016; Yi, Kim, & Tian, 2014), and psychology (Yi & Kim, 2014). In what follows, we introduce our Culturally Directed Model of Resilience Work. We highlight four culturally mediated processes from our data—social connections, confronting cancer, coping, and growth—that we believe are relevant to resilience in this model.

The Culturally Directed Model of Resilience Work

We propose a Culturally Directed Model of Resilience Work, which is informed by our findings and current literature in pediatric cancer survivorship across diverse cultural contexts. Four important points must be emphasized: First, in this model resilience is conceptualized as a dynamic process in which adaptation depends on interaction between personal and environmental factors (Margalit, 2003; Velichkovsky, 2009). Second, because what constitutes “risk” and “doing well” is culturally variable, the process of resilience as a whole is influenced by culture. Third, individuals are active agents in the process of resilience. When one faces a major life challenge, protective and risk factors interact to help or hinder the person in adjusting to the challenge. This is not a passive process; rather, the individual actively participates and responds to the situation and culture contributes to the individual's response. We call this process "resilience work," meaning that effort is put forth in multiple social domains to create a resilient responses. Fourth, resilience experiences accumulate and become part of the person. During and after one has experienced a major stressor, one may find growth in his or her identity, coping skills, and social capital, and become a better, more resilient person (Garland et al., 2010; Velichkovsky, 2009). When confronting the next life challenge, he or she deals with the situation with up-scaled sets of protective factors enhanced by the previous stress experience.

In the following sections, we will examine four factors affecting the Culturally Directed Model of Resilience Work: Social Connections; Confronting Cancer; Coping; and Growth. Our discussion will be based on insights from the KCCSS findings and current literature in pediatric cancer survivorship.

Social Connections

Family, friends, teachers, neighbors, health care staff, and other significant people in a child's social ecology all have the ability to help them overcome adverse situations. Family members, as immediate caregivers, play a particularly critical role in helping children cope with cancer. Resilience is clearly not only the result of the individual's positive behavioral patterns and functional competencies; rather, it is the combined effect of the family and individual's psychosocial health and well-being (McCubbin & McCubbin, 1996). Likely due to the importance of the family's role in pediatric cancer survivorship, most of the studies on resilience in this field examine the family members' social resources rather than those of the cancer-affected child (Kawakami et al., 2013; Rosenberg, Baker, Syrjala, Back, & Wolfe, 2013). A recent review article by Gray et al. (2014) found that out of 72 articles published between 1980 and 2012 on cultural issues surrounding children with pediatric cancer or their families, only eight articles included the perspective of patient informants themselves. For example, Brody and Simmons (2007) explored the resources that help fathers adapt to life after their child's diagnosis. They found that support from extended family, the church, and health care professionals were necessary for fathers to remain positive during their child's illness. There is no doubt that family members' psychosocial health and well-being are important—children with cancer who reported higher family function were more resilient than their counterparts (Kim & Yoo, 2010). Nonetheless, more empirical studies on social resources directly connected to the *child* need to be conducted. In the following passages we suggest several cultural factors that should be considered while exploring this topic.

The degree and nature of care the family provides is affected by a variety of cultural differences including boundaries, roles, and dynamics. For instance, involvement of extended family members such as grandparents, aunts, and uncles in the child's care differs by ethnic groups. Yi and Zebrack (2010) found that, for Mexican and Hispanic children with cancer, extended family systems were an essential part of the coping process. In Korea, where cancer is extremely stigmatized, the family may struggle with communicating the needs of their children and asking for social support outside of the family (Yi, 2009). Further, in some cultures gender and ethnicity may determine the psychological support that is available within the family (Yi, 2009). For example, female cancer survivors reported significantly less support from friends and higher negative affect compared to males; and ethnic minorities such as African Americans, Asians, and Hispanics reported lower friend support than whites, in Wesley, Zelikovsky, and Schwartz's (2013) study on adolescents with cancer in the USA. Attention should be paid to these factors when attempting to understand social connections in pediatric cancer survivorship.

The parent–child relationship is vital in every child's development and even more imperative for a child going through an adverse circumstance like cancer (Orbuch, Parry, Chesler, Fritz, & Repetto, 2005). Again, this relationship varies cross culturally. Parents provide many different kinds of support for their child, including instrumental, informational, and emotional support. For instance, in both Native American and African cultures relationships are oriented towards sharing, networking, and cooperation and these in turn become positive factors in fostering resilience. Among Latinos, family relationships and parental influence have a strong role in fostering resilience and encouraging youths to stay away from high-risk behavior (Gunnestad, 2006). One of the relevant roles that parents can play to promote the child's resilience is modeling through words and actions. Phillips and Jones (2014) provided an example of a Latina mother whose words (e.g., "You can get through this," "You're strong," "We're gonna take care of you," and "We're gonna help you.") gave her child emotional support to cope with cancer. By contrast, in India parents are discouraged from informing children about their disease and including them in the decision-making process of treatment (Seth, 2010). This can delay the treatment process and the receipt of counseling services post treatment (Seth, 2010). For more on the role parents play in promoting children's adjustment to chronic illness, see Hoehn et al., this volume.

Since they may miss large parts of school education and activities, cancer-affected children are challenged with achieving social development milestones (Brown, Bolen, Brinnkman, Carreira, & Cole, 2011). Missed experiences in school and the associated lack of development and skills in making friends contributed to social isolation of childhood cancer survivors in many studies (e.g., McLoone, Wakefield, & Cohn, 2013; Yi & Zebrack, 2010). In the KCCSS, it was found that although children were interested in going back to school, they hesitated due to a lack of confidence in school activities, and had anxiety about relationships with peers (Yi, Kim, Hong, & Akter, 2016). The participants who reported being bullied by peers were isolated; in contrast, some of the participants received assistance from their peers and for them school reentry was easier. Unfortunately, some of the participants also had a difficult time with teachers who were unwilling to understand their school adjustment problems. Without support from their peers and teachers the participants felt isolated, which affected their coping process.

Studies conducted in western countries produced similar findings. McLoone et al. (2013) report that negative social reactions are the most challenging aspect for successful school reentry for children with cancer. Specifically, peer teasing and rejection were identified as the major barriers (Chekryn, Deegan, & Reid, 1987; Fraser, 2003; McLoone et al., 2013). Investigating negative cultural perceptions about cancer and the accompanying difficulty of school reentry is especially important since negative social environment is often a better indicator of posttraumatic stress symptomatology than lack of positive support (Ullman & Filipas, 2001; Zoellner & Maercker, 2006). For more on the transition to adolescence in chronically ill children, see Lennon et al., this volume.

Finally, in the KCCSS (Kim & Yi, 2012), pediatric cancer survivors expressed a strong need to connect with other survivors and wanted to be involved in mentor-mentee relationships, especially with cancer survivors who went on to find success in their careers and other areas of life. These "veteran" survivors can act as role models and also provide hope for stressed parents (Parry & Chesler, 2005).

Confronting Cancer

How and when a child learns of their illness will influence their ability to be resilient. Disclosure of diagnosis varies greatly by culture. Gray and colleagues' review paper (2014) stated that parents in some countries (i.e., Taiwan, China, and Japan) prefer not to inform the child of his or her illness. Perhaps the parents are reluctant to discuss such a difficult topic, struggle with how much information should be provided, or worry about the stigmatizing effects of illness on the child and the family. By contrast, in western cultures the child's autonomy is valued (Seth, 2010), and medical professionals generally believe that disclosure of diagnosis helps the child deal with treatment and increases their participation in care.

Gray et al. (2014) also point out that disclosure of diagnosis helps children seek social support; however cultural influence may vary in this aspect too. Mayer et al.'s (2005) cross-cultural study reports that US physicians preferred informing school personnel and classmates about the health status of children, while Japanese physicians did not. Indeed in Japan it is common for cancer-affected individuals to undergo extended hospitalization in order to avoid social stigma until the effects of treatment have completely disappeared.

Although Wong and Chan (2006) suggested that the practice of not disclosing diagnosis to the child has been decreasing in China, we found in the KCCSS that a majority of the Korean qualitative interview participants were not told of their diagnosis at the time of treatment (Yi, Kim, Grahmann, & Wu, 2016). Without communication, opportunities for modeling resilience and obtaining social support might be missed. It is important to note, however, that the impact of disclosure and communication about cancer experiences can vary across social networks even within the same cultural context. In a follow-up study to the KCCSS conducted with 68 childhood cancer survivors in Korea, it was found that in addition to individual-level factors, some network-level factors (i.e., the relationships the survivors held and the nature of social support they were engaged in) impacted their discussion about diagnosis and cancer experiences (Kim, Yi, Prince, Nagelhout, & Wu, 2016).

The Self-Sustaining Process Model (Hinds & Martin, 1998) posits that adolescents experiencing cancer go through four phases: *cognitive discomfort*, *distraction*, *cognitive comfort*, and *personal competence*. Working through these four steps enables cancer survivors to become competent and resilient. Ishibashi et al. (2010) found that adolescents who were directly informed of their cancer experienced resilience, successfully moving through each of the four phases of the model. Those who learned of their diagnoses indirectly did not experience a complete passage through the phases.

Although parents and other caretakers may have good intentions when they don't tell children of a cancer diagnosis (perhaps wanting to protect the child from seemingly unnecessary pain and suffering), these findings indicate that doing so might actually hinder the child from successfully confronting the reality of the situation and ultimately being able to grow from the experience (Hatano, Yamada, & Fukui, 2011; Yin & Twinn, 2004). Even worse, the child often still indirectly learns (such as by overhearing a discussion) what is happening, regardless of the parents' desire to keep it a secret. A majority of the survivors interviewed in the KCCSS reported that they sensed something was wrong even though they did not receive any information about their diagnosis. Consequently, many resorted to searching online or worrying alone to try to fill the gap between the lack of information and the sensed reality (Yi et al., 2016a). Indirectly or incorrectly learning about the cancer diagnosis seems to be common in cultures such as Korea where cancer is a taboo with negative public perception. Secrecy can produce a preoccupation with the matter even after the truth is disclosed (Lane & Wegner, 1995). Stress resulting from the secrecy surrounding cancer among pediatric cancer survivors is a fruitful area of future research.

About 40 % of the KCCSS participants expressed agonizing over the question "Why did I get cancer?" Some survivors attributed their cancer to internal factors, such as being bad, or to bad eating habits, stress, characteristics, heredity, genetics, or to magical thinking (e.g., "I thought of negative things, so I got cancer") while others attributed their cancer to an external cause, such as bad luck, a medical condition, or the environment (Yi et al., 2016a). The common theme in the questioning was that the survivors wanted to find out why they were suffering and to come to terms with the situation by settling on answers that seemed reasonable to them. Kleinman (1988) suggests that sickness raises two fundamental questions for the sufferer: "Why me?" and "What can be done?" Humans make sense out of chaos by repeating and pondering questions, creating theories, and attributing causes to situations (Kelley & Michela, 1980). Surprisingly little research has been done on how the cancer-affected child deals with such questions, especially in those cultures where cancer talk is secretive. Illness attribution studies have been mostly conducted on parents' attribution of cancer causes (Cimete & Kuguoglu, 2006), with few on the *patient's* causal attribution. Caretakers might be able to more directly confront cancer together with their child if they gain a better understanding of the process of understanding the illness.

In Yuen, Ho, and Chan's (2014) study, hope and posttraumatic growth was mediated by cancer-related rumination among young adult childhood cancer survivors. Intervention studies are warranted to discover how to best balance the stress of confronting hard questions with the comfort of making sense. Conversely, if meaning is not successfully made, the patient may end up suppressing their feelings of dissonance, which may harm them more in the long run. A study of the victims of the Perth flood revealed that thought suppression was one of the best predictors of symptom severity, even after statistically controlling for the emotional intensity of the specific circumstances (Morgan, Matthews, & Winton, 1995). The possibility that thought suppression contributes to the persistence of PTSD was also suggested by a prospective longitudinal study of patients injured in motor vehicle accidents (Ehlers, Mayou, & Bryant, 1998). How thought suppression occurs and works in different cultures is not known and warrants future research. With this caveat, pediatric cancer survivors should be encouraged to confront cancer and should be supported by parents, caretakers, and other social connections to make meaning from their experiences.

About 20 % of the participants in the KCCSS were classified as psychologically distressed (Kim & Yi, 2013), a higher prevalence compared with findings from the Childhood Cancer Survivors Studies in the USA. Although further studies on the predictors of such distress are needed, we theorize that the cultural norm of suppressing and tabooing cancer talk may play a role.

Coping

Culture also influences the way individuals manage life challenges and adjust to new circumstances. A recent review by Gray et al. (2014) describes how adolescent and young adult Latino patients coped with their cancer diagnosis by employing positive attitude, humor, and meaning finding (Jones et al., 2010). While European American and Latino American mothers of children recently diagnosed with cancer shared some coping strategies (e.g., gathering information, seeking professional help, participating in activities, problem solving, positive thinking, orienting in the present, reframing, avoiding, and practicing religion), they also coped in culturally distinct ways. In Johns' study (2009), European American mothers used compromise such as negotiating with the medical team for their children's treatment plans while Latina American mothers normalized the situation and kept perspective. Other studies indicate that Iranian, Latino, and Chinese families incorporated information-seeking strategies as a way of regaining a sense of control (Aguilar-Vafaie, 2008; Johns et al., 2009; Wills, 1999), while South African families tended not to because they perceived receiving information about their illness an unhelpful additional stressor (Jithoo, 2010). People tend to choose the coping strategies that are compatible with the specific cultural settings that they belong to.

Incorporating coping strategies is part of the "resilience work" concept that we propose—that individuals consciously put efforts into making resilient choices and achieving resilient outcomes. From that perspective, it is prudent to ascertain why cancer patients and survivors in certain cultures tend to use particular strategies to deal with stress. In the current literature on children with cancer, research is focused on what kinds of coping strategies are widely used (Li, Chung, Ho, Chiu, & Lopez, 2011) and what outcomes, especially positive or negative, they seem to produce (Aldridge & Roesch, 2007; Castellano et al., 2013; Park, Edmondson, Fenster, & Blank, 2008). Despite knowing that cultural influences play a significant role in resilience, understanding why pediatric cancer survivors use specific types of coping strategies and whether such strategies are culturally bound and resilience-promoting has not been fully explored.

The same coping strategy might be both adaptive and maladaptive in different contexts (Gray et al., 2014). Buse, Burker, and Bernacchio (2013) explored cultural variations of coping strategies (including locus of control, emotional regulation, somatization, self-enhancement, dissociation, family and community support, and spirituality such as rituals and ceremonies) in resilience as a response to traumatic experience. They found that although perceived internal locus of control is considered a resilient response in individualistic cultures, it may not apply to individuals from Japanese and Latino cultures where passive resignation to adverse circumstances and acceptance of one's fate is valued.

In the KCCSS, childhood cancer survivors in Korea used diverse coping strategies, such as *Approach Coping*, representing problem-solving activities directed at the source of the stress; *Social Coping,* representing behaviors directed toward relationships with others; and *Avoidant Coping,* representing behaviors that orient the focus away from the problem (Yi, & Kim, 2016). Unlike in Western cultures, where humor may be used to avoid the stressful situation in a positive way, in Korea using humor as a coping strategy was related with poorer mental health. Social coping, such as seeking social support, was also related to poorer mental health in this population, demonstrating the different meanings and nature of coping strategies in cultural context.

Moos (1984, 2002) offers a coping and stress model that elaborates on the exchange among the environmental system, the personal system, and transitory conditions. His model investigates how the social climate and ongoing stressors interact with individuals' personal characteristics and resources. Moo's transactional model also theorizes that culture plays a key role, influencing each coping strategy that an individual employs, and subsequently affecting the individual's health and well-being (Chun, Moos, & Cronkite, 2006; Olah, 1995). In cultures oriented toward individualism, personal autonomy, individual rights, and self-fulfillment are emphasized. On the other hand, collective cultures place a higher emphasis on duty and obligations to the in-group, and fulfillment of social roles (Chun et al., 2006).

Interdependent view influences an individual's cognition, emotion, and motivation in collective cultures, such as Asian ones (Markus & Kitayama, 1991). Research has shown that strong connectedness with others is employed in coping with stress in these cultures, such as Asian American families of September 11th victims (Yeh, Inman, Kim, & Okubo, 2006). Participants shared that their feelings of loss is not individual, but a loss for the entire family; if a family member is sick, the family is sick too. As a result, it is the family's responsibility to take care of each other during stressful times. Similarly, they seek emotional help from their friends, church members, and community. A recent study by Nguyen and Clark (2014) indicates that collectivism predicts both positive attitudes and higher levels of self-efficacy among Vietnamese American women's breast and cervical cancer screening. The authors argue that Vietnamese women may feel it is mandatory for them to take care of their health so that they can take care of their families; this perspective motivates them for cancer screening.

Although coping strategies are too complex to simply dichotomize, approach and avoidance are two basic modes of coping with stress found in the literature (Roth & Cohen, 1986). We propose a more flexible and culturally sensible approach for thinking about coping in multicultural patient populations: it may be most advantageous for pediatric cancer survivors to oscillate between approach and avoidant modes of coping. Pediatric cancer survivors should be helped to confront (i.e., actively understand and process) their thoughts and all the accompanying emotions about why they got cancer, even while sometimes forgetting and avoiding the fact that they are dealing with it. Coping should be treated as a skill that can be learned, rather than a stable characteristic like a trait. Janoff-Bulman (1992) said that traumas may shatter deeply held and unexamined assumptions about how we believe the world and ourselves to be. Testing and reevaluating assumptions can take place spontaneously through the two-track cycle of re-experiencing (confronting or approaching) and avoidance. Pediatric cancer survivors should be helped to smoothly navigate this coping "dance."

Growth

Individuals respond differently to traumatic life events. When trauma strikes, our fundamental assumptions may be reexamined or contested in the face of our own vulnerability and fragility (Janoff-Bulman & Frieze, 1983). It is hypothesized that individuals with more rigid pre-trauma views are more vulnerable to posttraumatic stress responses (Foa, Ehlers, Clark, Tolin, & Orsillo, 1999). This might suggest that children, with fewer pre-formed world views, would be less vulnerable to the after effects of trauma stress. Pediatric cancer survivors frequently ponder existential questions about life and death and its meanings, and many survivors report feeling as if they have quickly grown and matured vis-à-vis their peers (Yi & Zebrack, 2010).

Parry and Chesler (2005) explored how cancer can lead to positive psychosocial outcomes, including thriving and experiencing posttraumatic growth. Long-term survivors of childhood cancer reported a variety of positive changes, including increased psychological maturity, feeling greater compassion and empathy, having new values and priorities, recognizing new strengths, increased recognition of vulnerability and struggle, and making changes in life outlook and coping skills. These themes are consistent with the general themes of posttraumatic growth, such as feeling a greater appreciation of life, feeling personal strength, expecting new possibilities, feeling related to others, and experiencing spiritual change (Tedeschi & Calhoun, 1995).

Positive life changes after a cancer diagnosis are commonly reported at the rate of 53–95 % in adult cancer survivors (Stanton, Bower, & Low, 2006), and growth experiences after cancer seem to be common across diverse cultures (Ho, Chan, & Ho, 2004; Kamibeppu et al., 2010; Schroevers & Teo, 2008; Thombre, Sherman, & Simonton, 2010). It is difficult to confirm what makes some people grow more than others after cancer as there is a lack of congruence regarding posttraumatic growth associations. Despite inconsistency in direction of relationship, as summarized in a study by Yi, Zebrack, Kim, and Cousino (2015), some studies have shown that PTG is correlated with minority status (e.g., Bellizzi et al., 2009), gender (e.g., Tallman, Shaw, Schultz, & Altmaier, 2010; Tang et al., 2014; Zwahlen, Hagenbuch, Carley, Jenewein, & Buchi, 2010), age (e.g., Bellizzi & Blank, 2004; Yonemoto et al., 2009), socioeconomic status (e.g., Danhauer et al., 2013; Wang, Liu, Wang, Chen, & Li, 2014), time lapsed since diagnosis/treatment (e.g., Danhauer et al., 2013), and optimism and social support (e.g., Danhauer et al., 2013; Michel, Taylor, Absolom, & Eiser, 2010; Nenova, DuHamel, Zemon, Rini, & Redd, 2013).

Posttraumatic growth is influenced by cultural factors (Calhoun, Cann, & Tedeschi, 2010); thus deeper understanding and empirical examination of pediatric cancer survivorship in the context of culture is merited. Complicating the matter, both positive and negative impacts of cancer seem to coexist. In a Photovoice project (Yi & Zebrack, 2010), which is a participatory visual research methodology, one childhood cancer survivor's self-portrait showing half of her face bright with exposure to the sun and the other half shaded is a poignant representation of the complex and Janus-like impact of cancer as a trauma. Such complexity might be inevitable, because growth can occur only with trauma major enough to transform the person (Tedeschi & Calhoun, 1995).

Posttraumatic growth is frequently associated with identity work or change in self, described as "I AM" by Grotberg (1995), as "personal competence" by Hinds and Martin (1998), and as "personal strength" by Tedeschi and Calhoun (1995). As a child experiences cancer, she adopts a social identity, or knowledge that she belongs to a social category or group (Hogg & Abrams, 1988). In this case, she self-identifies as a cancer survivor. An identity of "cancer survivor" might have different cultural connotations and meanings, but has not yet received adequate research attention. In a follow-up study of the KCCSS (Yi, Kim, Choi, & Kim, n.d.), we asked Korean pediatric cancer survivors to respond to an appropriate and preferred appellation for those who completed cancer treatment. The majority preferred "those who are cancer-cured" to "cancer survivors." Although these are preliminary findings requiring further qualitative inquiry, we theorize that "cancer-cured" is more appealing to Korean survivors as cancer is so heavily stigmatized in their culture. "Cured" connotes separation and detachment from cancer. This obviously contrasts with other cultures, such as the USA, where those who experienced cancer are encouraged to proactively support and advocate for each other as a community of survivors.

Posttraumatic growth is thought to be promoted by sharing, telling stories, and making sense of experiences (Tedeschi & Calhoun, 1996). Cultural factors seem to influence whom you share the cancer experience with and what consequences such cancer disclosure might bring. Gray et al. (2014) summarized in their literature review that families from collectivist cultures are more comfortable sharing information with other parents of children with cancer over friends, relatives, and neighbors. Due to stigma surrounding cancer, about half of Koreans in a national survey reported that they would not disclose it (Cho et al., 2013), likely resulting in less social support. In the KCCSS (Kim et al., 2014), childhood cancer survivors had experienced bullying, prejudicial insults, avoidance, social rejection and isolation, and discrimination during and after cancer treatment. Such stigma experiences lead them to feel self-pity, self-conscious about being different, and anxious and selective in disclosing their cancer history and building social relationships. In the KCCSS (Kim & Yi, 2014), public stigma perceived by childhood cancer survivors impacted their psychological distress through self-disclosure, internalized shame, and perceived availability of social support, demonstrating the role of cognitive and social resources in promoting psychological health even in stigmatized settings. Whether missing social interaction opportunities, due to public stigma, interferes with potential growth is a question requiring empirical cross-cultural study.

Though child cancer survivors often report becoming more resilient and ready to confront future life challenges (Rosenberg et al., 2013; Rosenberg, Yi-Frazier, Wharton, Gordon, & Jones, 2014), there is some evidence that both positive and negative effects of trauma erode over time. Posttraumatic stress symptoms seem to decline considerably for the majority of survivors within 3 months post-diagnosis or following treatment completion (Manuel, Roth, Keefe, & Brantley, 1987; Mundy et al., 2000). Similarly, posttraumatic growth may be stronger in the immediate year or two following diagnosis and treatment than after several years of survivorship (Stanton et al., 2006). In the KCCSS (Yi & Kim, 2014) shorter time since diagnosis was associated with greater levels of posttraumatic growth. Cancer is a chronic illness with physical and psychosocial late effects requiring life-long surveillance and attention (Yi et al., 2014). If resilience dwindles over time, it might be prudent to develop culturally sensitive interventions that sustain these positive effects.

Conclusion

Having examined the cultural factors that affect resilience in pediatric cancer survivorship in the previous sections, we now turn our attention to five suggested directions for future research and practice. First, further research is required to explore the way children and families communicate about and process the cancer experience. A supportive environment for existential question-asking is an important feature of productive communication and role modeling for resilience within the family. Second, the child's social relations and resources in the cultural context should be researched, given that stigma and misunderstanding about cancer and survivorship exists in certain cultures. Perceptions and attitudes of the child's parents and friends are critical and greatly influence the child's adjustment and resilience. Mentor and mentee relationships among survivors should be encouraged, especially in those cultures where cancer history and survivorship identities are not disclosed for fear of rejection. Third, unique or aggravated challenges that specific social factors, such as gender and ethnic minority, pose in different cultures should be sensitively ethnographically studied. Fourth, coping strategies in the context of culture should be examined. The two-track approach of actively confronting and purposely avoiding the challenges of cancer may be a starting place to build an intervention. Finally, the complex dual phenomena of coexisting stress and growth in pediatric cancer survivorship should be studied. Combined, these areas for future study should reveal effective practice guidelines for promoting resilience in pediatric cancer survivors and their families. Although researchers have voiced the need for developing psychosocial interventions for children with cancer, such research is limited (Kazak, 2005). Moreover, evidence-based studies on culturally sensitive interventions are non-existent, perhaps because there is limited participation of racial and ethnic minorities in psychosocial interventions compared to their white peers (Guidry, Torrence, & Herbelin, 2005).

Because different cultural attributes and values affect survivors' behavior and participation (Guidry et al., 2005), assessment of the person's background is the key area in which cultural attributes need to be considered in developing interventions. Research has also suggested that cultural beliefs directly affect cancer control and survivorship (Aziz & Rowland, 2002; Guidry et al., 2005); thus, a "one size fits all" intervention style is unrealistic (Guidry et al., 2005). Language education and cultural competency training are also imperative for health care providers serving ethnic minority groups (Aziz & Rowland, 2002; Guidry et al., 2005). For more on fostering resilience by attending local coping practices, see Munford this volume. For example, in collectivist-oriented cultures, the relationship with the immediate family and extended family may provide Latino patients a strong support network (Nápoles-Springer, Ortíz, O'Brien, & Díaz-Méndez, 2009). A study conducted on a peer support intervention for Spanish-speaking Latinas with breast cancer indicates that involving family members could help alleviate the stress on the patient (Nápoles-Springer et al., 2009). In a shame and stigma-prevalent culture, narrative therapy intervention might be potentially effective due to its emphasis on objectifying the problem and separating the person from the problem (White, 2007).

Children who go through cancer diagnosis and treatment demonstrate resilience in different ways. Pediatric cancer patients are not just victims, but a flourishing population gaining strength from adversity. Developing culturally informed methods to strengthen resilience will positively influence cancer survivors, their family members, and their community across diverse cultural contexts.

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Part III
Interventions, Therapies, and Techniques

Chapter 9
Promoting Resilience in Paediatric Health Care: The Role of the Child Life Specialist

Cathy Humphreys and Chantal K. LeBlanc

The experience of hospitalization can have a negative impact on children's[1] development (Rollins, Bolig, & Mahan, 2005, p. xvii). Since the mid-1930s, research on children's reactions to health care encounters, hospitalization, or surgery demonstrates that children may endure negative impacts such as nightmares, developmental regression, increased fear and pain responses, and changes in behaviour post discharge that can persist over time (King & Ziegler, 1981; Rennick, Johnston, Dougherty, Platt, & Ritchie, 2002; Rollins et al., 2005; Stevens et al., 2011; Thompson, 1989). Furthermore, there is an array of stressors embedded within hospitalization such as the lack of predictability of hospital routines, disruption of supportive relationships, sudden unanticipated events, and the limited control children are given which can lead to diminished resilience (Bolig & Weddle, 1988; Rutter, 1987). Certified Child Life Specialists assess individual, family, social, and health care variables in order to mitigate these negative effects and promote resilience and adaptive responses. They use play, preparation, active coping strategies, education, and expressive activities as interventions to promote resilience in paediatric patients.

This chapter will first provide a historical context of paediatric health care and the development of the child life profession as a response to the vulnerability of children in this environment. We will then use a case study to provide context and to discuss the variables the child life specialist uses to assess a child and their family's[2] protective and risk factors in responding to stress and adversity within the

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[1] Children refers to infants, children, and youth.
[2] Family refers to the child's primary caregiver(s) and sibling(s).

C. Humphreys, C.C.L.S., B.A.Sc., C.L.St.dipl. (✉)
McMaster University, Hamilton, ON, USA
e-mail: humphrc@mcmaster.ca

C.K. LeBlanc, M.H.S., C.C.L.S.
IWK Health Centre, Halifax, NS, USA
e-mail: Chantal.LeBlanc@iwk.nshealth.ca

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health care setting. In the final section, we will use the case study to explore child life interventions and to demonstrate how a child life specialist promotes resilience and adaptive responses in the health care setting.

Historical Context

Many paediatric hospitals and health care facilities now employ Certified Child Life Specialists to provide psychosocial support and interventions for children and families. The child life specialist (CLS)[3] role is "…designed to minimize stress, encourage normalization, enhance preparation and promote children's normal growth and development" (Turner & Fralic, 2009, p. 40). Although this profession is still quite young, it emerged and grew in response to awareness of the developmental and psychological effects of hospitalization on children in the early part of the twentieth century. During this time, hospitalized children were routinely separated from their families, and parents were restricted to visiting only a few hours per week (Davies, 2010). Jolley (2007) reported children were traumatized by their hospital admission because of separation from parents and because of the emotional neutrality of health care providers in their efforts to be professional and objective in their assessment and treatment of young patients[4]. While health care professionals cared about their patients, this emotion was often withheld during patient interactions. The harmful effects of these conditions were compounded by the fact that hospitalizations were excessively long compared to today's standards (Thompson, 1989). Infants and children experienced developmental regression, excessive fears, and altered behavioural patterns which persisted for days to months following discharge (King & Ziegler, 1981; Rennick et al., 2002; Rollins et al., 2005; Stevens et al., 2011; Thompson, 1989). Children were not informed about the details of their medical care out of a belief that it would protect them from experiencing unnecessary anxiety. Instead, patients grew to fear their next treatment, remained uninformed, and yearned for their loved ones to take them home. Over time, it became clear these factors not only had a negative impact on children's responses to treatment, but also adversely effected children later in life. In response to the accumulating evidence that the environment and poor quality of human interaction were negatively impacting hospitalized children, social and environmental factors as well as the psychological approach to caring for children began to change (King & Ziegler, 1981; Pond Wojtasik & White, 2009; Thompson, 1989; Thompson & Stanford, 1981).

The initiation of play programmes for hospitalized children began utilizing volunteers and staff known as "play ladies", "play leaders", or "play teachers" (Rubin, 1992; Thompson, 1989). The earliest noted play programme began in 1922 in the United States and in 1936 in Canada with nine programmes identified by 1949 in North America (Child Life Council, 2014a). The initiation of play in hospital was

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[3] CLS represents child life specialists for ease of use in this chapter.

[4] Patient refers to paediatric patients including infants, children, and youth.

thought by some to be frivolous and that if a child was hospitalized s/he was too ill to "play" (Pond Wojtasik & White, 2009). Play is however the most natural activity of childhood and the incorporation of play in the health care environment is an essential element in reducing the level of threat perceived by children in their new surroundings (Thompson, 1989). This is a fundamental belief in the child life profession.

By 1960, the American Academy of Pediatrics (AAP) developed a report and recommendations for the care of children in hospitals, recommending all paediatric units should have a playroom supplied with appropriate materials such as games, toys, and books. This respected paediatric authority also recommended that an effort should be made to recruit volunteers to supervise the playroom. In 1978, the Canadian Paediatric Society created a position statement "Child Life in Health Care Settings" advocating to hire child life professionals to meet the psychosocial needs of hospitalized children. The acknowledgement of play as an important daily need for children in hospitals was a significant step in improving patient care. It signalled recognition of the psychosocial needs of children and the impact hospitalization could have on child development (AAP, 1960; Canadian Paediatric Society, 1978; Plank, 1962).

A commitment to meeting the emotional and developmental needs of children during medical care is the foundation for the child life profession (Thompson, 1989). As noted previously, child life specialists promote effective coping and the development of adaptive responses to stressful situations through play, preparation, education, and expressive activities. While CLS now work predominantly within hospital inpatient paediatric units, they also work, to varying degrees, in many different settings where children receive health care. These include areas such as emergency rooms, diagnostic imaging, outpatient clinics, day surgery/operative care areas, rehabilitation settings, hospice and palliative care programmes, and some dental and physician offices (AAP, 2014). Child life specialists also work in mental health programmes, community-based organizations, and private practices (LeBlanc & Chambers, 2013). Today, there are over 480 child life programmes listed in the Child Life Council's Directory of Programs (Child Life Council, 2014b), in 18 countries around the world (LeBlanc & Chambers, 2013) with more than 4900 certified child life specialists worldwide. Child life programmes are considered to be "…a quality benchmark of an integrated patient-and family-centred health care system, a recommended component of medical education, and an indicator of excellence in pediatric care" (AAP, 2014, p. 1472).

The Role of Child Life Specialists and Resilience Theory

As early as 1988, child life specialists Bolig and Weddle reported on "Resiliency and Hospitalization of Children". Although contemporary research continues to extend our knowledge, this foundational article within the child life profession portrays an initial attempt to anticipate the risk factors as well as potential protective factors in the assessment and implementation of psychosocial plans for hospitalized patients. Over the past 20 years the child life field has embraced an ecological approach to resilience. Child life specialists believe in the inner strength of children and that they can cope and adapt effectively with adversity when provided with appropriate child-centred supports suited to their developmental level, temperament, and coping style. We also believe a child's resilience is impacted by their family's resilience as well as support from their larger community, e.g. school and neighbours, all concepts identified in the resilience literature (Bolig & Weddle, 1988; Eriksson, Cater, Andershed, & Andershed, 2010; Gaynard, Goldberger, Thompson, Redburn, & Laidley, 1990; Hamall, Heard, Inder, McGill, & Kay-Lambkin, 2014; Stewart & Yuen, 2011; Ungar, Ghazinour, & Richter, 2013; Zolkoski & Bullock, 2012).

This is compatible with an ecological model of resilience focusing on the processes/interactions between the child and their environment put forward by Rutter (2012) who defines resilience as "…a reduced vulnerability to environmental risk experiences, the overcoming of a stress or adversity, or a relatively good outcome despite risk experiences" (p. 336). Rutter supports the need to focus on individual differences in children's response to adversity and what individuals *do* to adjust and cope with challenges (2007, 2012). Some children demonstrate resilience when exposed to health care stressors while others may not. Furthermore, the capacity for resilience may diminish when faced with multiple stressors within a child's environment. A 7-year-old sibling named "Steven" noted in a child life session, "My sister has a brain tumour, my mom lost (miscarried) our baby, my grandpa died, and now I have diabetes. It's too much!" The cumulative effect of multiple stressors may be more than the child or their family can respond to effectively (Bolig & Weddle, 1988; Padesky & Mooney, 2012; Stewart & Yuen, 2011; Ungar et al., 2013; Zolkoski & Bullock, 2012). There are many factors that can be assessed to help determine risk to a child's resilience, as well as the strengths or protective factors which may act to support coping and hence maintain or enhance resilience (Gaynard et al., 1990; Hollon & Skinner, 2009; LeBlanc & Chambers, 2013).

Ungar et al. (2013) add to the evolving understanding of resilience by proposing that resilience is influenced by the quality of the interactions between the individual and the environmental and social systems, as well as the quality of the resources in the environment to support the child's well-being. The interactions between these systems can help mitigate/protect or can pose additional risks for a child facing adversity. Ungar's research shows that the more a child is exposed to adversity, the greater the need for a quality and stable environment to nurture and sustain well-being. This aligns with the theoretical and philosophical underpinnings of child life practice, and is the foundation for interventions to support children and families. Child life specialists assess individual and environmental (e.g. family, social, health care) factors as well as the quality of the relationships and the resources available to prevent or mitigate the negative effects of health care experiences. Child life specialists believe that children thrive when the health care environment is as child and family-centred as possible, when parents/caregivers are able to physically and emotionally be present, when children are supported, listened to and understood, and when their developmental and emotional needs are met (AAP, 2014; Luthar, 2013; Rollins et al., 2005; Thompson, 2009). The following section outlines the common evidence-based variables which a CLS uses to assess risk and vulnerability to health care experiences.

Assessing Risk, Coping, and Resilience

The following section will review some of the individual factors, family factors, and health care factors CLSs review to assess risk and resilience in children and families. While we recognize that these factors/variables[5] often interact and influence one another, we will treat them separately here for clarity.

The hypothetical case study below is a typical referral for child life specialist involvement.

Case Study 1

Cameron is a 4-year-old boy who has been admitted to the hospital for urological surgery for the third time in 2 years. Prior to the surgery, Cameron's Mom called the clinic several times asking questions about the need for the surgery, and the expected duration of the admission. She also reported financial and emotional stressors. The family was unable to come to a preparation session, usually planned for the week before surgery, due to the lengthy distance to the hospital and financial stressors.

On the day of the surgery, Cameron's mother reported to the nursing staff that Cameron had a terrible time with pain management during the last two surgeries and was tearful when he learned he needed another surgery. She also described him as a child who didn't do well with new people, did not cope well with changes to his routine and that it was always a fight to give him medicine. Cameron asked his mother if he would need any needles or "tubes" and if it would "hurt".

Post-surgery, Cameron's mom told the nurse she was worried that Cameron seemed to "not be himself". Cameron was withdrawn, avoided eye contact, and was described as "whiny" and tearful by nursing. He did not want to take his pain medication and refused to get out of his bed. Nursing staff reported that Cameron's Mom was "anxious" and very worried about him. She was having difficulty setting expectations, following through on medication administration and nursing/physician recommendations for getting him up and moving.

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[5] Variable—child life literature speaks of "variables" whereas the resilience literature speaks of "risk and protective factors", for simplicity we will use "factors".

This case contains several risk factors to resilience that would be explored as part of the CLS assessment and intervention plan. In what follows, we will review the individual factors, family factors, and factors of the medical environment that have been shown to impact resilience as they relate to Cameron's case.

Individual Factors

The child's developmental level, temperament, state/trait anxiety as well as coping style and perceptions of previous health care experiences are known individual factors which impact a child's adaptation to health care. Although there are other factors which may influence a child's understanding and overall adjustment (e.g. mobility), we will limit the focus to these five developmental and psychosocial factors.

Age/Developmental Level

It is well recognized that young children are at high risk for coping challenges in the hospital. It is reported that children functioning developmentally below the age of 4 years show more behavioural and emotional distress to intensive care (Small, 2002), hospitalization and painful procedures (Young, 2005) and surgery (Kain, Mayers, O'Connor, & Cicchetti, 1996). As in our case study, this is likely related to Cameron's limited cognitive ability to understand and make sense of the information related to those experiences.

Children's perceptions, fears, and abilities to understand what is happening change dramatically as they age. It is important to understand these variations in coping are tied to cognitive development not necessarily chronological age. Not all children develop at the same rate, and many children with communication disorders such as autism or developmental delays must receive health care. Learning disabilities can also impact a young person's ability to understand the situation. Cameron's cognitive abilities can impact how he understands his surroundings, comprehends the information being shared, interprets the context of the situation, effectively communicates his wants and needs, as well as his ability to feel safe and in control. For a full developmental account of resilience see Lennon et al, this volume.

Temperament

There are many definitions and frameworks used to study child temperament. For the purpose of this chapter, temperament will be defined as a "consistent and stable pattern of behaviour or reaction" (Koller, 2008, p. 3). Temperament and coping style are key assessment variables for child life specialists (Gaynard et al., 1990; Koller, 2008; McClowry, 1990) as knowledge about a child's most natural way of responding to events (e.g. ease in adjusting and adapting to change, the intensity of reactions, withdrawing or approaching novel situations, etc.) will aid in developing individualized care plans designed to support a child within health care contexts that are full of new people, situations, and surroundings. In a recent parent perception and satisfaction survey of child life specialist interventions, parents who rated their child as having a more challenging temperament were significantly more likely to indicate the need for and to receive more child life interventions during hospitalization (LeBlanc, Naugler, Morrison, Parker, & Chambers, 2014). Higher temperament scores were correlated, for example, with parent perception of the need for developmental support in which the child life specialist focuses on specific play activities to support or improve developmental skills; preparation for their child's health care experiences; expressive play, the opportunity to play through emotions related to stressful experiences; and family facilitation/support which includes the provision of parenting support, explanations about their child's behavioural and coping responses, advocacy on their behalf with the team and/or support for siblings. In the case study above, Cameron's mother reports he has difficulty with new people, does not like change to his routine and she describes challenges giving him medication. These behaviours provide clues that he may be a child with a challenging temperament and further assessment information from the mother would be needed.

Children who seek information, ask questions, and take an active part in regulating their feelings of stress demonstrate more positive responses to health care compared to children who disengage or avoid the stressor repeatedly. Disengagement can in turn result in poor emotional, behavioural, and physical responses/outcomes (Compas & Boyer, 2001; Eriksson et al., 2010; Graham McClowry, Rodriguez, & Koslowitz, 2008; Kain et al., 1996; Kuttner, 2010).

Trait and State Anxiety

Trait anxiety (relatively constant across situations) and state anxiety (related to the current situation) are both important individual factors explored by child life specialists. Children with trait anxiety reportedly perceive their coping as less effective, are more fearful during hospitalization (Koller, 2008) and are at higher risk for posttraumatic stress responses (Manne, 2008). Children with higher state anxiety demonstrate more negative pain memories (Noel, Chambers, McGrath, Klein, & Stewart, 2012). Children who are known to be anxious or who exhibit situational anxiety are at higher risk for coping challenges, and thus are a high priority for child life interventions to promote resilience. In the case above, Cameron's tearfulness, avoiding eye contact, "whining", and being withdrawn illustrate anxious behaviours that would prompt the child life specialist to identify him as a priority for CLS interventions. Further assessment would be needed to determine if Cameron is typically an anxious child or if this is situational.

Coping Style

Coping is the way one responds to a stressful situation, and the effortful regulatory processes one undertakes to adapt or adjust to that stressful experience (Skinner & Zimmer-Gembeck, 2007). Child life specialists recognize that a "protective" factor in one situation may be a "risk" factor in another (Rutter, 1987; Ungar et al., 2013) and therefore seek to identify and promote coping styles that are adaptive in the hospital context. For children like Cameron, with previous health care experiences, past coping responses may help predict upcoming coping responses, however this is not guaranteed. This fits with current knowledge of resilience in that a person may demonstrate patterns of resilient responses in many situations but not in all situations. Ones coping response and resilience may change depending on the situation, the environment, perceived threat, and the confidence one has in the ability to manage the stress successfully (Rutter, 2012; Ungar et al., 2013; Zolkoski & Bullock, 2012). For example, having medical interventions in a facility known to a child and family, with familiar staff, may prompt a very different response than if that same child and family required health care in a different country where they did not speak the language, understand the cultural context, or trust the health system. For a detailed account of cross-cultural coping styles please see Yi this volume.

Perceptions and Memories of Health Care Experiences

Children repeatedly report fear of pain, needles, and medical procedures, as well as being distressed by separation from family, friends, and pets (Chappuis et al., 2011; Lindeke, Fulkerson, Chesney, Johnson, & Savik, 2009; Salmela, Salanterä, & Aronen, 2009; Wilson, Megel, Enenbach, & Carlson, 2010). Children, who perceive their injury or illness as life threatening, perceive treatment as more intense, or that their risk of recurrence is high and their complications as more severe are at higher risk for negative coping responses and tend to be less resilient than children who do not believe their life is in danger (Manne, 2008). Childhood health care experiences can have long-term effects on adult health behaviours. For example, Pate, Blount, Cohen et al. found that children who report childhood fear and pain associated with medical interventions are at greater risk of becoming fearful adults, have higher pain responses and/or avoid health care follow-up (as cited in Young, 2005). Building empowered perceptions and memories of the health care experience is therefore a key focus for child life interventions. In the case above, we would further explore Cameron's past experiences and memories of health care encounters to determine if these past experiences will impact his current experience.

Family Factors

Child life specialists aim to recognize the diversity of individual and family strengths and needs in their assessment process. In this section, we will review parental anxiety, parental involvement in care, marital status and education level as well as the family's support network since these are commonly agreed upon factors which influence family resilience.

Parental Anxiety

Specialized paediatric treatments or surgical interventions are sometimes only available within larger health centres. Take, for example, a child with autism leaving his Northern aboriginal community for the first time by airplane to undergo surgery in a larger treatment centre. Changes in environment, routine, sensory stimuli, availability of family and community supports and, at times, restricted environments for cultural practices can significantly add to parental and child stress. This may begin before the family even walks through the doors of the hospital.

Parental anxiety (particularly maternal anxiety) is a key variable in the CLS's assessment process. It is predictive of a child's negative response to health care and correlated with procedural distress (Koller, 2008), poor coping for young children after an admission to the intensive care unit (Small, 2002; Small & Melnyk, 2006); post-surgery (Kain et al., 1996) as well as post-traumatic stress disorder and post-traumatic stress symptoms (Manne, 2008). Clinically, we have observed this association countless times. In our case study, Cameron's mother demonstrates anxious behaviours; calling multiple times, needing reassurance and likely experiencing significant and ongoing worry about her child, and anticipating negative responses to the health care experience. For more on the role of parents in promoting paediatric resilience see Hoehn, Foxen-Craft, Pinder, and Dahlquist, this volume.

There is a need for specific support for parents who demonstrate anxiety. A collaborative interprofessional approach with social work, psychology, and nursing is necessary to enhance family resilience and provide culturally competent care that is both respectful and responsive to the diverse needs of patients and families. Ignoring the psychological and emotional needs of parents can impact the success of the interventions for the child *and* the family. There is also a risk that maladaptive parental coping will impact post-hospitalization adjustment (Rennick et al., 2002; Small, 2002; Small & Melnyk, 2006). The source of the parental anxiety varies but may include family functioning, language barriers, potential impact to cultural or religious practices, social or economic stressors, health care stressors (the seriousness of their child's condition, level of pain, need for information, collaboration with the team), and/or the coping response of their child and extended family.

Parental Involvement in Care

The parents' ability to be actively involved in treatment and emotionally support their child during hospitalization is related to positive outcomes (Gaynard et al., 1990; Koller, 2008). When a parent is unable to physically or emotionally be present with their child, this can have an impact on parent–child attachment, the child's overall development, and coping in hospital (e.g. a parent with a pre-existing mental health diagnosis struggling to cope with her child's new diagnosis).

Child life specialists take care to plan interventions, not only to improve coping in hospital but also for the transition and recovery period after discharge. In our case study, Cameron's mom is described as "anxious" and very worried about her son. She was having difficulty setting expectations, following through on medication administration and nursing/physician recommendations for getting him up and moving which can unintentionally have implications for his pain management, length of stay, and transition home. Interprofessional collaboration and support from other members of the team such as the hospital social worker may be needed to provide support, address her worries, and promote engagement with the health care team during Cameron's recovery. When parents are not able to function in their typical manner and provide care as usual (e.g. parents whose infant has major surgery, and requires multiple tubes and equipment post-operatively can feel nervous and uncertain about if and how they can even hold their baby), this can lead to behavioural and emotional stress responses for children (Small, 2002). A preschool child, like Cameron in this situation, is often upset wanting parents to do all the care rather than medical staff, and parents often report feeling helpless and worried their child will be traumatized because of the experience. Consistent parenting, routine and a goodness of fit between parents and child are known to be protective factors for children, thus important to consider within the medical context (Eriksson et al., 2010; Graham McClowry et al., 2008).

Family Support

It has long been recognized that family support and/or social supports can mitigate or provide a protective role for children who experience adverse life events (Manne, 2008; Padesky & Mooney, 2012; Ungar et al., 2013). Having a positive relationship with at least one parent, a positive family climate, high socio-economic status, a secure attachment, parental monitoring and assertive parenting and pro-social sibling relationships have been found to be protective factors (Padesky & Mooney, 2012; Ungar et al., 2013). Child life specialists often explore these areas to help assess the potential strengths inherent within the family system with the knowledge these protective factors may help mitigate some of the negative effects or interpretation of hospital experiences (Eriksson et al., 2010). For more on respecting the inherent strengths and capacities of families, see both Munford and Mattingly, this volume.

Medical/Environmental Factors

There are factors specific to the health care environment that impact the child and their family's ability to adapt to stressors and be resilient. These factors are important considerations within child life assessment. In this section, we will discuss two factors of the medical environment: length of stay and medical procedures.

Length of Stay

There is some indication that length of stay may be a risk factor for some children. Although somewhat counter intuitive, relatively short lengths of stay, 2–3 days have been linked with greater negative effect on young children post discharge than shorter or longer stays (Rennick et al., 2002; Small, 2002; Teichman, Raphael, & Lerman, 1986; Tiedeman, 1997; Wright, 1995). We hypothesize that the short duration may minimize children's access to child life specialists and normalization play, but is still enough time for multiple invasive procedures. This likely results in heightened distress with little opportunity for child life interventions such as normalization play, health care/expressive play, or discussion via play that give children the chance to express and process their experiences and promote their internal capacity for resilience. Alternately, children who experience lengthy stays of greater than 2 weeks, and those with chronic illness who experience repeated admissions are also at risk, presumably because of the disruption to their social supports, routine, as well as the severity of illness and number of procedures discussed below (Rennick et al., 2002; Small, 2002; Tiedeman, 1997). Length of stay therefore becomes an important factor for CLSs in assessing and prioritizing patients.

Medical Procedures

The literature tells us that the number of invasive interventions is more important for predicting resilience than where the invasive interventions occurs (intensive care unit vs. medical floor), whether the child had previous hospital experiences (Koller, 2008; Rennick et al., 2002; Small, 2002), or the perception and retained memory of the experience(s) (Chen, Zeltzer, Craske, & Katz, 1999; Noel et al., 2012). Additionally, the number of interventions is found to be predictive of distress, notably depression, anxiety, fear, and post-traumatic stress for hospitalized children (Rennick et al., 2002; Rennick, Morin et al., 2004; Saylor et al., 1987). Hence, it is not so much about the diagnosis per se, as it is the number of perceived invasive/painful experiences and the child's perceptions/memories of these experiences which are indicators of potential risk to resilience targeted by child life specialists.

Strategies to Promote Resilience in Health Care

At the core of promoting resilience is the CLS appreciation for systems theory. Systems theory recognizes that if one part of the system is impacted, so too are the other parts of the system, albeit in different ways (Cox & Paley, 1997). For children, their ecological "system" consists of anyone interacting with them on a regular basis: parents, grandparents, siblings, peers, etc. It is recognized that one cannot treat/support the child without active participation from caregivers, and, that siblings, particularly those of a chronically ill child, are also at risk for coping and threats to their resilience (Gannon & Shute, 2010; Hamall et al., 2014; Rosenberg, Baker, Syrjala, Back, & Wolfe, 2013). Individuals who work with children and youth in the context of health care have a responsibility to treat them in a way that respects their individuality (temperament and personality), their culture, and their developmental level while promoting resilient behaviours. Child life specialists are in a unique position because the focus of their role is primarily on the developmental and emotional needs of children and on minimizing the impact of stress/trauma for children experiencing challenging life events. Consequently, the interventions they use are strongly linked with strategies described in the literature as increasing protective factors and/or promoting resilience in children as well as adults (Bernard Van Leer, 1995; Bolig & Weddle, 1988; Padesky & Mooney, 2012; Zolkoski & Bullock, 2012). The following section will highlight specific interventions utilized by CLSs to help mitigate negative effects of hospitalization and promote resilience.

Child Life Specialist Interventions

Child life specialists use a repertoire of interventions to help support the developmental and psychosocial needs of children and their families. At times there can be role overlap in achieving family goals among health care team members (e.g. social work, recreation therapy, psychology), yet each professional brings a unique "lens", expertise and various interventions. Table 9.1 provides an overview of commonly used interventions and the ages/developmental level in which they are typically employed (this varies depending on the developmental abilities of the child). The case study on page 9 provides the background to discuss several CLS interventions in greater depth.

Returning to Cameron's Case, with Cameron's mother's permission, the CLS would focus on building rapport, by bringing in novel toys/distraction items, and developing a therapeutic relationship. This would promote engagement in a trusting relationship and create an opportunity to offer other play activities which may encourage the release of emotions. It is well recognized that play provides children an opportunity to be in control of their environment, make choices, help develop a sense of mastery and control, practice developmental and social skills, and is perceived by

Table 9.1 Summary of interventions commonly used by child life specialists

Intervention	Developmental age at which intervention could be utilized	Definition
Play	All ages	Activities of choice, that are perceived to be “fun” by the child
Developmental support	All ages	One-on-one play sessions to help maintain and/or encourage progress in developmental skills (e.g. sitting, crawling, communicating, socially engaging, and playing skills)
Expressive play	All ages	Play session that helps the child express feelings/worries/questions about hospitalization; work through feelings. This may include the use of toys, art, role playing, etc
Procedural support	All ages	The CLS helps provide support when a procedure/medical test (such as an IV or blood work) is taking place and uses specific strategies to help the child cope better with the procedure such as altered focus/distraction activities
Family facilitation	All ages	Provides information to help the family understand the hospital system; listens to concerns and provides emotional support; may provide parenting guidance; provides emotional support and individualized interventions for brothers and sisters; encourages parent–child interactions
Preparation	>2 years	Using conversation, photographs, and/or play to explain health care procedures in a way that makes sense to the child, that allows questions to be asked and coping strategies to be learned. This may also include preparation for transition to a new unit, facility, home, community programme, etc
Health care play	>2 years	Play session using materials related to health care that helps the child express feelings/worries/questions about hospitalization; develop coping strategies; clear up misunderstandings and work through feelings about painful or scary experiences. This might include using a body outline doll and medical supplies
Therapeutic dialogue	>5 years	Talking to explore concerns, coping strategies, clear up misunderstandings and work through feelings about painful or scary experiences

Table adapted with permission from LeBlanc et al. (2014)

them as enjoyable (Bolig, 2005; Glenn, Knight, Holt, & Spence, 2013; Lifter, Mason, & Barton, 2011). Children consistently report that play, recreation, and playing in the playroom are the best parts of a hospital experience (Chappuis et al., 2011; Horstman & Bradding, 2002; Lindeke et al., 2009; Lindeke, Nakai, & Johnson, 2006; Wilson et al., 2010). In child life practice, most interventions are provided through purposeful playful practice, using activities that match children's developmental and emotional needs, offering choice and control during structured and nonstructured play sessions. For more on the important role imagination can play in young children's ability to cope with medical procedures see Clark, this volume.

Health care play, specifically *medical play*, is a play modality whereby a CLS offers a cloth body outline doll, markers and medical supplies to age appropriately "play through" the child's medical experiences. Medical play can be used to model and prepare children at their developmental level for medical procedures, such as surgery, medical tests such as ultrasounds or MRI, or medical interventions such as IV insertions and casting. It can help children feel less distressed, help them understand medical procedures and "work through" their health care experiences (Fereday & Darbyshire, 2008).

In the case of Cameron, he would be encouraged to colour his hospital friend in any way he wished. Colouring is a familiar activity and allows the child to regain a sense of control. This promotes active coping, and is reported to promote coping. The CLS would act as a guide and/or an "assistant" for Cameron who may take on the role of doctor or nurse in providing care to the "hospital friend". Children often wish to "do what happened to me" and may repeatedly wish to give "medicine", needles, or do surgeries over and over again, especially if the child has experienced many interventions or perceived them as very difficult/traumatic.

Medical play may be an intervention offered/suggested for various reasons during a child's hospitalization. It can be guided by the CLS or entirely child-led, depending on the needs of the child and the goals of the CLS. The CLS monitors the child's verbal and non-verbal responses and facilitates the play. At times it serves to facilitate psychological preparation for an upcoming medical procedure and provides a vehicle to explain in a developmentally appropriate way what will happen and why it will happen. As in this case, it can also be a *post procedural support* intervention to allow for the processing of the experience. It may allow for clarification of misconceptions, to better understand medical interventions, to manipulate the equipment used, and to understand the sequence of the steps needed to complete medical procedures.

In this case, depending on Cameron's initial response, the CLS may also consider *therapeutic play/expressive play* as an intervention either in addition to or instead of medical play. Therapeutic play is described as specialized play activities to help support emotional well-being (Koller, 2008). Activities that promote expression can take many forms such as drawing, writing, journaling, photography/photojournaling, dance, dramatic play, puppetry, the creation of games, and/or targets related to negative experiences, to name a few. The use of a Playmobil® hospital set, puppets, dinosaurs, or the making of play dough may be types of play activities that would permit Cameron to engage in active play and to promote the release of emotions without the need for a lot of reflection or discussion of his emotions; skills beyond his developmental level. Matching Cameron's pace for information and for play is critical in this process. Providing information and explanations, in a way that makes sense for the child and at the rate he is ready to hear and understand, requires constant reassessment of verbal and non-verbal cues from the child.

Exploring Cameron's favourite *play* activities may also help to determine what will encourage him to be an active participant in his health care experience. Engaging Cameron, and being empathic to his situation, will help him know he is respected and he does have control over some aspects of the situation. Getting up and ambulating will also enable him to meet and potentially engage with other hospitalized children which will foster peer interaction and increase Cameron's awareness that others are experiencing illness and health care as well. Having opportunities to meet other patients (either in person or through the use of specialized online programmes[6]) with similar health conditions and experiences may be especially important, particularly for those children with chronic conditions, to minimize the sense of "being different". This is particularly noteworthy because of the often limited opportunities for such connections and peer support in home and/or school communities (e.g. a child with cancer will likely not have another peer in his class or even his school with the same diagnosis.).

Given Cameron's previous experiences with health care and his current verbal and behavioural responses, the CLS would explore, through *therapeutic dialogue*, Cameron's understanding about the need for admission and his surgery. Children and youth, when provided with the opportunity to speak to a neutral person in child-friendly language about their perceptions, their fears, and worries, are very capable of articulating their concerns and needs. The CLS may also inquire about the aspects of hospitalization that are "hard work" for him, as well as explore the positive aspects of his current situation. This allows Cameron an opportunity for further explanations and clarification, as well as the chance to develop specific strategies for coping with medical interventions that are based on his specific temperament and coping style. Strategies could include deep breathing, imagery, distraction strategies such as squeezing stress balls/toys, using a tablet or television show to avert his attention from stressful or painful procedures or other strategies known to promote coping.

During the CLSs' assessment of the health care factors which may influence the child's/family's resilience, the CLS would collaborate with the health care team and inquire about future invasive or potentially stressful experiences that may need to occur during the course of the current admission. In Cameron's case, it would be common to remove urinary catheters and IV tubes, procedures that are often stressful and painful for children. Additionally, for Cameron, the need to get up and start moving around created worry and stress for him and his mom. In response, the CLS would provide preparation and support prior to and during this experience. She would also engage Cameron and his mom in developing a coping plan for catheter removals, advocating for appropriate pharmacological support and developing a plan for slowly increasing Cameron's mobility.

Children who receive developmentally appropriate *preparation* about forthcoming health care procedures and have opportunities to rehearse coping strategies benefit from a "…sense of trust, reduc[ed] uncertainty, enhanc[ed] belief in their ability

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[6] One online programme for Canadian school age children and youth with chronic illness is Upopolis https://www.upopolis.com/login.html.

to cope with a procedure, minimiz[ed] distress, optimiz[ed] treatment outcomes and recovery times, and minimiz[ed] pain intensity" (Jaaniste, Hayes, & vonBayer, 2007, p. 125). Similarly, there is some evidence to suggest that providing timely and effective information to children leads to better-informed patients with less behavioural distress, thereby enabling procedures with enhanced efficiency, decreased distress, and increased satisfaction (Cavender, Goff, Hollon, & Guzzetta, 2004; Gursky, Kestler, & Lewis, 2010; Jaaniste et al., 2007). The inclusion of such practices has the potential to save health care dollars, and prevent fear and avoidance of medical care later in life and enhance resilience (Stewart & Yuen, 2011).

Parents and children report needing to know what's happening and why, about the prognosis, and what to expect, in a way that makes sense for them (Boyd & Hunsberger, 1998; Horstman & Bradding, 2002; Rosenberg et al., 2013). It is important to ensure temperament; coping style and developmental ability are all considered when sharing information with the child and family. For example, information shared will be very different for a typically developing 3-year-old versus a typically developing 12-year-old, versus a parent. Some children cope best with a lot of information and details while others will only want to know what is absolutely necessary and prefer not to discuss or hear further details. Others will prefer their parent be the conduit for information. Assessing each child's preferences and emotional needs is therefore imperative in customizing care.

Unfortunately in Cameron's case, he and his family were not able to benefit from this intervention. His mother declined a preoperative preparation visit due to their distance from hospital and financial stressors. If they had been able to attend such a session, in advance of the surgery, some of their anticipatory anxiety could have been alleviated; coping strategies could have been explored, modelled, and then implemented during the admission. The use of Telehealth or other technologies will hopefully increase access to such preparatory interventions.

The CLS's role also encompasses *family facilitation/support*, meaning support for parents and siblings. For the purpose of this case study, the CLS would explore Cameron's mom's concerns for her son, explain common child responses to health care, be a liaison with the medical team as it relates to her observations, concerns and questions (as needed and desired) as well as provide support strategies for any siblings at home. The CLS would provide general emotional support and encourage a focus on their individual and collective strengths and strategies for adapting to and coping with the stressors. Given the noted level of maternal worry, the CLS would likely encourage the supportive services of the team's social worker. This referral would allow his mother to have a direct support person during the admission who may be able to assist with practical needs (financial stressors) as well as the emotional stressors of having repeated health care visits, observing her child in pain and distress as well as being away from her home and family.

Additionally, the CLS would inquire about other siblings and their emotional responses to the family separation, their understanding of Cameron's medical condition and explore strategies to help the family stay connected. Siblings of children with chronic conditions are known to be at risk for emotional challenges and risks to their resilience. Bellin and Kovacs (2006) support the need to identify and address sibling specific concerns and emotions. Their findings highlight the need for interventions to promote sibling protective factors to ensure sibling needs are being met. Most of the CLS interventions listed in Table 9.1 are valuable for siblings who demonstrate an impact to their development and/or coping, and may also be offered to promote their resilience.

Summary

According to Ungar et al. (2013), the more a child is exposed to stress and adversity, the more important the quality of the environment and the availability of resources to nurture and uphold well-being. Child life specialists have a critical role in providing an environment within the hospital that nurtures resilience. Their primary focus is on the developmental and emotional needs of the child and the family, and incorporating interventions such as play, developmentally appropriate psychological preparation, education, and expressive activities. Child life practice is closely aligned with resilience theory through its focus on "enhanc[ing] the optimal growth and development of infants, children and youth through assessment, intervention, prevention, advocacy, and education" (CLC, 2014c).

We have demonstrated the ways child life specialists actively assess child, family, social, and health care factors to better understand the potential and current risk to child and family resilience. This dynamic assessment process focuses on individual strengths and responses to adversity/stress over time. The information from CLS assessments enables the medical team to create an integrated psychosocial plan of care that incorporates the child life specialist's goal to "…reduce the negative impact of stressful or traumatic life events and situations that affect the development, health and well-being of infants, children, youth and families" (CLC, 2014c).

Evidence of the effectiveness of child life specialist interventions continues to grow. The landmark child life study whereby children who participated in a child life programme were found to be less distressed, had a better understanding of the hospital and procedures, were more cooperative during treatment, and had a more favourable recovery following surgery than a control group provided early evidence of the impact CLS could have in promoting resilience in health care settings (Wolfer, Gaynard, Goldberger, Laidley, & Thompson, 1988). The American Academy of Pediatrics (2006) notes that child life services may help to contain costs by reducing the length of stay and decreasing the need for analgesics. These findings further illustrate child life's preventative potential and the benefit of play and psychosocial interventions in supporting children and families experiencing health care encounters.

A common phrase within the child life community is, "It takes more than medicine to make children well". While the historical focus of child life involvement has been in paediatric inpatient areas, the recent growth in services to the varied clinical areas where children, youth, and families receive paediatric services (as well as community programmes) demonstrates a growing recognition of the need for individualized biopsychosocial support for children and families across health care settings (Hamall et al., 2014; Rutter, 2012; Ungar et al., 2013).

Only through interprofessional collaboration, and exploration of the interconnected systems and environmental factors that influence each child and family, can the most appropriate and effective interventions be implemented. It therefore remains critical for the child life profession to continue to integrate evidence into best practice and urge further research to enhance our knowledge. By translating knowledge into practice, we can enhance coping, promote resilience, and optimize emotional adjustment and developmental outcomes across health care contexts.

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Chapter 10
Imaginal Coping: Resilience Through a Play of Tropes

Cindy Dell Clark

Let me tell you the story of one of the greatest laughs I've ever gotten in my life. I'm in the cancer ward at Sloan Kettering and I'm visiting a friend who's dying. He's got about a month left … And he says to me 'what are you doing tonight?' I said 'I'm going down to the Cellar' [a comedy club where the comedians are served a snack of hummus]. He couldn't swallow …. As we're talking about me going down to the Cellar, he coughs up this horrible thing. And he says 'I'm so sorry.' I said 'It's okay, it's getting me in the mood for the hummus.' I mean it was a big laugh. And he's dying. And that's why I say it really was one of the greatest laughs I've gotten in my life, because in that moment, he was happy.

Jerry Seinfeld

Everyday life, shared in a social context, is fraught with moments requiring resilience. No cultural setting affords its members a utopic existence exempt from discomfort, threat, frustration, or loss. Adaptation and flexibility, therefore, are requisites of the human condition. Comedian Jerry Seinfeld's use of comic relief is no isolated example of shared meaning-making intended to lighten and reframe meaning under duress. Expressive forms of exchange that turn meaning towards a new direction are also daily practiced by those who interact with children who are ill—from family members to friends to hospital clowns.

Two decades ago, I conducted ethnographic research among Chicago-area children aged 5 through 10, as they and their families dealt with the day-to-day issues of childhood diabetes and asthma (Clark, 1998, 2003, 2007, 2013a). I found that the vicissitudes of illness and medical treatment were a common catalyst for *imaginal coping* in these American families—defined as coping that agilely reframes meaning through imaginative, non-literal modes of discourse such as humor, ritual, pretense, story, and metaphor. Imaginal coping seeped into family life one way or another among the resilient families I met in research. Whether or not consciously intended, parents and children showed readiness for as-if acts of pretense that

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C.D. Clark, Ph.D. (✉)
Department of Anthropology, Rutgers University, Camden, NJ, USA
e-mail: cdellcla@camden.rutgers.edu

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addressed problematic issues of meaning raised by illness. Parents encouraged imaginal coping wittingly or unwittingly by humor, by participating with children in their play or rituals, or by offering props able to be used in fantasy and play (such as toy medical kits or comforting plush toys). Precedent to imaginal coping was an open attitude towards bending meaning, placing meaning up for grabs. This alchemy turned the residue of bodily dysfunction into a cause for laughter and uplift.

Often, imaginal coping was mediated by symbols from the prevailing culture, incorporated into fantasy as fodder for subjunctive pretense. An 8-year-old boy with diabetes carried a play figure from a TV series, a white-garbed Power Ranger, as his would-be company during medical visits. He imagined that when his blood was drawn or his blood pressure taken, the Power Ranger experienced similar probes and interventions alongside him. In his imagined alternative reality, he had a powerful ally as company at the clinic, albeit one imaginally constructed.

A 5-year-old boy with severe asthma, who often awoke with nocturnal attacks but was too afraid of the dark to walk to his parents' room for help, fantasized that the Teenaged Mutant Ninja Turtles pictured on his bed sheets could come to life; one of them, he imagined, would run to fetch the doctor if he was truly in mortal danger, an assumption that reassured him as, on his own, he filled and operated his machine nebulizer to deliver relieving medication to his bronchi.

In a recent autobiographical portrait of how the Suskind family managed young Owen Suskind's autism, Ron Suskind (2014) described how popular culture motifs from Disney movies became daily resources for soothing and encouraging their son. Disney dramas became central family references that could engage and build bonds with Disney-obsessed Owen. Reviving scenes from Disney films in joint play, Disney characters became guides and inspirers of Owen's development.

Suskind's memoir vividly documents how resilience for children often comes not through straight-on, single-minded logic, but through emplotting and vivifying difficult issues in trope-rich stories. By virtue of fictive symbolism, issues are thereby distanced from the literal problem and made more approachable. Coping, close accounts reveal, is socially and culturally situated, symbolically mediated, and inherently re-interpretive of a child's experience. Resilience, in the end, is not so much a passive adaptation but a symbolic echoing and remaking. Resilience is inherently improvisational, pivotal, and dynamic. To approach resilience in its everyday habitat is to see that restorative meanings are derived not from reality-testing or factual indoctrination, but from tacit, socially warranted improvisation and human creativity. Resilience is not clinically engineered or dictated, but rather seeps into daily discourse by drawing on the human bent towards meaning that is storied and poetic. Resilience involves trespassing across ontological planes of meaning, rather than conforming to a singular notion of reality. Resilience requires space to trace its own, improvised path.

In the present chapter, I will draw and expand on my prior US-based work on imaginal coping in several respects. First, I will discuss the close correspondence between imaginal coping and important assumptions and mechanisms of prescribed therapeutic interventions by child-directed mental health and other professionals. Additionally, I will show how imaginal coping unleashes and capitalizes on the double-edged meanings of metaphor, through the so-called bisociative principle inherent to its therapeutic and interpersonal impact. Finally, I will consider the role of institutional prerogatives in hospitals that favor the exclusive logic of biomedicine, curbing playful resilience to a secondary, separated position. Imaginal coping thus may be curtailed in some hospital settings more so than at home.

Overall, I intend to show that flexibility and adaptability in children are accomplished by retreat from fixed, literal representations towards a more multiplicative flexing of meanings. When cultural material is appropriated for everyday resilience, the healing power comes not from molding meaning in conformance to ontological authority or institutional power, but from freeing up constraints upon subjunctivity to allow for adaptive tensile strength.

Subjunctivity as Therapeutic Advantage

I have written elsewhere (Clark, 2007) that formal therapeutic uses of play appear to be not-distant cousins of imaginal coping, in terms of the structural dynamics of meaning that underpin each process. That is, spontaneous acts of imaginative reframing that children and families initiate in an everyday context bear certain processual similarities to the therapeutic practices of clinicians, such as play therapists, child life workers (see Humphreys and LeBlanc, this volume), social workers, occupational therapists (see Mattingly, this volume), or others who employ as-if scenarios therapeutically. Five dynamic properties are held in common by imaginal coping and formal clinical play interventions.

1. The child undertakes an active, self-directing role.
2. Other(s) act to support or scaffold the child's playfulness.
3. The playfulness employs ontological reframing through suspended disbelief and engagement, as the child engages with an as-if version of reality.
4. The playfulness is oriented to include unresolved ambiguity and multivocal, flexible symbolism.
5. An experience of restructured meaning occurs, accompanied by affect-laden release or relief.

These similarities are worth considering in depth, for two reasons. First, if the types of activities that make up imaginal coping hold similar dynamics of signification as established forms of professional intervention, this builds a case that subjunctive processes deserve respectful clinical support for adding to day-to-day resilience. Second, this comparison underscores that enhancing resilience requires a humanistic basis, one inclusive of poetics, expressive symbolism, and flexible stances on reality—alongside the presumed logical singularity of biomedicine.

1. *The child undertakes an active, self-directing role.* Although children make use of social support and cultural iconography to configure and reconfigure dilemmas of meaning, each child has an agentive, active role in shifting signification towards resilience. That is, children exercise their imaginative powers at their

> own volition. Boys I interviewed who used a nebulizer treatment for asthma, required to sit still tethered to the nebulizer for a seemingly prolonged period, applied imaginal coping in personally inventive ways. One boy imagined that his toy airplane could fly away through the nebulizer's cloud-like mist, and this gave him a sense of escape-by-pretense. Another boy used a toy car during nebulizer treatment (as well as during asthma exacerbations), imagining that the car would drive far away from the situation at hand, to another setting. A third imagined that he himself was a pilot, with the nebulizer's face mask imagined to be a pilot's mask; he reasserted control over his fate as, imagination in flight, he took control of the "cockpit." Each boy devised a way to escape the monotonous experience of being tethered to a nebulizer, doing so with agency and self-reinvention.

Mattingly and Lawlor (2001) have written about how occupational therapists allow children to cultivate healing dramas, their term for narrative enactments that accompany prescribed sessions of individualized therapy or rehabilitation. In the most transformative sessions of therapy observed across their extensive research, imaginative play has constituted an impressive scaffold for the required physical movements of rehabilitation. Success at child motivation, they have documented, comes from a degree of power-flipping; the occupational therapist honors the child's choice to insert a particular game or pretense into a rehabilitating activity. Therapy is thus emplotted and embodied through a subjunctive narrative assertively shaped by the child.

In one example of such a healing drama, Mattingly and Garro (2000) recounts how a 9-year-old with vestibular problems, Sarah, requested that her therapist join her in an imagined reenactment of the Olympics. As Sarah ran through the moves required by therapy, she was vibrantly engaged in a pretense with the therapist about earning points for each complete step of therapy, as if she were "going for the gold" as an Olympian. "Forty-two points, I've done it," the girl announced at the end of a very productive session of therapy. Mundane movements of therapy were reconfigured to involve athletic challenge, suspense, even a lasting memory as the therapist claimed, 7 years later, that she still thought of Sarah each time she watched the Olympic games on television. For more on the link between narrative drama and resilience see Mattingly, this volume.

Another ethnographer studying occupational therapy, Melissa Park, similarly has written of professionals who accomplished profoundly transformative therapy by making way for a child's subjunctive recasting of therapeutic acts. "Acts can change the scenes to be in keeping with one's character," Park (2008) alluded. An autistic boy observed as part of Park's inquiry, Archer, asked his occupational therapist to join him during therapy in reenacting the Disney film narrative, *Finding Nemo*. Young Archer wanted to pretend to be Nemo, a lost fish on a quest (with the occupational therapist in the role of Nemo's supportive sidekick Dory). Although the boy usually dreaded and fled unfamiliar situations, in his chosen role as Nemo he willingly went face to face with the unknown. Archer, pretending to be Nemo, went about the therapeutic movements with a therapy ball (said by him to be a "shark") or made his way through "unfamiliar seas" (actually, therapeutic apparatus) as if he were Nemo, exploring. This pointed the way for making the therapy meaningful, motivating, and ultimately confidence-building. Archer chose an as-if scenario that was resonant with his own life issues, and emerged authentically self-assured.

In a quite similar way, the premise of formal play therapy is also that the adult therapist should not impose meanings on the child, a goal in line with research findings showing that a priori interpretation inhibits rather than fosters the therapeutic process (Birch, 1997). In her seminal, still used guide to play therapy, Virginia Axline (1947) dictated that play therapists shouldn't dictate, or even direct, children's actions during play therapy. Play therapy shares with imaginal coping the principle that it is a child's prerogative to use their imagination as they wish, with the adult in a supportive role. Play therapy, like imaginal coping, is a child-discovered, child-directed, and child-driven sort of playfulness. Just as a therapist for adults needs to be attuned to the client's particular narrations (Wyatt, 1986; Stolorow, 1993), therapeutic support for children requires being open to children's subjunctive initiatives. (In occupational therapy, as the Chap. 3 by Mattingly in this volume exemplifies, talented occupational therapists incorporate children's overtures, in that case choosing to role play a "witch" serving food at a tea party—a playful guise for therapy.)

2. *Other(s) act to support or scaffold the child's playfulness.* With the proviso of a child determining the direction of playfulness, professionals do scaffold children's play by providing a conducive setting, materials, and a receptive stance towards the meanings conveyed. In play therapy, a therapist supports the child's play enactment by earning and maintaining trust, encouraging playful involvement, and monitoring and responding to the play and its meaning.

In social worker-directed play groups at Sloan Kettering Cancer Center, play leader Margaret Adams (1976) adhered to these principles of play therapy. She maintained that communication of trust, acceptance, and receptivity to each child were important to helping children cope with their anxiety and emotional disturbance during hospitalization. Adams' account described how puppets and materials for medical play were made available in a space specifically set aside for play. Social workers invited children to avail themselves of whatever material they chose, leading to intriguing, transformative interplay. A group of 11-year-old girls used medically themed playthings to administer meticulous "treatment" to puppet-patients, in a child-empowering doctor–patient role reversal. (Such role reversing medical play is common in at home imaginal coping, as well.) In initial sessions, the girls concentrated on techniques of treatment and administration, pretending to meticulously treat patients, to schedule doctor visits, to assign patients to treatment rooms, and even to mimic "grand rounds" at which they, in joint pretense, discussed the progress of each puppet-patient. As the girls became more comfortable with their social workers and each other, by the third session they used the "work on their patients" as a springboard to sharing their negative feelings towards their own real situations. "When we're uncooperative the staff should try to find out why and not just get mad at us," summed up a recurring concern. Through the availability of the puppets (and a safe context for using them) they articulated how their feelings of anger, anxiety, sadness, and homesickness underlay occasions when they refused to cooperate with hospital routines. By allowing children space and support for play, children could appropriate puppetry to express their sincere, deep misgivings about hospitalization, which until then had been expressed only indirectly, through resistance.

Tim, another 11-year-old in the Sloan Kettering play program, used puppet role play to express his inner sense that he was dying, during a play group session (Adams, 1976, p. 423).

> In one play session [Tim] calmly announced that his [pretend] patient was dying. We took the role of 'assistants' and asked if there wasn't some form of treatment that would help the patient. [The therapists] became quite active in trying to save the patient's life, as did the other children, but despite our efforts, Tim insisted that the patient was indeed dying … Over a period of time, Tim reenacted this scene frequently, and, as the puppet (rather than himself) he communicated what his own needs were. He said that he was "nervous" and wanted to have his mother spend the night and his father [to] take off from work to be with him. … He didn't want to be in a room alone, and wanted to be near the nurse's station. He wanted to see his brother before he died. … [The therapist] took the role of listener and encouraged him to let the nurses know he wanted to stay in a room near the station. When Tim flatly told his puppet 'Oh shut up, nobody's going to miss you.' [the social workers] took an active reassuring role to contradict this fear. When Tim became terminally ill and was no longer able to leave his room, regular and frequent checks by his nurses and continuous visiting by his parents allayed his fear of being alone.

If play in a clinical context seeks not to impose interpretations on the child, but rather to encourage the child's free expression, this corresponds to the way spontaneous play and ritual, at home, also is based on receptive conditions and supportive responses. The Suskind (2014) family epitomizes such child-responsive imaginal coping. The entire family, and ultimately many of the other professionals who treated Owen, followed Owen's lead in employing Disney-themed play and drama as a means of social connection. When Owen watched *The Little Mermaid* obsessively, his family noted which scenes were so gripping to Owen that he would stop, rewind, and play the tape back over and over. Owen, who initially had stopped using language, made sounds at certain scenes in movies. His parents persistently sought to decode what these signs might indicate. They took Owen to Disneyworld, and keen to observe his reactions, encouraged Owen to interact with the displays. Suskind's account of this intricate family interplay details step by step how Disney plots and characters became the family's common ground, a space shared on Owen's terms, as they responded to Owen with evolving understanding.

The imaginal coping I uncovered in ethnographic research also had a supportive, call-and-response quality. The boy who used toy cars to cope with asthma treatment had a mother who remembered to bring a plastic car along to every medical appointment. She advocated for her son's right to have the car with him during X-rays or other procedures. When another girl with asthma enjoyed her mother's entertaining way of administering inhaler medication (by clapping and counting out the needed inhalations in silly ways), her mother incorporated such entertainment as standard practice. The fun ritual of silly, inventive counting came to accompany each inhaler use.

Thus support and scaffolding for home-based imaginal coping paralleled closely the professional therapeutic principle that a child's initiative ought to be met with reflective exchange that makes play a mutual "creative workshop" (Gilmore, 2005) albeit not an imposition by the supportive adult(s).

3. *The playfulness employs ontological reframing through suspended disbelief and engagement, as the child engages with an as-if version of reality.* While it is sometimes assumed that resilience amounts to "adjusting" to a stark reality, imaginal coping reveals another option altogether. As Winnicott (1953) and others (e.g., Garbarino, Dubrow, Kostelny, & Pardo, 1992) have demonstrated, the use of imagination and play enables a casting off of ontological correctness for entry into what Winnicott called "transitional space." Assuming that a child maintains a sense of trust, transitional space involves a kind of mental capacity to disengage reality-testing, to throw aside external constraints, and to suspend disbelief on the child's part. Some children experiencing severe trauma exhibit insufficient trust or flexibility to play, a telltale sign of posttraumatic stress (Rachamim, Mirochnik, Helpman, Nacasch, & Yadin, 2014; Raynor, 2002). Such a breach of play must be dealt with prior to commencing formal play therapy (Gilmore, 2005).

Play creates an alternate plane of reality, a plane in which stowed away themes from the child's actual life can be safely dramatized, via metaphor. Conforming to conventional reality is not the point of healing drama or play. On the contrary, a withdrawal from everyday reality ironically summons children's wherewithal to address troubles such as fear, anger, vulnerability, or loss, within an as-if plane. This occurs in play at home, as with Owen Susskind's long fascination with sidekicks in Disney movies, his way of coming to terms with a sense of being in a secondary role alongside his popular, socially able brother. A similar sleight of hand occurs in intentionally therapeutic clinical settings, as when occupational therapy is played out as an Olympic-caliber struggle, or as a saga of a fish lost at sea, swimmingly finding his way. In play therapy, a child who feels vulnerable might imagine that Spiderman or Superman saves the day, and gain reassurance within the fictive domain (Rubin, 2007; Rubin & Livesay, 2006; Clark, 2013a). As semiotician Umberto Eco (2009) theorized, fictional characters serve as paramount examples of the real human condition, set apart from the stressful world where children actually navigate.

Even meditation or prayer, sources of resilience for both adults and children, involve a capacity to suspend disbelief and to engage with trust towards a non-empirical plane. Few material resources are needed to adopt religious strategies for coping (Denney & Aten, 2014). Still, turning to faith for comfort, support, meaning or control does require a sense of trust, and a capacity to shift beyond a singular, conventional reality towards an alternative, transcendent plane.

4. *The playfulness is oriented to include unresolved ambiguity and multivocal, flexible symbolism.* Imaginal coping, like play in general, can have an uncanny quality, a striking sense of equivocation, mixed meanings, ambiguity (Sutton-Smith, 1997). Meanings in play or ritual are up for grabs or out of conventional order, rich in nuances and layered significances. The inchoate is thus tolerated and complexly expressed through the symbolic, in a similar way as religious

ritual concretizes the inchoate (Fernandez, 1974). Players use figures in play as avatars, in polyvocal ways suited to flexible dialogue.

In a playful ritual at home repeated four times daily, a mother and her 5-year-old son took a subjunctive approach to the embodied experience of insulin injections (Clark, 2003). They together imagined that the syringe used for injecting was a zebra. The syringe-zebra metaphor was resonant on a physical basis, in that the demarcated lines of the syringe were readily envisioned as zebra stripes. But the zebra's full metaphorical force traced to an intangible mix of traits. To the mother, the zebra was a creature of care and affection. "The zebra is going to kiss you now," she would say just before injecting the child. But to the boy, the zebra was a creature who inflicted violating hurt. After each injection, the boy would stomp on the empty syringe and scold it for hurting him: "Bad zebra, bad zebra: You hurt me!" The zebra can be compared to culture-embedded ritual symbols (Levi-Strauss, 1963; Turner, 1967) in that, as in cultural rituals, the zebra embodied in tangible form an irresolvable contradiction, at once embodying loving care and inflicted discomfort. The mother and son united in sharing the symbol imaginatively, but the implicated meanings remained opposed, so that neither had to diminish their own angle of experience. Metaphors allow sharing without imposition.

Children's interactions with hospital clowns similarly are fraught with paradoxical multivocality (Clark, 2013b). Clowns, who many see as unfathomable or unsettling, stand at the threshold between reality and fiction in order to bring sanctuary and release to child patients (Gryski, 2003). As a result, clowns are often associated with potent enchantment. Masked in face paint or fake noses, clowns unleash an appreciation of the ironic by suggesting that there are layers of meaning below what is see-able at the surface. As Levi-Strauss (1963) said of shamans (close associates to clowns in many cultures) clowning pulls the lid off fixed, conventional ways of organizing meaning. The irony of clowning lies in being able to re-sort meanings in an alternative order, by inviting a child to gain symbolic distance from a problem (through subjunctive playfulness) and to focus on the elastic flexibility of story, pun, trickery, and metaphor. Clowns use frivolity for serious ends, especially to empower patients in powerless situations. Such was the impact when a clown wrapped a child's parent in toilet paper to simulate the parent having the same injuries as the young patient. The play increased parental sensitivity to the child's felt predicament (Linge, 2011). Whether dancing with the hospital curtains or getting physicians to ineptly dress in the gowns and gloves needed to enter isolation (Ford, Courtney-Pratt, Tesch, & Johnson, 2014), clowns implicitly put a twisted and equivocating lens on sterile, set conventions.

Dense figurative forms like narrative, metaphor, and character-avatars are likewise present in prescribed play therapy. A boy embroiled in anger might use clay in therapy to build a venting volcano. An anxiety-ridden girl who feels threatened might form, out of clinic furniture, a fortress. Metaphoric references are hinges of transformation, in which the possibility of new associations of meaning are held out for consideration. Whether in clowning, play at home, or prescribed therapy, figurative tropes introduce in real time a concretized scenario laced with alternative possibilities.

Super-heroes and Disney films are two instances where pop culture holds grist for metaphor; popular culture is replete with nuanced, lenticular symbols ripe for resilient imaginings. It has been said that the function of fiction is to abstract out and simulate themes of social experience (Mar & Oatley, 2008; Oatley, 2009), a truism that has enriched the coffers of Hollywood and licensing agents whose fictions are daily and widely consumed by US children. At home, American children dealing with illness sleep with toy versions of cinema animals or reassuring super-heroes, often on beds fitted with character-adorned sheets, while wearing pajamas portraying beloved characters. Kids celebrate birthdays at character-themed parties, held in settings decorated with motifs from characters' films. With or without toy figures as props, US children fantasize over their favored fictions—be it *Toy Story* or *Thomas the Tank Engine* or *Spiderman* or *Nemo*—whose characters and plots capture a large share of children's mental attention and affection (Alexander, Miller, & Hengst, 2002; Rubin & Livesay, 2006). Clinicians can gain insight from the revealing attachments of their patients, evident in the form of t-shirts and toys that go in and out of examination rooms daily throughout America.

It may be that the densely packed, pivoting significance of popular children's fiction is also what extends its appeal so widely. Cheryl Mattingly (2010) has called Disney and similar popular culture a "lingua franca" familiar to adults and children alike, understood in discourse shareable across age, class and ethnic lines. Features and characters from children's media, she has written, level the usual age-linked and other cultural boundaries and help give a common ground of reference between clinicians and families. Popular films' fantastical quality extends their broadly felt value for staging imaginal coping (Mattingly, 2010, p. 198).

> Popular children's films, as reinvented in family life, offer a shared stock of stories known not only to children and parents but other children (almost) everywhere, and even other relevant adults, like clinicians, who play a significant role in these children's lives. Because so broadly shared, they can be drawn upon, improved in everyday life. These stories … are too complex and too fantastical to serve in any literal way as guides to action. But they can function to spark the imagination, as sources for envisioning possible lives, possible futures. They are precisely the sort of material necessary for trafficking in the subjunctive and as a 'staging ground for action' rather than merely an 'escape.'

5. *An experience of restructured meaning occurs, accompanied by affect-laden release or relief.* The theories behind play therapy treat affective processes and cognitive processes as jointly responsible for therapeutic change. Notably, then, more than meaning is at stake (Gilmore, 2005). Two sorts of affective involvement theorized as part of play therapy include: (1) catharsis, taken to be a process in which unexpressed, unconscious, hidden, latent emotions are released to relieve tension and anxiety (Ginsberg, 1993) and (2) abreaction, a process by which a stimulus indirectly brings to mind previous experience, and thereby reduces painful, difficult feelings (Oremland, 1993). In short, play therapy—and, by associated logic imaginal coping—not only address how things are compre-

hended and parsed, but also helps to release feelings (through catharsis) and reduces affective discomfort (through abreaction).

Consider the example of a boy dysfunctionally embroiled in anger, who builds play-dough volcanoes repeatedly at therapy time. The volcano acts as a symbol of anger at the verge, and over time precipitates abreaction. Cathartic release is also potentiated, when the boy playfully "explodes" his creation with mess everywhere, a way to release fury, but at safe distance from a real world setting (Scheff, 1979). Play heals emotion by means of both abreaction and cathartic release.

Laughter likewise precipitates cathartic release. Clown antics, a controlled test has shown, reduce pre-operation anxiety in children (Vagnoli, Caprilli, Robiglio, & Messeri, 2005). In interaction with patients, health care providers have been observed to use comic forms of address like "my ladyship" or "my lord" (Aronsson & Rundstrom, 1989). Such whimsy, by raising the dependent child's subjunctive social rank, might well provide cathartic release, perhaps for the physician, too.

In a clinic studied by Rindstedt (2014), clowns offered children pieces of candy, pretending that they were medication, and gave out silly prescriptions. A lollipop was to be licked precisely every three quarters of an hour. Chewable "pills" of sugar were to be taken after the child brushed his teeth. When revisiting the children at a later point, the returning clown would inquire whether the prescribed silly actions had been taken, and would pretend to be upset if "medical advice" hadn't been followed as "prescribed." In the course of making a mockery of medical roles, this lampoon afforded children with the affective release of laughter, even as it reframed familiar impositions by doctors. Medical clowning often raises issues of a child's relative status, not only by mocking physicians, but also by elevating the role of a child. One clown, for example, asked a very sick child to sign an autograph, with the clown in the role of subservient fan (Ford et al., 2014). Clowns intentionally make mistakes for children to correct, another common ploy to empower the child. Being playfully empowered is not merely a cognitive shift, but a positive affective turn as well.

Bisociation and the Power of Metaphor

In research disciplines that seek a singular, context-free, "objective" truth (including biomedicine) learned habits of thought may undervalue the human capacity for thick- or double-meanings. Multiplicity of meaning, nevertheless, is empirically commonplace and serves to catalyze everyday resilience. Expressive symbols and narratives, my ethnographic evidence suggests, encode complex juxtapositions of meaning, corresponding to dynamic, multivalent social relations of children. It may well be that dialogic, mediated, and poetic modes of significance are crucial for repairing selfhood and maintaining shared social space in families (Valsinger & Han, 2008), particularly in cases of child illness.

That humans can think across multiple symbolic planes, and are thereby prone to use metaphor as a means of understanding, is well established in anthropology and cultural psychology. Research into human creativity has similarly highlighted the human capacity to mediate between separate planes of meaning; creativity is, in essence, a breaking through of walls of fixed thinking through a mental leap to a less accustomed framework or context.

Some decades ago Arthur Koestler (1969) documented how paradigm-changing scientific insight, like other creative leaps, depends fundamentally on playful excursions across distinct domains of thought. He held that such mental excursions are a counter force to culturally constructed habits of tracking experience within set schools of thought. Koestler coined the term *bisociation* for the gathering of meaning simultaneously from disparate planes of reference, placed in counterpoint or confrontation. Bisociation, he further theorized, culminates in a pronounced affective impulse when a satisfying connection is made. A subjective sense of insight, laughter, or profound poetic or aesthetic appreciation accompanies bisociation. Archimedes' mythical exclamation of "eureka" upon the "aha!" moment when he connected his bodily displacement of bathtub water to the problem of how to measure density is such a pulse of insight. Kekule famously told of his own moment of intense realization, after daydreaming about a snake grasping its own tail and connecting the image to the ring-shaped structure of benzene. There is an affective bounce that accompanies bisociative connection.

Stories or performances often involve a series of connected bisociations, which Koestler explained as a "series of minor explosions or a continuous state of mild amusement." In my work on child chronic illness, I have noted that humor (including humor within narrative) is maximally arousing when it touches on an underlying tension or dilemma, especially the threat of illness to selfhood or survival. Consider a joke that Judy McKinty (2013) found circulating in an Australian pediatric hospital.

Doctor, doctor I've only got 59 s to live.
Hang on, I'll be with you in a minute.

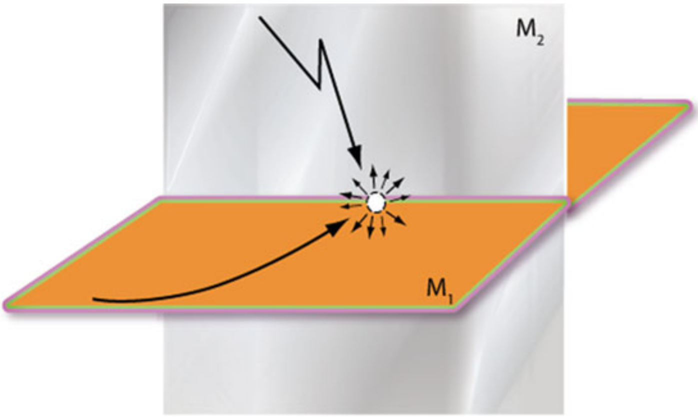
To appreciate or "get" the joke, the listener must mediate between two planes of meaning, a literal plane in which time is specified precisely ("59 s"), and at the same time a figurative or idiomatic plane germane to medical, bureaucratic environments ("I'll be with you in a minute"). When these contrasting frameworks of meaning conjoin in the mind of an interpretive listener, affective amusement and the physical release of laughter arises. The amusement, I hypothesize, gains intensity in light of the grave situation implicated, in which delayed medical attention portends deadly consequences. The bisociative implication coincides with tension in need of cathartic release. When meaning and affect come into alignment, comic reaction intensifies.

Humor can be precipitated by bisociative connections made in the course of daily life. An informant of mine, an 8-year-old girl with diabetes, Mary, experienced a frightening insulin reaction, falling asleep so deeply that her mother could not awaken her (Clark, 2003). "I had dark circles under my eyes and I was very pale," Mary recalled. Her mother force-fed her glucose tablets and the candy Life Savers to raise her blood sugar level, and the child rallied for a moment. Calling the ambulance, her father continued to give her red Life Savers to eat while waiting for emergency help to arrive, in the course of which she coughed and spit out some of the Life

Savers. When the ambulance arrived, the technician spoke into his walkie-talkie "She's spitting up blood! She's spitting up blood!" Deep laughter punctuated Mary's recounting this detail to me, recalling how the technician had the misperception that the red color of the Life Savers around her mouth was blood. The same story was regularly told within the family as a tale of tragedy-turned-to-comedy, a source of deep amusement that red candy, indeed candy named Life Savers, was taken as dangerous indicator. The bisociative pulsation in the story (benign Life Savers connected with bleeding) coincides with a pronounced affective tension—the life-threatening close call that had been averted.

Example

M1: First plane of meaning (red candy)
M2: Separate plane of meaning (red bleeding)



The figure above, adapted by Chris Thornton (cited in Clark 2016) from an illustration by Arthur Koestler, portrays bisociation visually. The planes of M1 and M2 are brought into connection by metaphor or double-entendre, with an explosiveness located where the meanings collide. The "burst" signifies the explosive release of appreciation or amusement.

The bisociation principle provides a cogent explanation for the pervasiveness of humor shared by children at camps for serious illnesses, such as diabetes camp, asthma camp, or cancer camp. Everyday interactions between campers who share an illness are systematically punctuated by kids' in-group sharing of jokes and humor (Clark, 2003). At an overnight camp for kids with diabetes, campers sang songs whose lyrics lampooned their common troubles such as blood tests ("Don't take a prick at my finger, my finger") or insulin reactions (What a reaction, doodle lee do/Some folks shake and some get clammy, doodle lee doo). Campers at an asthma camp took delight in novelty items distributed at camp, such as a cup with floating confetti given out by a pharmaceutical company, in which some of the colorful floating confetti was shaped like inhalers. Merry singing and happy-looking confetti were in effect bisociative, in the sense of placing life-saving medical interventions for a serious illness against another framework altogether: celebration and fun.

A skit that was performed at a camp for kids with severe asthma demonstrates Koestler's principle of bisociations set in series, oscillating over time within a narrative. The skit (conceived by young female campers) had a bisociative premise, connecting severe breathing problems to the nursery story *The Three Little Pigs*. In the girls' version of the classic tale, the wolf had asthma; he could not "huff and puff and blow your house down" because of his asthmatic disability. This asthma-to-wolf juxtaposition repeated the wolf's failed huffing over three empty threats to three pigs, culminating in the wolf's decision to seek biomedical treatment for his lungs. Children roared and shed tears of amusement when the physician measured the wolf's breathing capacity (with the same instrument the children used, a peak flow meter); the meter reading was such a low number, no actual being could have sustained life at that level. Across these events, the humor built in intensity over the series of bisociations, eliciting sustained, ever rising heaves of laughter.

Therapeutic humor, one might say, constitutes a micro-vacation from one's troubles, an instantaneous reference to another plane of meaning (placed in bisociation with real troubles) as a referential escape hatch. The point of the joke, in the most hilarious cases, reframes the very issue that needs cathartic release. It is no wonder that comedians like Jerry Seinfeld are fulfilled when they can bring happy laughter to a dying friend through humor. Comics are skilled and culturally sensitive healers who know how to engineer contrasting references (bisociations) into mini-explosions of remade significance and joy. Children in the USA too, have this capacity, not only in inventive stories or jokes shared at camp, but also in their larger appreciation for subjunctive pretense with its metaphor-rich, bisociative power.

Imaginal Coping in Hospitals

Unlike camps or playrooms, hospitals are sanitized spaces in which singular notions of meaning (derived from biomedicine) drive diagnostic processes and responses. Lines of authority in hospitals are clear, such that in the clinical hierarchy, the more biomedical training a person has undergone the higher their rank. Even children with critical illness quickly discern the pecking order. In a hospital leukemia treatment center studied by Bluebond-Langner (1978), children adeptly discerned that specialists in hematology ranked highest, followed by (in order) residents, interns, nurses (who were, in kids' eyes, tied with occupational therapists, lab technologists, and teachers) and finally, at the bottom rank, medical students.

Patients in hospitals are powerless and under gaze, essentially marginalized rather than central to a hospital's pecking order. Patients come and go, but the social hierarchy of the hospital stays when they depart or die. The marginalized social position of child patients, along with their pointed dependency, has implications for the resilience-seeking strategies children initiate. The actions and processes set by medical conventions are singularly biomedical, not necessarily open to alternative interpretive realms. In a tightly managed hospital without a playroom or child life department, children's special character-adorned bed sheets used at home or their familiar, security-giving toys may not be admissible due to concerns for germs or allergens. There is a resonance of children's hospital experience with the famed tale of the *Velveteen Rabbit,* in which a fictive boy with scarlet fever is not allowed to keep his lapine transitional object, banished by the biomedical presumption that it carries germs.

A touching story told to me by Grace, a girl of seven years who recalled how she had a traumatic experience when hospitalized upon diagnosis of diabetes at age two. Grace remembered vividly being put and kept in a "jail bed," trapped behind metal (crib) bars. The cage-like crib and hurtful procedures performed by the staff put Grace in a vulnerable panic. Her only reassurance was imaginal, in the form of an out-sized plush tiger, an uncle's get-well gift. Grace imagined that the tall tiger, positioned in her hospital room next to the door, was a powerful as-if guard who would pounce and kill a staff member before they could go so far as to mortally wound her. But Grace had these imaginings privately, which backfired when a nurse removed the tiger, mistakenly assuming that it was the tiger that caused Grace's distress. As Grace recalled the removal of her tiger-protector 5 years ago, she sobbed aloud at the memory. "And I was only 2 years old," she added, sympathetic towards her younger self whose private imaginings were truncated when most needed.

Pediatric treatment is embedded in biomedical assumptions of objective reality, yet children are given to dwell in made-up ontological universes (overlapping in time with the hospital's given universe). Inadvertently, imaginal coping can be overlooked, dismissed, or pre-empted by adults in charge. Even in hospitals fitted with playrooms that are meant to give a place of refuge from medical interventions, the spatial layout in effect communicates that fantasia is systematically zoned to stay in places where there is no conduct of medicine. The privileging of biomedicine in hospitals has an impact of cordoning off playful acts of psychological resilience, setting that activity aside to be the bailiwick of less prestigious specialists, such as social workers, child life specialists, or hospital volunteers. Imaginal activity gets delegated to the lowest realms of the hospital power hierarchy. Children with procedural distress such as needle phobia in many cases may be sent for help not in real time as treatment proceeds (as happens when imaginal coping is used at home) but at a separate appointment with a play therapist or social worker.

The case of Maria. In a hospital-based ethnography conducted in Padua, Italy, Elena Righetto (2014) spent time with Maria, an eleven-year-old who had experienced chronic kidney failure and a partial amputation of her leg and foot. When Righetto met Maria, she was hospitalized following a second attempt at kidney transplantation. Maria had to stay in isolation, to prevent post-surgical infection. All entrants to her room were required to wear a mask and disposable medical coats. When a clinician entered her room, Maria had some leeway about how to interact. Nevertheless, her state was one of extreme physical weakness and powerlessness. The medical practitioners, in contrast to Maria, were masters of the rituals of the hospital, as Righetto put it, "the only ones who could read the signs (for example, test results) and indicate the course of treatment."

Maria confided to Righetto that she had recently pushed the limits of her situation. Trying on her leg prothesis one day, she walked right out of the room, scaring the doctors who, to quote Maria, “looked like they had seen a ghost” at the sight of Maria outside isolation. This breach of procedures shows how, with the best of intentions, standard hospital conventions intended to protect children also can limit children’s agency. Children hospitalized are in effect, objects of care rather than privileged subjects.

When Maria was free to leave her bed and room without biomedical surveillance, she also exercised a greater freedom of imagination. Walking down the hospital corridor with Righetto, Maria held Righetto’s hand and whispered to her: “We’re entering a magic world, reeeaaally magic, in which only princesses can go! I can, because I’m a princess, and now, thanks to my power, I create [make] you a princess so you can come with me.” Maria placed her hand on Righetto’s head to sanctify Righetto as a princess. Thus the ethnographer was honored to enter Righetto’s subjunctive world in which her status was high (a princess) and her powers great (capable of magic). Pretending to be in the realm of princesses, Maria sang a song and rubbed her abdomen, pronouncing her transplanted kidney to be a great (and royal) gift. In the room where they were, other children also played, but Maria continued her singing and belly rubbing in their presence. It was when another patient’s mother entered the room that Maria truncated her imaginings. “Cover your belly, what are you doing?” this adult pronounced. “It’s no good to show it and show your scars!” At this proclamation Maria dropped her princess demeanor at once, capitulating to the order and ceasing to sing. Soon after, a nurse arrived, surmising that Maria’s belly rubbing had a physical origin, pain, not taking into account that Maria had resumed her upbeat singing.

If the status of being an as-if princess gave Maria a way to yield power in an intimate way, her uplift in status was nevertheless conditional, conditional on noninterference from adults whose interpretations and preferences trumped her own. In her imaginal world, she could have a safe space to consider the new kidney inside her. Maria, an amputee, was not unfamiliar with the need to subjectively respond to a major bodily change. Like amputation, transplantation alters the integrity of the body, raising questions of self and social standing (French, 1994). Such a situation can lead to feelings of diminished capacity, whether the patient is a child or a grown-up; carving out space in which to address these issues through pretense (framing her kidney as a self-enhancing, high status “gift”) was Maria’s way of seeking resilience, albeit her efforts were fragile to adult disregard and purview.

Conclusion

Biomedical treatment in hospitals needn’t necessarily be dubious of resilience through subjunctivity. Nurses in a Swedish children’s hospital observed by Rindstedt (2013) made artful use of as-if references to ameliorate painful procedures, much as the mothers I’ve studied at home often do. Skilled nurses used apt metaphoric references as they went about needle procedures. One said, to a child sitting on her mother's lap, "You'll soon have a ride to the roof, Mom and you!" before she operated the lift mechanism of the chair. In another example, a nurse cleaned and washed the site ready for injection, and then showed the child the needle, commenting "The little butterfly … will help us. Yes!" Such use of metaphor (that is, bisociation) catalyzes resilience on the fly, in real time as treatment occurs.

The sterile objectivity and patient disempowerment of the typical contemporary hospital forms an ethos others have critiqued extensively, for limiting access to a full spectrum of religious, cultural, or family ritual during procedures, even for adults. What is clear from my research with children is that great dividends come from honoring a child's subjective bent towards playfulness as a means of addressing fears and troubles during illness, surgical transformation, and compliance with uncomfortable procedures. When hospitals have child life professionals on hand, or offer playrooms free for play, these availabilities expand children's latitude for bisociation and subjunctivity. More can be done. Child life specialists lack the power of hospital administrators or physicians (Cole, Diener, & Wright, 2001; Mitre & Gomes, 2007), which limits how broadly they can support children. Zoning playtime away from clinical routines and away from biomedical personnel subverts a wider opportunity to ease children's stress in real time, during treatment.

If pediatric treatment is to ultimately become patient-centered in the fullest sense, there remains an open issue that sets the biomedical ethos against children's subjunctivity. Does playfulness risk subverting the rules, hierarchy, efficiency and biomedical logic of institutionalized care? Or on the flip side of the issue, do institutional and ontological prerogatives unwittingly truncate children's resources for resilience, making their medical interactions less positive than they could be?

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Chapter 11
Acceptance and Commitment Therapy (ACT) to Foster Resilience in Pediatric Chronic Illness

Michelle M. Ernst and Michael W. Mellon

The prevalence of children and adolescence living with chronic illness is rising, with estimates suggesting that nearly one in four children may be impacted by a chronic medical condition (Van Cleave, Gortmaker, & Perrin, 2010). Children with chronic medical conditions and their families face a host of challenges, such as coping with illness-related procedures (e.g., IV treatment), executing sometimes considerable treatment burden (Sawicki, Sellers, & Robinson, 2009) and managing illness-related physical symptoms (e.g., pain; Compas, Jaser, Dunn, & Rodriguez, 2012). These challenges can understandably cause heightened distress in children, and indeed studies across illness groups demonstrate heightened risk for distress and psychopathology for these children (Hysing, Elgen, Gillberg, & Lundervold, 2009). Notably, having a chronic illness can also interfere with typical childhood activities and milestones, such as missing school or participating in social activities (Ernst, Johnson, & Stark, 2010). The impact of chronic illness can extend beyond the identified "patient" of the family such that parents and siblings of children with chronic illness also report experiencing higher levels of distress (Pai et al., 2007). What is perhaps more remarkable, however, is that the majority of children with chronic illness and their families *do not* evidence marked differences in their emotional or behavioral functioning compared to healthy children despite considerable adverse experiences (Hysing et al., 2009).

Thus, many children and their families demonstrate resilience in the face of the challenges associated with having a chronic condition. Resilience has been

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M.M. Ernst, Ph.D. (✉) • M.W. Mellon, Ph.D., A.B.P.P.
Department of Pediatrics, Division of Behavioral Medicine and Clinical Psychology,
Cincinnati Children's Hospital Medical Center,
University of Cincinnati College of Medicine, Cincinnati, OH, USA
e-mail: michelle.ernst@cchmc.org; michael.mellon@cchmc.org

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conceptualized in various ways, but can be defined as "the capacity of a dynamic system to withstand or recover from significant challenges that threaten its stability, viability, or development" (Masten, 2011). A key feature of current conceptualizations of resilience is that it reflects a *process* in which an individual engages with a stressor or adversity within a larger system (Hilliard, Harris, & Weissberg-Benchell, 2012; Rutter, 2013), and that this process can lead to the achievement of positive outcomes despite this risk. Resilience can be time- and domain-specific, such that children can evidence strengths in isolated facets of their lives (Herrman et al., 2011). At the same time, developmental cascades related to resilience can be seen, in which positive behaviors developed in one domain can subsequently spread to other domains (Sapienza & Masten, 2011). Importantly, resilience denotes that a person is able to continue on a typical developmental trajectory despite, or within the context of, the adversity. For this chapter, resilience is presented from the perspective of pediatric psychology, an orientation which highlights the dynamic interplay between child development, family systems, and chronic illness. This perspective emphasizes the interface between biopsychosocial variables that affect coping and wellness.

A number of individual characteristics have been positively associated with resilience in children and adults. For instance, cognitive factors such as attentional control, effective problem-solving, and self-reflection have been shown to predict better outcomes (Rutter, 2013; Sapienza & Masten, 2011), as have emotional factors such as emotion processing and emotion regulation (Zolkoski & Bullock, 2012). In addition, self-concept variables such as self-esteem, self-efficacy, sense of agency and mastery, and the ability to integrate adversity into a cohesive sense of self appear related to resilience (Zolkoski & Bullock, 2012). Resilience is also associated with behavioral factors such as participation in "normal routines" and chores (Zolkoski & Bullock, 2012) and having positive relationships with peers (Sapienza & Masten, 2011). Finally, meaning-making and spiritual support have demonstrated positive associations with resilience (Sapienza & Masten, 2011). For children specifically, having a warm relationship with a responsive parent who has effective parenting skills has been shown to promote resilience (Rutter, 2013; Sapienza & Masten, 2011; Zolkoski & Bullock, 2012). On the other hand, factors that have predicted poorer outcomes related to coping with adversity include avoidance of stress-related thoughts or emotions and disengagement from the stressor (Compas et al., 2012).

Resilience has been less studied in chronic illness populations, but emerging data suggest that both general factors as above and disease-specific factors influence outcomes (Hilliard et al., 2012; Stewart & Yuen, 2011). In chronic illness populations, these resilience factors have been shown to be associated not only with psychosocial outcomes but also with illness-related outcomes such as adherence and improved physiologic markers (Stewart & Yuen, 2011). For example, in the diabetes literature, resilience has been related to diabetes knowledge as well as factors such as stronger cognitive capacities (e.g., executive functioning, memory), family cohesion, and the ability to balance family needs with illness-related needs, whereas mood issues, family conflicts, and parental stress have been shown to decrease resilience outcomes (Hilliard et al., 2012). Researchers have looked at the impact of self-concept in young adults with diabetes, and found that the more strongly a person identified with their illness as central to their self-concept, the poorer their diabetes outcomes (Luyckx, Rassart, Aujoulat, Goubert, & Weets, 2014). By contrast, in congenital heart disease populations, strong sense of identity (Luyckx, Goossens, Van Damme, Moons, & i-DETACH investigators, 2011) and strong child–parent relationship (Moon et al., 2009) were associated with better psychosocial outcomes. In adolescents with cystic fibrosis, acceptance of the illness (defined as the appreciation of the need to adjust to the illness and tolerating the unpredictable nature and aversive consequences) has been related to improved mood (Casier et al., 2013). It may be that, with chronic illness, in which there are situations that cannot be changed, resilience factors related to self-concept and personal identity are implicated. As evidenced from the coping literature, the ability to maximize one's fit to the current situation (i.e., "secondary control") has been most consistently associated with positive outcomes across illness groups (Compas et al., 2012). This is in contrast to "primary control" coping in which one strives to influence or change the adverse situation, and which appears to be less consistently effective in coping with chronic illness (Compas et al., 2012).

One construct that has recently been proposed as important for positive adaptation is psychological flexibility. While definitions vary, a common theme is that psychological flexibility is the ability to behaviorally adapt to fluctuating demands in service of important values and despite short-term negative thoughts or emotions (Kashdan & Rottenberg, 2010; McCracken & Vowles, 2014). Psychological flexibility is characterized by a person's willingness to experience all thoughts, feelings, and mental images as they are and without judgment, while behaving in ways that are consistent with one's chosen life values. There is overlap between the factors associated with resilience and those associated with psychological flexibility. For example, psychological flexibility is postulated to be related to the ability to make attentional shifts to focus on salient aspects of the current situation, similar to the notion of attentional control and related to effective problem-solving. In addition, psychological flexibility highlights the ability to be open to a full range of emotional experiences while maintaining a range of behavioral options in response to these emotions, which are important features of emotion processing and regulation. Finally, a key component of psychological flexibility is engaging in behaviors that are in the service of important and meaningful goals and values. This emphasis is consistent with the defining feature of resilience: persistence in important developmental tasks despite adversity. Thus, interventions that promote psychological flexibility may target variables critical to resilience promotion.

Acceptance and Commitment Therapy (ACT) is a behavioral therapy designed to foster psychological flexibility through experiential learning, specific language techniques, and mindfulness (Hayes, Villatte, Levin, & Hildebrandt, 2011). It has demonstrated effectiveness similar to other psychological treatments (including "traditional" cognitive-behavioral therapy) across a range of psychological disorders (Ruiz, 2012), and has been used with both children and adults (Coyne, McHugh, & Martinez, 2011; Ruiz, 2012). ACT is considered to be part of the "Third Wave" of behavior therapies which include "mindfulness" approaches (Cullen, 2008; Hayes, 2004). These mindfulness therapeutic approaches emphasize the importance of context in which presenting problems exist, and intervene, not by changing the topography of behaviors and cognitions, but by altering the functional impact of these problems. Mediational analyses typically demonstrate that improvements in therapeutic outcomes are mediated by changes in ACT-related behaviors, such as acceptance of aversive thoughts/experiences (Ruiz, 2012). We believe, based on the similarities between the concepts of resilience and psychological flexibility, that ACT may be an effective behavioral intervention to foster resilience in pediatric populations. The remainder of this chapter will provide an overview of ACT, review the application of ACT in pediatric illness within the context of resilience, and use case vignettes to highlight the application of ACT.

Acceptance and Commitment Therapy

From its early days, behavior therapy has played a profoundly positive role in fostering human adaptation. Early applications of token economies in the psychiatric hospital for patients with schizophrenia (Ayllon & Azrin, 1968) and stimulus control procedures to teach profoundly retarded adults to be toilet trained (Azrin & Foxx, 1971) document the positive impact of behavioral procedures. However, the application of positive and negative reinforcement seemed to have limits when extended to verbally and cognitively competent individuals who “think” in a more complex manner. This frustration led to the development of procedures which focused on the cognitive processes that were hypothesized by clinicians to be related to many emotional and behavioral disorders and were named “cognitive behavior therapy” (CBT). However, similar disappointments were reported as the theorized “cognitive” processes that caused the “distortions” of thinking and subsequent mental anguish did not correlate with predicted changes in the clients’ behavior (Hayes & Strosahl, 2004). This dilemma resulted in what Hayes et al. (2004) call the “Third Wave” of behavior therapies in the form of mindfulness oriented therapies, of which ACT is considered exemplary.

The basic position of ACT is to study the whole human in a particular context in order to predict and influence the behaviors of people with the goal of leading them to greater psychological flexibility and thus, adaptive and meaningful lives. Notably, ACT is supported and expanded by the scientific work of Relational Frame Theory (Hayes, Barnes-Holmes, & Roche, 2001), which is an account of human language or cognition, and ACT is continuously informed by the discoveries of how human language operates in a manner associated with emotional and behavioral sequelae. For example, humans have the capacity to anticipate (using thinking as mental “language”) the most terrifying future scenarios and prepare for events which have a low probability of occurring, and to become anchored in a painful past, reliving each minute detail, as if by doing so the past will finally make sense and/or have a different outcome. The struggles with the future and the past prevent a person from acting successfully in the present moment. In addition, ACT proponents acknowledge their roots in applied behavior analysis, with an emphasis on the function or purpose of behavior. Clinicians using ACT endeavor to foster optimal psychological flexibility by increasing the client's awareness of the detrimental influences of language which lead to effortful suppression of difficult thoughts, feelings, and mental images, in addition to maladaptive rule following. These struggles block the person's awareness of how well their behavior comports to the most salient and informative influences in the present moment. Through ACT, clients can become more open to their emotional and cognitive experiences (i.e., "open up"), face the present moment and its demands with clarity (i.e., "be present"), and engage in important and necessary behaviors that are aligned with what the client values (i.e., "do what matters") (Coyne et al., 2011).

Hayes et al. (2004) have conceptualized the six main components of ACT in what is termed the "Hexaflex" (see Fig. 11.1). The Hexaflex demonstrates the adaptive processes associated with psychological flexibility and a meaningful life experience.

Acceptance is a key ACT component and is exemplified by a person's willingness to be aware of and allow difficult thoughts and feelings to be experienced without judgment. Importantly, this is differentiated from what a person may *want*

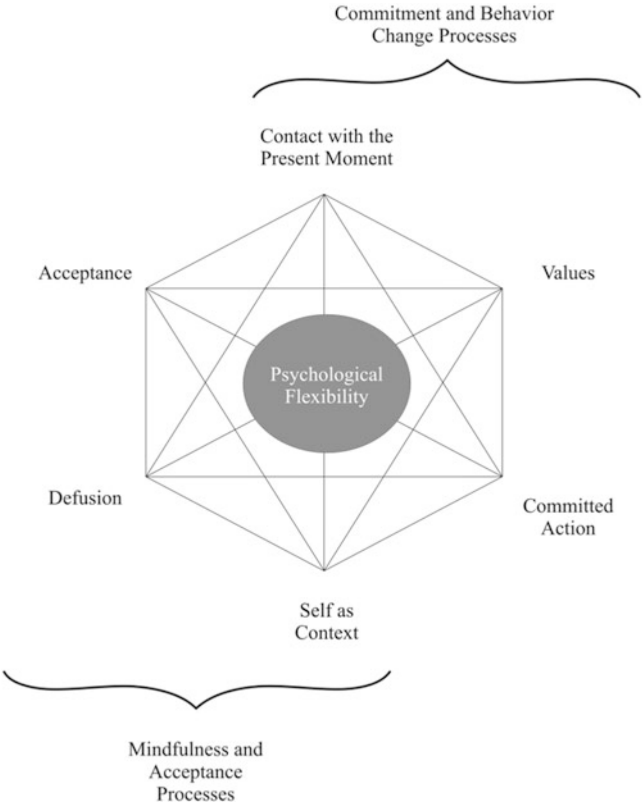

Fig. 11.1 Six core ACT processes. From: Hayes, S. C., Strosahl, K. D., & Wilson, K. G. (1999). *Acceptance and commitment therapy: An experiential approach to behavior change*: Guilford Press

to experience—that is, a person may not *want* to be reminded of their diabetes, but may be *willing* to be reminded of their illness (for example, during blood glucose testing) in order to attain important goals such as participating in sports; this is in contrast to *Experiential Avoidance,* which reflects efforts to avoid coming into contact with aversive thoughts, feelings, or mental images.

Cognitive Defusion is the process of being aware of the functional impact of language on guiding one's responses, and the recognition that thoughts are merely "verbal events" rather than "truths" that should automatically guide behavior. Then, a person can attend to and respond from mental rules or language that is in the service of important values. In contrast, *Cognitive Fusion* refers to a person creating mental rules that contribute to maladaptive behavior because the person is indifferent to or blind to the adverse impact of applying those mental rules. For example, a person who is "fused" with their thoughts may respond to the thought "I will likely have pain if I go to the party" by not leaving the house, while a person who can defuse from this thought will recognize this as simply a thought the brain is having which may or may not be true and can look to other factors for deciding actions (e.g., the value of peer interaction). Cognitive defusion can assist with experiential avoidance because recognizing thoughts such as "I can't stand feeling this distress" as simply mental activity can foster acceptance of distress. This perspective is echoed in this volume (Clark, 2016) with the concept of imaginal coping through play or use of metaphor by allowing for "multiplicative flexing of meanings."

Contact with the Present Moment involves attaching one's awareness to the information provided by our five senses in order to stay in contact with moment-to-moment experience. In this way, a person can more effectively respond to what the actual moment requires. In contrast, *Dominance of the Conceptualized Past and Future* places one's awareness at a time in which meaningful action cannot occur and one's efforts are devoured by the struggle to control aversive mental experiences. For example, if a patient is trapped by their memories of what life was like pre-diagnosis, they will be less likely to effectively manage their illness and experience the range of emotions (some of which may actually be enjoyable!) that the present moment offers.

Self as Context defines self as a transcendental experience through which all sensory inputs and mental assessments flow. It is by this transcendental perspective and a focus on what our senses are experiencing in the present moment that a person becomes freed from the struggle of experiential avoidance of difficult thoughts and feelings, and the oppression of fusion with the limits of our thoughts, which allows for a more flexible approach to the world. In this way, a person does not allow identity to be defined by labels or constructs such as "pain patient." The contrasting perspective is *Self as Content*, which refers to defining one's self by one's verbal conceptualizations, which are often composed of negative self-assessments or judgments. A person's identity literally becomes the language they use to describe themselves.

Values in life are those chosen areas that are important to individuals—they are the guideposts for meaningful behavior and what fosters persistence in actions long enough to provide satisfaction and meaning in the long journey of life. This satisfaction is said to energize or reinforce one's efforts to persevere. Importantly, ACT makes a distinction between values and goals: values are a direction in life or a way of being (e.g., "being a member of a group") whereas goals are specific outcomes in that direction (e.g., "being on the soccer team"). This point can be especially salient for individuals whose illness has posed limits on specific activities—goals may need to change but movement in the direction of the value remains feasible. Values identification and clarification can foster this important process of "regoaling," which is described in the palliative care literature as the ability to redefine and reengage in new goals within the context of changing cognitive or physical capabilities (Goldstein, 2016). Without a compass to guide oneself, people are vulnerable to the burdens of life and are unable to sustain efforts long enough to experience meaning.

Committed Action refers to sustained behavioral choices in the direction of important values. This element of the Hexaflex may be more consistent with typical referents in clinical psychology involving objective behavior change. Awareness of chosen values allows a person to engage in committed action toward satisfying life experiences in spite of the setbacks and burdens. For example, a parent may be more willing to commit to allowing their adolescent with cancer to engage in developmentally appropriate activities despite their perception of their child as vulnerable if they are able to link this behavioral pattern to their value of fostering self-efficacy in their children.

The goal of ACT is to guide the client toward a willingness to nonjudgmentally stand with the difficult thoughts, feelings, and mental images in order to suspend the struggle to control them. The person learns through experiential activities to better understand the powerful impact of our language and thoughts on behavior and willingly carry these mental processes toward a more meaningful life experience through acceptance. The client learns to simply watch these ongoing mental processes, as they are, in the context of the "here-and-now," and learns that the thoughts do not define who the client chooses to be. Once loosened from the struggle with the help of mindfulness exercises, relaxation, and the rich use of metaphors to describe the struggle, the person is then guided into defining what they value in life and then charts a course of meaningful action toward that way of living. In spite of real adversity, clients are able to behave more adaptively and flexibly with ACT and make choices which are consistent with their chosen values, thus contributing to a tremendous sense of satisfaction in life. This, we believe, is consistent with findings within the resilience literature. Table 11.1 lists examples of ACT interventions to increase psychological flexibility in the various domains of the Hexaflex (Hayes & Strosahl, 2004; Hayes, Strosahl, & Wilson, 1999).

ACT and Chronic Illness

ACT has been studied across a range of medical conditions. Of note, ACT interventions tend to not directly target physical symptom management, but instead target behavioral engagement in expected developmental activities. In randomized control studies, ACT has been shown to be effective in coping with a range of medical conditions including cancer (Hawkes et al., 2013), epilepsy (Lundgren, Dahl, Yardi, & Melin, 2008), diabetes (Gregg, Callaghan, Hayes, & Glenn-Lawson, 2007), and

Table 11.1 ACT therapeutic exercises

Hexaflex component	Therapeutic exercises	Therapeutic target
Acceptance of difficult thoughts, feelings	Creative hopelessness. Bryan the unwanted party guest. Tug-o-war. Ice in the hand	"I have IBD and I am now an illness"
Defusion from mental rules	Talking Tom Cat. Give physical features to a feeling-draw picture. Expanding verbal statement. Hold hand up and move it "later" or "before"	"Because I have IBD I cannot live a normal life"
Present moment focus	Body scan exercise. Notice all sensory inputs	Notice what my sensory experiences are versus my mental experiences
Self as context	Leaves on the stream. Body cut out and post it notes of events and thoughts	Notice that thoughts and feelings come and go and I am the vessel that contains them
Chosen values	Jewels in your crown. Diamonds on an arrow of life	Choosing what my life will be about
Meaningful action	Goal setting and behavioral activation: even tiny steps count	Taking a step in the chosen direction regardless of how large

From: Hayes, S. C., & Strosahl, K. D. (2004). *A practical guide to acceptance and commitment therapy*: Springer
Hayes, S. C., Strosahl, K. D., & Wilson, K. G. (1999). *Acceptance and commitment therapy: An experiential approach to behavior change*: Guilford Press

chronic pain (Wetherell et al., 2011; Wicksell, Melin, Lekander, & Olsson, 2009), with outcomes equivalent to "traditional" cognitive-behavioral treatment when directly compared (Wetherell et al., 2011). Outcomes have included improved functional ability (Wetherell et al., 2011; Wicksell et al., 2009), quality of life (Hawkes et al., 2013; Lundgren et al., 2008; Wetherell et al., 2011; Wicksell et al., 2009), disease management (Gregg et al., 2007), and physical (Lundgren et al., 2008; Wicksell et al., 2009) and emotional (Wetherell et al., 2011) symptom reduction. In addition, post-traumatic growth has also been related to ACT interventions (Hawkes et al., 2013). These positive outcomes in functional improvement and disease management are perhaps most directly related to resilience, in that these improvements demonstrate an increased ability to participate in a developmentally expected pattern of behaviors despite the presence of adversity, and the ability to engage meaningfully in and master aspects of the adversity.

ACT and the Family

Masten (2011) argues cogently that fostering resilience in children is most successful when the systems in which the child operates are targeted for intervention. This may be particularly salient in situations which impact those critical systems, such as pediatric chronic illness which affects the entire family (Pai et al., 2007). Hoehn, Foxen-Craft, Pinder, and Dahlquist (2016) have outlined a number of ways in which parents can foster the adjustment of children with medical illness, including managing their own emotional reactions during medical procedures, mitigating against the parenting trait of over-protectiveness, and encouraging the opportunity for their child to participate in "normal" activities which foster independence and social experiences. "Mindful parenting" is a model which applies concepts found in psychological flexibility to parenting interactions such as present moment focus (i.e., "listening with full attention"), nonjudgmental acceptance of self and child, and parenting in accordance with goals and values (Duncan, Coatsworth, & Greenberg, 2009). Mindful parenting interventions have been demonstrated to improve child behavior management comparable to established behavior management programs with greater positive impact on the parent–child relationship (Coatsworth, Duncan, Greenberg, & Nix, 2010). As strong family relationships have been shown to contribute to child resilience (Moon et al., 2009; Rutter, 2013; Sapienza & Masten, 2011; Zolkoski & Bullock, 2012), interventions that enhance family adjustment may contribute to increased resilience. ACT-based family interventions have not been widely conducted in pediatric chronic illness population, despite evidence experiential avoidance predicts poorer parent psychological adjustment (Greco et al., 2005; Whittingham, Wee, Sanders, & Boyd, 2013). However, a very recent pilot study conducted with parents of children with life-threatening illnesses utilized ACT to target each of the core Hexaflex components, and demonstrated significant improvements in parent psychological flexibility and decreases in parental distress (Burke et al., 2014).

Case Vignettes

The following case vignettes illustrate the use of ACT strategies to foster resilience in the face of chronic illness-related adversity. The use of ACT for pain management has been widely reported (Masuda, Cohen, Wicksell, Kemani, & Johnson, 2011). Here, from our own clinical practices, we present four different chronic illness scenarios from the point of view of pediatric patients and families supporting chronically ill children.

Coping with sibling death. Jean was a 19-year-old woman who was referred by a medical team related to depressive symptoms (overwhelming feelings of guilt, tearfulness, and complete social withdrawal) that emerged annually at the time of her brother's birthday and death. Jean was diagnosed with Wilson's disease, the disease that caused her brother's death. Jean completed several measures of psychosocial functioning that indicated mild anxiety and significant depression. In addition, she completed the Acceptance and Fusion Questionnaire for Youth (AFQ-Y; Greco, Lambert, & Baer, 2008) with a total score of 39 (87th %-ile) with clear evidence of struggles to avoid and suppress difficult thoughts and feelings of her brother and the belief that her history prevented her from having a meaningful life.

Given that she was born after her brother died, Jean indicated that it was difficult because she could never thank him for his gift of life in the knowledge of the disease before it became fatal.

ACT intervention occurred across three sessions and strategies included a present moment focus with the body scan technique and awareness of sensory experiences in order to increase her willingness to confront her feelings in a nonjudgmental way. Jean was also instructed to use the "Leaves on the Stream" exercise (picture thoughts as leaves floating by on a stream; Hayes & Strosahl, 2004) as a means of cognitive defusion. Finally, Jean was supported in her practice of acceptance of her experience as she addressed an empty chair (Hayes et al., 1999) as if her brother were sitting in it and listening to her. She was quite tearful but was able to say "thank you" to her brother and that she would utilize the gift of life to her fullest potential as a graphic arts student in college. Each time a difficult thought related to her brother came to mind she would simply say: "Thank you, Mark, for the gift of life." Jean's following visit resulted in her saying that she was "1000 % better" as she did not feel guilty about her brother's death. She was also able to finally have a positive discussion with her mom about her feelings. Thus, Jean was able to maintain full participation in her own life within the context of her sibling's death.

Procedural anxiety. Bobby was an 11-year-old boy with Crohn's disease complicated with an anal fistula. He was referred by the Gastroenterology Service following his refusal to complete scheduled blood work necessary to determine why his current medication regimen was not effective in resolving his fistula. Bobby demonstrated significant avoidance in that he would not meaningfully engage in the initial session and found it very difficult to describe his experiences before and during the blood work. Bobby eventually reported that, following a difficult blood draw in which four attempts were required to complete the task, he had developed a very graphic mental image of a massive needle being stabbed into his arm and pushed through to the back of his elbow while grinding it back and forth. This image would occur as he was preparing for blood work, and was accompanied by rapid heartbeat, shortness of breath, and feeling faint. He then would have the thought "just had to get out of there," which he would follow by leaving.

ACT strategies included a cognitive defusion technique in which Bobby said out loud his panicky thoughts into a cell phone application called "Talking Tom Cat" which repeats what Bobby said in a much higher and comical frequency. Bobby immediately began to smile and giggle at how silly his voice (and the panicky thought) sounded, thus changing the functional impact of the verbal statements. This strategy is an example of what medical anthropologist Cindy Clark (2016) would call "subjunctive play," in which meaning is re-structured and accompanied affective release and relief. The therapist accompanied Bobby to the procedure room and coached him with relaxation while talking about his thoughts out loud into the phone application and periodically laughing. From that point forward, Bobby was able to cope with the necessary blood work even though he experienced pain. Thus, Bobby was able to experience mastery and agency, key components of resilience.

Parent–child bonding. Beth was a 2-month-old infant diagnosed prenatally with severe congenital heart defects. She was intubated and listed for cardiac transplant. The family was referred to treatment because Beth's mother Sue was noted to be very reticent to interact with Beth even after her condition improved and she was extubated and listed for heart transplant. At the first meeting with the psychologist, Sue expressed her concerns about Beth's quality of life, but more prominently expressed her concerns related to whether she, herself, would be able to cope with the uncertainty of raising a child with a heart transplant who may have significant medical complications and early death. She described herself as a constant worrier who was prone to catastrophic thinking, originating in early childhood.

ACT strategies included normalization of a range of cognitive reactions based on wanting to avoid aversive experiences (wishing for Beth to pass away to avoid constant worry and prolonged grief), highlighting lack of success of avoidance strategies ("deciding" to bond with Beth not being an option because it would not prevent grief if Beth were to die and bonding was already happening), and exposure to unwanted experiences coupled with cognitive defusion (imagining Beth at various ages while observing cognitive/emotional responses). This shift from experiential avoidance was framed as something that Sue would do only in the service of one of Sue's most important values—being a "present" parent to Beth. Later, clarifying Sue's values for her parent role (e.g., helping her child develop the competencies to handle difficult situations) provided Sue the venue to imagine how Beth's experiences might still allow for a good quality of life in which Sue could effectively and meaningfully provide parental guidance. Sue committed to bedside attendance goals and was successful by recognizing the futility of distancing herself from Beth and by using cognitive-defusing techniques (e.g., "thank you for sharing" to her mind). In addition, Sue was taught mindfulness strategies to encourage her to fully engage in the present moment, allowing for increased opportunities for delight, satisfaction, and meaning in her interactions with her developing daughter. During the course of treatment, Sue was able to better tolerate the anxiety of the uncertain prognosis, which allowed her to discuss with clarity what would be in Beth's best interest separate from her own emotional need to avoid anxiety and pain. Sue reported continued worries about Beth's future, as to be expected, but was able to engage meaningfully with her and experience positive interactions as Beth continued to recover from her transplant and tracheostomy and demonstrated developmental growth. Beth was discharged home at age 9 months.

Adherence. Tami was a 16-year-old obese female with type 2 diabetes who was referred due to nonadherence with daily blood glucose monitoring or corrections, poor diet, and lack of exercise. She reported a long history of nonadherence, stated she wanted a "life change" and wanted "everything to change" (especially health behaviors) but felt stuck. She reported that she "never" took care of herself, slept most of the day and described herself as "lazy." She also reported that she would think about doing a health-related behavior but would "talk herself out of it" with thoughts related to her historical inability to persist in health-related goals.

ACT strategies focused on highlighting the tremendous value Tami placed on "being healthy," and noticing the committed actions that she already was engaged in which reflected this value (e.g., took oral medication regularly). The cognitive defusion technique of "Passengers on the bus" metaphor (Hayes et al., 1999), in which thoughts are considered annoying-but-ultimately-powerless passengers on the bus that the person is driving toward a value, was used, and Tami began to have experiences doing committed actions regardless of what her thoughts were (i.e., regardless of what her various "passengers"—unhelpful thinking patterns that she named—said to her). Exercises helping her to see herself as the context for her thoughts and feelings loosened her identification with her self-identity of being "lazy" (one of her unhelpful verbal "rules" about her behavior) and she was able to move forward in setting more age-appropriate expectations for herself in terms of establishing and frequently following a daily schedule with age-appropriate responsibilities, health behaviors, and pleasant activities.

Summary

The key feature of resilience includes a process in which an individual engages with a stressor or adversity (i.e., chronic illness) and continues on a typical developmental pathway. The child shows a willingness to allow room for the adversity or illness in order to achieve a greater life purpose. We have reported that a child's emotional and cognitive regulation, sense of an integrated self, willingness to continue in meaningful life activities, and having a positive and supportive relationship with caregivers are associated with resilience. These findings, we argue, are consistent with the ACT conceptualization of "psychological flexibility" whereby a person is willing to accept without judgment the difficult thoughts and feelings that occur with the demands of a chronic illness, and actively engage in both illness management and meaningful activities in the service of important values. A "psychologically flexible" child sees herself as being larger than the illness and not constrained by the verbal rules that may come with the logical attempts to avoid or suppress the difficult thoughts and feelings, the latter being associated with poor coping.

The goals of an ACT consistent intervention are to bring into one's awareness the mental traps of suppression/avoidance of difficult thoughts and feelings related to illness and the limiting effects of rigid verbal problem-solving. This process involves the promotion of mindfulness of the differences between mental experiences and sensory experiences and the awareness that one's sense of self is greater than the verbal world that can ensnare and limit. Once the awareness of self and the mental traps is promoted, a person can find more flexibility in their behavioral repertoire which will allow for meaningful action based on one's chosen values.

As clinicians, we have all witnessed the child with a chronic illness who rises above the challenges of a difficult medical condition by maintaining or even expanding their behavior repertoire versus the child who is poorly coping as exemplified by narrowing typical developmental experiences. We believe that ACT has the potential to increase a child's resilience through increased psychological flexibility.

Promoting psychological flexibility in the parent–child relationship is also a relevant target of intervention. Parents who can support their child in coping with illness-related distress, as opposed to avoiding it through protective parental actions, may facilitate better coping in the child. Parents are just as vulnerable to the narrowing effects of experiential avoidance and cognitive fusion in their efforts to "solve" the problem of their child's illness. If parents can emphasize a present-moment focus in their interactions with their child, they are more likely to find a satisfying and meaningful experience versus anticipating the horrifying possibilities of the future.

Clearly, more research needs to be done on how to promote psychological flexibility within the parent–child dyad, through investigational work within the family. In addition, clinical research is required to demonstrate the efficacy of ACT for children with chronic illnesses and their families, delivered individually or within group interventions. Given the limits of healthcare resources, exploring the application of ACT within group interventions of children with chronic medical conditions is sorely needed. In fact, we are currently developing a group intervention for the parents of children recently diagnosed with inflammatory bowel disease (IBD) with the goal of increasing psychological flexibility in the parent at the start of their child's journey with IBD. The future of children coping with chronic medical illnesses is looking more positive as clinicians are applying evidence-based and promising interventions to promote resilience.

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Part IV
Social Structure and Policy Formation

Chapter 12
Creating a Context for Resilience in Medical Settings: The Role of Collaborative Professionals and Informal Supports

Michael Ungar

Some years ago I was a consultant for an interagency team that was providing physical and mental health services to a single mother and her four children. The three eldest had significant physical and mental health challenges including one child with diabetes, another with autism, and two with severe emotional disorders. Two of the children had also suffered unintentional physical injuries that had required hospitalization. The eldest child also coped with limitations to her hearing and sight. The mother herself struggled with a lifelong depression and the traumatic after effects of both family violence as a child and spousal abuse. To make matters worse, the family lived in subsidized housing that was to be demolished and its residents relocated to a new less urban development. At the case consultation that I attended, the mother had come to discuss her children's complex needs and ask for more in-home resources.

There were 14 professionals who attended the consultation with the mother, each detailing treatment plans for one or more family members. It sounded impressive, but also unworkable. Finally, exasperated by the demands each part of the medical system was placing on her, and the endless cycle of appointments that she was required to attend, the mother stopped listening and turned to look at the wall behind her. Her case manager, a medical social worker, paused the meeting and asked the patient if she wanted to say something. Turning back to the group, she stared at everyone for a moment and finally told us, "I'm fed up with all of you. Every time you give me an appointment I have to drag my kids with me on buses. You all have these special times I have to meet with you, but I'm done. From now on, if you want me or my kids to show up, I'm available Wednesdays. Just Wednesdays. You work it out." With that, she got up and left.

M. Ungar, Ph.D. (✉)
School of Social Work, Resilience Research Centre, Dalhousie University,
Halifax, NS, Canada
e-mail: Michael.ungar@dal.ca

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To this day, I admire the mother's courage to name the system's failure in front of her treatment team. Her "resistance" (as one of my colleagues referred to her behavior) forced us to better coordinate hospital visits, provide more in-home supports, and find solutions for transportation. A local donor was even found through a community Wraparound program that helped the mother acquire a used car at a very low cost.

The example highlights a problem with how we conceptualize resilience. Remarkably little has been written about resilience that focuses on service design and delivery, or the relationship between services and people's informal supports. This is odd given that most individuals who show vulnerability to disorder tend to also rely heavily on health and social services. In this chapter I will explore a systemic understanding of resilience and the processes by which the physical and social ecologies of medical services (e.g., where services are provided, how they are coordinated, and how well they match a patient's culture), along with their interaction with people's own social supports and the broader social policy context, helps or hinders resilience when children or their caregivers are experiencing physical or mental disorder. This understanding of resilience and its relationship to the structure of integrated medical and social services reflects advances to the study of resilience occurring in the social sciences, including social psychology, social work, and medical anthropology. This perspective on resilience will be discussed in relation to the design of interventions that are sufficiently complex to enhance the promotive and protective factors that nurture and maintain patient well-being.

A Systemic Understanding of Resilience

Resilience is typically thought of as a process whereby an individual and the individual's environment interact in ways that enhance psychological, physical, and social development. The emphasis is on individual factors, or community factors, but seldom the mandated and non-mandated services that make it more or less likely people successfully cope with adversity. For example, Masten (2014) describes resilience as "the capacity of a dynamic system to adapt successfully to significant challenges that threaten its function, viability, or development" (p. 6). The definition is helpful as it conceptualizes resilience as a systemic process, highly dependent on the quality of the environment (including medical and social services) to facilitate recovery and growth after exposure to potentially traumatizing experiences or social disadvantage.

Support for this systemic view of resilience grew as researchers in the field of child development conducted large cohort studies in which subgroups of children exposed to the same adversity as their peers emerged with far fewer problems. Where the field once speculated that these outcomes were attributable to individual characteristics like temperament, work by Rutter (1987), Garmezy (1991), Werner (1990) and others begun over 40 years ago shifted the focus to promotive and protective processes that were related to better than expected outcomes.

In the past decade, our understanding of these processes has become more nuanced. For example, a study of levels of anxiety and depression in twins aged 3–12 showed that the environment becomes progressively more important in explaining a model that accounts for children's positive and negative changes over time (Boomsma, van Beijsterveldt, Bartels, & Hudziak, 2008). The older the child, and the more the child increases her encounters with a shared environment (her extended family, school, community, and service providers), the more changes in psychopathology and well-being can be explained by contextual rather than individual processes. Specifically, in this longitudinal study of both monozygotic (MZ) and dizygotic (DZ) twin pairs who were part of a voluntary Netherlands Twin Registry, an additive genetic influence was found for the MZ group when measuring anxiety and depression across ages. Genetic factors could explain 63 % of the variance of anxiety at age 3, but delinked to 41 % by age 12. By comparison, shared environmental factors accounted for 8 %, then 23 % of the variance while the non-shared environmental factors were reasonably stable across the decade, ranging from 26 % at age 3 to 36 % at age 12. Given these patterns, we can see that individual variance in both positive and negative developmental outcomes is accounted for less by individual factors than a child's interaction with her environment as those interactions increase.

Though this study of twins was focused primarily on psychopathology (with resilience implied as the absence of disorder), systemic studies of resilience show a similar pattern of results for developmental outcomes. For example, data from over five thousand youth who participated in the Western Australian Aboriginal Child Health Survey was used to assess the impact of 18 individual and ecological factors on resilience, ranging from a young person's age and sex to the educational status of their primary caregiver, family functioning (including exposure to family violence), substance abuse by parents, community socioeconomic index, prosocial friendships and connection to Aboriginal language and culture (Hopkins, Taylor, D'Antoine, & Zubrick, 2012). Interestingly, younger children seemed to be on the whole more resilient than older youth. Modelling emotional and behavioral resilience using hierarchical logistic regression, however, identified only three independent and significant variables. Prosocial friends were associated with better scores on emotional and behavioral indices such as Goodman's Strengths and Difficulties Questionnaire. Ecological variables, however, like living in an area with a higher socioeconomic status, and connection to Aboriginal language and culture, the two other significant factors in the study, were both associated with *lower* levels of resilience. These results, which the authors note are "counterintuitive" (p. 436), reflect the experience of just 10 % of the sample who resided in neighborhoods with a higher mean household income. In that context, the findings might be explained as the result of young people feeling "threatened by negative stereotypes of disadvantage and race" (p. 436) when they reside in contexts where they are far more identifiable as minorities. Knowledge of one's culture may also place an emotional burden on young people when they feel responsible for its sustainability, or negative emotions when awareness of one's culture brings with it a broader understanding of experiences of historical oppression. While the study's authors are very careful to not argue for the *status quo* to protect Aboriginal young people from emotional and behavioral problems, they also highlight the need for far greater attention to the dynamics of racism and social marginalization that expose children to more risks as their family's socioeconomic status improves.

Though the above two studies are very different (one is biologically focused, the other sociocultural), they both share an ecological orientation that broadens our understanding of resilience. In both research examples, there is a great deal of complexity with regard to the contextual, cultural, and temporal dimensions of resilience and psychopathology that affect at-risk populations that are likely to have contact with medical systems. This complexity is a factor when assessing resilience even when the focus is on individual well-being. Unfortunately, this systemic understanding of resilience and its relationship with medical and social services has been explored in only a small number of studies. I attribute this oversight to a view of individuals as highly agentic and their problems their own responsibility to solve. Resilience, like other aspects of healthy functioning, is not apolitical. The extent to which services are made available to people will make resilience more or less likely to occur.

In his description of the ecology of human development, Bronfenbrenner (2005) made this same point though his focus was not service provision. He wrote:

> It is true that individuals often can and do modify, select, reconstruct, and even create their environments. But this capacity emerges only to the extent that the person has been *enabled* to engage in self-directed action as a joint function not only of his biological endowment but also of the environment in which he or she developed. There is not one without the other. (p. 144)

It is this idea that environments facilitate growth that is the basis for a discussion of resilience that is relevant to medical settings. Rather than focusing on individual processes that occur during treatment (many aspects of recovery have a well-developed evidence base), I want instead to consider more broadly the role medical systems, in interaction with people's informal supports and social policies, play in potentiating individual development under conditions of adversity. My research and clinical practice suggest that we are only as resilient as the systems that surround us.

This point is easy to see in studies of low birth weight that is a condition that contributes to many negative developmental outcomes just as a healthy birth weight can make a child more resilient to individual and environmental stressors. Low birth weight, of course, is most often a consequence of an impoverished or dysfunctional environment and not a problem attributable to the deficiency of an individual mother (Cook & Frank, 2008). In other words, even a fetus' resilience is enhanced by the quality of the mother's access to prenatal care and social policies that make food security a priority. In this regard, primary prevention health programs, as well as a family's capacity to sustain itself, along with government policies that shape access to services and social welfare, determine whether food is provided to mothers through philanthropy (e.g., food banks) or a more socially just system that addresses both hunger and the quality of food available to families living in poverty. Just as the studies of adverse childhood experiences have demonstrated a link between early experiences within a child's family (e.g., witnessing spousal abuse or the mental illness of a parent) and the incidence of physical and mental health problems among adults (Anda et al., 2006), the resilience of individuals cannot be accounted for by individual qualities alone. Bronfenbrenner (2005) advises us to study more than one system if we are to understand how processes operate across systems. This is never easy to do as systemic interactions are complex. What one system does (the food bank) can influence other systems (a child's growth and future potential to learn). Demonstrating a causal link between systems, however, can be difficult without prospective research that accounts for a wide range of factors relevant to medical and non-medical settings.

Where such research does exist (e.g., studies of Romanian orphans adopted by families in the United Kingdom (Beckett et al., 2006)), we see evidence that the impact of systems that make people resilient are more than additive. There is a cumulative, or cascading effect, as engagement with promotive and protective processes like a healthy family and a child psychiatrist helps to make other supports such as education and peers more available and accessible. For example, the child who receives treatment from a pediatrician for emotionally dysregulated behavior and is then able to participate in a regular school program may develop a network of socially desirable peers rather than associations with other troubled youth. The child's resilience is the result of reciprocal and temporal processes that change over time as they influence one another. When medical and social welfare systems make themselves both available and accessible, and build on the capacity of the other social supports individuals have, the result can be opportunities for successful coping even in contexts of extreme disadvantage (Betancourt, Meyers-Ohki, Charrow, & Hansen, 2013; Boothby, 2006).

A more ecological definition of resilience that can explain the impact of systems (including medical systems) on resilience should focus equally on the role individual and contextual factors play in processes of coping under adversity. In medical settings, then, we could say that the resilience of individuals is their capacity to *navigate* to the resources they need to do well, along with the capacity of systems to *negotiate* with individuals and their caregivers to decide how resources will be provided to ensure they meet people's needs in ways that make sense to them. It is these dual processes of navigation and negotiation, with an emphasis on the capacity of both individuals and systems, which explains how resilience is likely to occur as the result of services, supports, and social policies (Ungar, 2008; Ungar, Ghazinour, & Richter, 2013).

Navigation

To illustrate the importance of the principle of navigation to resilience in medical settings, consider research using GIS mapping technology which has shown that access to medical services by children with moderate to severe intellectual and physical disabilities can depend on a number of factors unrelated to the child's medical condition or motivation to engage in treatment (Skinner, Matthews, &

Burton, 2005). When families were asked to record the amount of travel they did to get their child service, researchers found that proximity to the service could only account for a small number of the differences between study participants. Instead, poverty and a community's investment in public transit appeared to influence children's access to services, with more economically advantaged families and those living in better resourced communities accessing better treatment for their children.

As this example shows, if resilience is understood as a process by which individuals at risk exceed expectations and cope well, then we have to change our perception of where the locus of control for change resides. The principle of navigation implies both the patient's desire to seek treatment and the availability and accessibility of treatment when it is needed. Research by my colleagues and I have identified specific treatment of service use that increase resilience and those that impact negatively on young people's developmental outcomes (Stevens, Munford, Sanders, Liebenberg, & Ungar, 2014; Ungar, Liebenberg, Armstrong, Dudding, & van de Vijver, 2013). As part of a larger study of risk factors, resilience, and service use patterns among a purposeful sample of 497 young people using multiple services (mental health, child welfare, special education, and juvenile corrections) we selected young people whose aggregate exposure to risk was above the median for the overall sample, then split this at-risk group into those that showed higher or lower levels of resilience in three domains: individual strengths, supportive relationships, and engagement with one's community and culture. Next, we asked the young people and their families to consent to having their files reviewed across multiple services. Where consent was granted and the agencies holding the files (all of whom were partners in our research) were willing to have their files reviewed, we were able to contrast what we heard from youth themselves about their use of services, findings from our quantitative data, and patterns of service use we could document in the files. Our results showed disturbing patterns of service use by young people, with many young people who needed services not receiving the care they required. Specifically, in one analysis of the data, Liebenberg and Ungar (2014) showed that while youth involved with the juvenile justice system had as much need for mental health services as youth already engaged in hospital-based psychological interventions, the young people who became involved with the justice system received far fewer mental health services. These different service use patterns were associated with the children's scores on measures of resilience.

If we focus on cases where the agency referring a young person to the study was a hospital or community-based mental health care provider, and the youth identified one or more other services that he had used within the last 6 months, we again see patterns that connect resilience to service use. In general, we found that young people who were exposed to greater risk (especially contextual risk factors like poverty and family violence) do not receive more services despite their obvious need (Ungar, Liebenberg, et al., 2013). Furthermore, our findings show that these same youth tend to have a worse experience with their service providers when asked whether services were available and accessible in ways the youth found helpful.

To illustrate these complex multiservice use patterns of young people who are using mental health services, it is useful to review patient files to see how service use patterns become associated with positive or negative outcomes. The following is a description of a 17-year-old woman named Molly (not her real name) and her involvement over time with mental health (including hospital-based inpatient and outpatient programs), child welfare, and correctional services. Molly's case history was pieced together using both interviews with Molly and the detailed review of her files held by three of the agencies that provided her with service.

Molly had a tumultuous upbringing fraught with inconsistent caregiving, poor attachments, and a history of physical and sexual abuse. She is the youngest of three children born to the same mother and father, and has three stepsiblings from her mother's most recent relationship.

At the age of 6, following an episode of sexual abuse by her stepfather, Molly and her siblings were sent to live with their biological father where it was later alleged that Molly suffered physical abuse by her father's partner. When Molly was 7, she and her siblings were removed from their father's care by Child Protection Services (CPS) and Molly was sent to live with her paternal grandparents. Just before she turned 12, Molly was returned to the care of her mother. However, at the age of 13, Molly was brought into the temporary care of CPS because of her running away and other high-risk behaviors. She subsequently experienced multiple placements, including foster homes and a specialized group home for girls. She also began seeing a private therapist in the community, paid for by CPS.

By age 14, Molly became involved with the justice system and was placed on probation following charges of assault, theft under $5000, joy riding, property damage, and mischief. However, her tendency to run away resulted in many breaches of her probation order, adding to her original charges and extending her time on probation to nearly 2 years.

At school, Molly's principal and resource teachers described her as a pleasant student who showed a good work ethic in the classroom. Molly's attendance, however, became increasingly sporadic as her use of ecstasy and cocaine increased. At age 16, Molly attempted to move back in with her mother but problems continued to escalate and after only 2 months Molly agreed to accept an emergency placement group home that serves youth with complex needs. Molly was also reconnected to the private therapist she had seen previously and referred to an adolescent mental health treatment center. However, her application was deferred and Molly underwent instead a psychological assessment where she was diagnosed with possible psychotic spectrum disorder and strongly impaired cognitive functions likely resulting from her significant and extensive drug use. Molly had reported hearing voices and experiencing visual hallucinations.

Subsequently, a "step wise" treatment and service plan was put into place for Molly to address her mental health and substance abuse issues. The services in this treatment plan included participation in an addictions program, follow-up assessment by an early psychosis team, individual therapy, and referral to a mental health inpatient program. Shortly after this, Molly was admitted to a secure residential treatment facility by her social worker and was persuaded to attend an adolescent mental health and addictions inpatient program to address her substance abuse. However, upon entry into the program, Molly fled and was missing for several days. It was suspected that she had become involved in prostitution to pay for her drug addiction.

By the age of 17, Molly had at least 35 breaches of her probation orders and 6 separate admissions to a secure residential treatment facility, primarily due to the longstanding difficulties she experienced at her group home. After 3 years of probation orders, Molly's case with correctional services was closed, concluding that Molly remains at "high risk to herself and thus to the community." Around this time, Molly also became involved with a community program that provides services for at-risk and homeless youth. A referral from the program helped Molly get admitted to the adolescent mental health inpatient program that she had been referred to earlier. She was discharged, however, only 20 days later due to a lack of participation and three elopements. Upon her discharge, the staff at the adolescent treatment center strongly recommended that Molly be provided a long-term secure facility that specializes in the treatment of concurrent disorders. At last contact, Molly was residing temporarily in a shelter for homeless youth.

Molly's history as a patient and client of multiple services shows the challenges systems experience providing care to young people with complex medical and social needs. Starting with a lack of family support, exposure to family violence and sexual abuse, and continuing through years of intervention, it is clear that the services offered to Molly were never able to fully engage her. However, a long-standing relationship with a private therapist, and Molly's willingness to return over and over again to residential programming suggest that she may have appreciated some of the efforts being made to help her despite her apparent unwillingness to sustain participation in any plan of care.

Did services make Molly more resilient? Would she have done far worse (become engaged in prostitution full-time and dropped out of school much earlier) if medical and social service providers had not reached out to her? The answer seems to be "Yes" to both questions. The systems showed reasonably good coordination of services, though each service, whether hospital or community based, remained in its own treatment silo. When consistent mental health care was provided (e.g., a private therapist; referrals to inpatient treatment) and offers of support were kept active despite relapses in Molly's behavior, Molly demonstrated some willingness to continue involvement with her service providers. While far from successful, Molly's service history shows that systems can be a resource for resilience. At the very least, they prevented Molly from a more serious decline in functioning. Though not typically thought of as a developmental pathway to resilience, many young people with complex case histories like Molly's show similar patterns of "hidden resilience" in which they use services to get their needs met when other socially desirable health resources are unavailable (Ungar, 2004).

A single case study like this provides only anecdotal evidence for a connection between resilience and medical services. Research on coordinated medical and social services, however, has shown that when children do navigate effectively, the results tend to be positive. For example, a study of 177 children enrolled over a

6-year period in the Mental Health Services Program for Youth, a coordinated system of care approach offered by Massachusetts juvenile justice, social services, education, Medicaid, and mental health agencies, showed that funding to provide extra supports and coordinated services to youth aged 3–19 could change the frequency of children's use of medical services (Grimes, Kapunan, & Mullin, 2006). All the children enrolled in the study were eligible for subsidized health care and, or, special education. All had a demonstrated impairment of longer than 6 months and were at-risk of out of home placement. Through the coordination of services, program participants were able to change their service use profile from the expected level of individuals with similar disabilities to more normative population standards for those receiving Medicaid. In other words, medical expenses decreased and health outcomes improved as a consequence of medical and social service systems changing the way they worked together.

Negotiation

If the provision of medical services was enough on its own to guarantee positive development among children, then once services were provided, and barriers to access addressed, we would expect high rates of compliance with treatment plans and very low rates of relapse. Instead, among the most socially marginalized young people like Molly, and their families, there is a high risk of treatment failure even when services appear to show fidelity to their evidence-based practice protocols (Lee et al., 2009). As the example above illustrates, simply providing medical and social services is not enough. Services must also be negotiated so they meet the needs of children and families in ways that are contextually and culturally relevant (Falicov, 2007; Ungar, 2015). For example, while the acculturation of new immigrants may improve employability, it may also threaten mental health (Grant et al., 2004). Programming to address the needs of immigrants is less likely to do harm if service providers help people find a "third culture" that resolves differences between an immigrant's heritage culture and that of his or her adopted country.

Likewise, an excellent example of services that pay attention to context and adapt services to children's needs is Child Advocacy Centers (CACs). These centers have a mandate to provide comprehensive, coordinated services for children who have been sexually or physically abused. As supporters of these centers argue, it is the coordination and co-location of services that reduces child trauma and improves the chances for recovery (Newman, Dannenfelser, & Pendleton, 2005). In this example, a necessary suite of medical, legal, and psychosocial services is made available and accessible in a way that increases a child's likelihood of experiencing resilience. While similar services could be delivered in very different ways, CACs respond to the needs of children for services that meet their need for less intrusive interventions and continuity of care.

Once again, research by my colleagues and I echo these same themes. Young people who experience members of their treatment team as sensitive to their culture and acceptable to their families are more likely to be engaged with as providers of medical and social services (Ungar, Liebenberg, et al., 2013). This pattern of negotiation appears in a number of studies that are not explicitly dealing with resilience such as studies of coping among young people who have experienced early onset psychosis (Lal, Ungar, Malla, Frankish, & Suto, 2014). In-depth qualitative research with those youth has shown that their treatment priorities may be very different from those of their medical team, with young people seeking to construct identities for themselves as more normal, while their care providers focus on the youth's exceptionality. For example, while young people want to participate in age-normative behaviors, their psychiatric teams tend to advise them to instead modify their behavior, insisting they avoid recreational substance use and educational stressors like post-secondary schooling to prevent further deterioration in their condition. Similar tensions are evident in how other populations of young people navigate their way to the experiences that promote resilience. For example, Lennon et al. (this volume) discuss the resilience promoting processes chronically ill children engage in during their transition to adolescence.

By thinking about resilience as partly the result of negotiations between individuals and their service providers, we move the focus away from the individual and focus instead on the process of finding the right fit between what an individual needs to nurture and sustain his well-being and how well these needs can be met by natural supports, treatment teams, and the social policies that shape social interactions. For example, when studies of coping and mental health are done with minorities, patterns emerge that indicate culturally and contextually specific means of coping under stress. Alegria et al. (2004) studied the psychiatric epidemiology and service use patterns of Latino and Asian Americans. Results from The National Latino and Asian American Study (NLAAS) show that "The risk of psychiatric illness is linked to social position at the primary level, environmental context at the secondary level and psychosocial factors at the tertiary level" (p. 209). These patterns, they explain, can account for much of the variance in rates of psychiatric disorder and patterns of service use among both groups, with positive health outcomes linked to whether patients make use of services that are tailored to their needs. Rates of service use appear to be highly responsive to the quality of the services provided, including the cultural competence of mental health professionals.

Implications for Program Design and Clinical Practice

Because resilience is a multisystemic process, a medical intervention that enhances resilience may not be centered on what a child's medical team does but instead on what multiple systems, both formal and informal, do to help a child. By decentering our focus, we shift the locus of change from individuals to the quality of interventions and the level of coordination between service providers, families, and community supports. This approach to resilience shares similarities with public health initiatives that have been popular for the past five decades. For example, in the

1960s, Kempe, Silverman, Steele, Droegemueller, and Silver (1962) identified the battered child syndrome, relabeling the problem of children who appeared with signs of physical trauma as not just a medical problem but also a social issue that required coordination with social services to remedy.

More recently, medical practitioners like Prothrow-Stith (1991) have asked us to think of violence among teens as a public health issue. She was appalled that so many of her colleagues in the 1970s were thinking about this as an isolated and racialized problem, or as a problem where medical practitioners had only one role to play: that of providing medical care after the violence had occurred. Instead, she renamed the problem as a health crisis that required a broader set of interventions: "I saw this problem not as one that, say, required better surgical techniques, but one that required the creation of public health strategies such as health education in the classroom; health education via the mass media; community awareness; hospital-based screening for risk determination." (p. 133). Like efforts to address heart disease and smoking, the solution to problems like child abuse and youth violence is not there in the emergency room or the psychiatric clinic, but occurring long before the patient becomes part of the medical system.

Recent research has refined our understanding of which services and supports, in which combinations, can influence resilience the most in medical settings. With one of their goals being to deepen our understanding of the service ecologies that predict resilience, Rey and Tapia (2014) examined aspects of resilience among 130 parents of children who had suffered a critical illness after the child was discharged home from a Pediatric Intensive Care Unit (PICU) in Madrid, Spain. That study explored whether measures of resilience could be used to predict anxiety, depression, and post-traumatic stress among the parents. Assessing the parents within 48 h after discharge, then again 3 and 6 months later, the study showed that among parents with low resilience immediately after discharge, resilience remained low, but parents with higher resilience scores after discharge showed a loss of resilience as time went on. Overall, and despite this potential for a drop in functioning among the more resilient parents, the low resilience group still showed far more anxiety, depression, and post-traumatic stress when their child returned home. The study has implications for interventions as it suggests that a child's informal support network may be more or less functional depending on how well caregivers feel supported in their role as care providers for their child. Rey and Tapia speculate that the higher resilience scores of some parents had much to do with their access to a supportive extended family network, proximity to the hospital (parents who had to leave their homes overnight to see their child in hospital experienced the child's illness as more stressful) and the severity of the child's illness. To the extent that the parents experienced less stressful environments, their capacity to maintain their own sense of well-being was sustained or threatened. While the study did not examine the impact of parental stress on child outcomes, related work on systemic resilience, such as that cited in this chapter, would lead to the reasonable conclusion that a healthier, more resilient parent will have a positive impact on his child's ability to cope with an illness. (For more on the role of parents in promoting child adjustment to chronic illness see Hoehn's chapter in this volume).

We can think, therefore, of medical services either being helpful and effective (meaning that the degree to which they are helpful can be shown through research) or unhelpful, ineffective, and possibly even harmful to an individual's psychosocial development under conditions of stress. Effective medical services should provide not only evidence-based interventions, they should also consider how to address the challenges at-risk populations experience when navigating and negotiating for treatment within complex medical and social services. Unfortunately, most of the research on how services makes children with complex needs more resilient has not been able to create a rigorous body of evidence largely because the interventions that show promise are too multisystemic to manualize. How can we randomize case assignment when children who are at the greatest risk of relapse and resistant to treatment engage with multiple service providers at the same time? How can a study ethically compel a child or family to accept a service that may not negotiate with them to provide interventions that they value and need? Sadly, while the research on resilience suggests there is a need for coordinated, multisystemic services, there has been little effort to identify best practices that are focused on how systems change individuals.

The programs that show promise, however, are those that address the contextual barriers to health experienced by at-risk populations (Prilleltensky & Prilleltensky, 2007; Ungar, 2015). Unfortunately, these interventions are often seen as nonessential, and the hours spent by clinicians in indirect service or support to caregivers of children with serious medical conditions may even be unbillable in some medical settings. This is somewhat contrary to the fact that most clinicians understand the need to think and act systemically if patients are to make and sustain psychological and behavioral changes (Madsen & Gillespie, 2014).

Where medical programs have helped young people cope better with adversity and become more resilient (i.e., the children exhibit behaviors which allow them and their care providers, families and communities to mitigate the impact of stressors and improve well-being) these programs tend to adhere to at least five practice principles which help individuals and families navigate and negotiate for meaningful resources. These practice principles include:

- Make services multisystemic and complex, paying attention to as many different needs of patients as possible.
- Make services coordinated, both within services as well as across medical and social service agencies.
- Ensure services are continuous, with as little disruption to a patient's connection to a service provider, team of providers, or social supports.
- Negotiate with patients to design interventions that meet their needs in ways that are meaningful.
- Make services culturally responsive by helping medical practitioners develop cultural competence.

Medical interventions that demonstrate these practice principles focus on making their interventions available and accessible. They also often try to influence policy development at the level of an individual hospital, health care system, or government to help shape the services that impact directly on the ability of patients to cope better under stress. When successful, patients are better able to navigate and negotiate for the services they need.

Conclusion

A patient's resilience does not necessarily mean the patient shows no symptoms of disorder, but is instead a measure of the patient's ability to cope with that disorder through the provision of meaningful medical services, social services, and informal supports. In this chapter, I have shown that resilience in medical contexts depends a great deal on how these services and supports are provided, emphasizing the need for ecologically complex, multisystemic interventions. While individuals may show a capacity to heal, that capacity for resilience under stress is greatly improved when resources are made available and accessible by multiple service providers who coordinate their interventions.

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Chapter 13
Building Strengths and Resilience: Supporting Families and Disabled Children

Robyn Munford

Introduction

The provision of effective support to families is a community concern and is closely connected with issues of rights and citizenship. Effective support enhances resilience and contributes to the full participation of disabled children in all aspects of community life. In the disability field policy makers and practitioners have, over many years, worked to define the philosophical thinking behind service provision and develop appropriate resources and programmes that meet the needs of families and of disabled children. Decisions about support and services are constrained by issues of resource allocation which means those charged with developing services need to have clarity over what works and what actually makes a difference in people's daily lives. Service engagement can be overwhelming for families; however, when practitioners are respectful and responsive they have an important role in supporting families to build agency and take control over their circumstances. Medical practitioners provide treatment and interventions that respond to a child's medical and health needs, but they also have a key role in assisting families to make sense of their adverse circumstances. They can support families to navigate to the right services at the right time. For example, medical practitioners facilitate pathways into other services, such as family support and education services.

In this chapter resilience and the provision of family support is considered from the perspective of social and community work practice. The ideas presented in this chapter draw on the author's practice and research with families over three decades. This chapter takes an ecological approach to resilience (Liebenberg & Ungar, 2009) and explores the experiences of families as they negotiate for medical services.

R. Munford, Ph.D. (✉)
School of Social Work, Massey University, Palmerston North, New Zealand
e-mail: R.Munford@massey.ac.nz

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Having resilience means that families can live meaningful lives, maintain a sense of control over their lives, and assert their rights as citizens to be included and to fully participate in their communities. The chapter begins with a discussion on the philosophical underpinnings of service provision for disabled people internationally. This is followed by a discussion on the challenges faced by families as they navigate to effective services. The next section takes an ecological approach and explores the approaches that can make a difference for families and children. Central to understanding the relationship between those requiring support and those providing this support, such as medical practitioners, is the recognition of the reciprocal nature of the support relationship. This relationship is perceived as a dynamic and complex relationship; successful partnerships between practitioners and families recognise the expertise of families and the skills they have developed in providing support to their children.

Disability, Support and Services

In the last three decades there have been major developments in the provision of support to disabled children and their families (Munford & Bennie, 2009, 2013). Several core ideas have influenced these developments; central to these are changes in the way disability is perceived including the rights of disabled people to experience ordinary lives (Ministry of Health, 2001). International conventions determine rights for disabled people and outline the resources they are entitled to, such as access to health services, being respected and having their dignity protected, and being supported to make informed choices about services.

Historically disabled people have been a disenfranchised group often excluded from defining their own needs and aspirations (Hallahan, 2010; Munford & Bennie, 2009, 2013). This experience for disabled people themselves has impacted on families who speak of the marginalisation they feel in their support roles as they struggle to locate adequate resources and cope with the negative responses of others who do not understand the needs and rights of disabled people (Munford, 1994a, 1994b). Over time the experiences of disabled people have been constructed by a range of perspectives that have functioned to define the nature of their impairments and their lived experiences including how services and support will be provided (Sullivan & Munford, 2005). The medical model has had a major impact on service provision and has its origins in the rise of medical science, economic rationalism and social Darwinism. The emphasis here is on disability as an individual problem; disabled people are viewed as the victims of personal circumstance and tragedy and the response to this focuses on diagnosis, prevention and personal adjustment (Munford & Bennie, 2009, 2013). Munford and Bennie (2009, p. 210) argue that “the medical model had a pervasive influence” and this has been “well illustrated by the large-scale institutionalisation of disabled people that occurred throughout the nineteenth and twentieth centuries”. With institutional care being the dominant mode of service provision many families were encouraged to have little or no contact with their family member.

Criticisms of the medical model emerged in the 1960s and gave rise to new perspectives on disability including the social model of disability. This perspective had a profound influence on thinking about disability and has changed the approach to service provision (Sullivan & Munford, 2005). The social model regards social reality as a product of social interactions and disability is seen to be constructed through the interactions between disabled and non-disabled people. The construction of disability is one of deviance and deficit where disabled people have stigmatised identities (Munford, 1994b; Munford & Bennie, 2009). The social model provides an analysis of the situations of disabled people and challenges the way in which their lives have been constructed by others. Central to this is reframing the interpretation of impairment and supporting disabled people to create meaningful lives.

The social model of disability has been critiqued for not having a robust enough analysis of the impact of structural experiences such as poverty and inequality. Being excluded from participation, feeling honoured and having one's identity respected is often intricately linked to having access to what are deemed to be normative societal resources such as employment and education. Such a perspective reminds us that individuals are social and economic beings and that it is not only the ideas in a society that will determine how they are to be perceived but it is the access to valued goods and services that will also determine the quality of their life.

The emerging perspectives on the experiences of disabled people have challenged thinking on policy and practice. Rather than being viewed as the inevitable consequence of impairment itself, disability is regarded as the consequence of living with impairment in a disabling society. The problems faced by disabled people are located not within the individual but in a social milieu and disability is thus understood as a political problem. Here disabled people assert their right to define issues on their own terms and to determine a course of action that might lead to changes in the structures and policies that can then operate in their interests (Munford & Bennie, 2009, 2013). Disabled people have worked collectively to create a shift in power and resources and this has included families and others who support disabled people in their daily lives.

The challenges that families face in accessing quality services are complex and range from personal and familial issues to structural and service issues (Merriman & Canavan, 2007). These issues are connected with the aspiration of families to enhance their strengths and well-being and to build capacity and resilience that can be sustained over time. The next section addresses some of the challenges families and the person they support face in their daily lived experiences including being able to easily access services including medical services, without stigma. Central to this is being able to exercise choice over service engagement and to be treated with respect and dignity. Of utmost importance is the facilitative role services can have in opening up opportunities for families and children. Historically, as has been outlined in the previous discussion, services have acted as gatekeepers to community participation and have constructed the experience of disability in ways that have restricted opportunities. This experience remains a major challenge for families as they negotiate for support for themselves and for their child.

Family Life: The Challenges

This section identifies the challenges experienced by families and their children. The *strengths perspective encourages us to move from defining the issues families face as "deficits" to defining these as challenges that can be addressed with the right supports*, *networks and services including medical services* (Munford, Georgeson, & Gordon, 1994; Munford, Sanders, & Maden, 2012). This approach aligns strongly with the developments in the disability field which require us to "… reconceptualise the 'problems' facing people with disability as issues of citizenship, participation, opportunity and support" (Munford & Bennie, 2009, p. 210). The ideas presented in the following sections draw on the author's practice and research with families over several decades. A review of this work has identified a number of challenges for families and children as they work to find the right supports and opportunities so that they can fully participate as citizens.

Finding the Right Support

Families often struggle to find the right service for their child. Service provision is determined by a range of factors including policy alignment with organisational practices that may extend rather than restrict opportunities. A major challenge for families is being able to form relationships with medical practitioners that are based on respect and authenticity. Families have expertise and a deep understanding of the needs of their child. The challenge for practitioners is to recognise this and to harness this in interventions. Successful interventions recognise the expertise of the family with regard to their child's abilities, challenges and care needs. Such interventions maintain a family's sense of autonomy and agency and position them at the centre of decision-making about services and interventions.

For many families adequate medical support is simply not available. It can be difficult to access the right support at the right time and agencies may have limited funds to spend on developing services. The provision of support is likely to be variable and in rural and isolated areas the choices are restricted. Moreover families often need to do a lot of work themselves to locate appropriate support and often speak of their disquiet when they have to assert their rights for services. They can often feel humiliated as they outline their need for support and are required to constantly recount the challenges in their daily lives (Munford, 1994a, 1994b; Munford et al., 1994). For these families locating appropriate support is not a seamless process.

Achieving a Sense of Coherence

Given the daily challenges families face they often struggle to maintain a focus on the positive experiences in their daily lives. Practitioners can encourage families to find the strengths within their family and their wider network, but at times it is difficult for families to keep "body and soul together". Achieving a sense of coherence and meaning about their situation can be difficult for families as they work to achieve the daily practical tasks in the care of their child (for more on supporting patient's sense of personal intactness in a palliative care context see Goldstein, this volume). It can be immensely challenging to manage the needs of all family members and at times factors external to the family can put added pressure on family life. A significant pressure that can undermine their sense of well-being is being able to manage the way "difference" is defined. Discourses about family life that construct and define the experiences of disabled people in terms of deficits can place emotional pressure on the family. Despite the important achievements at the policy level the daily experiences of families are often imbued with added stress as they learn to cope with the negative responses to their family member's "different" identity. This "difference" can be negatively constructed and put pressure on families as they come to terms with others' interpretations of their family life.

Medical practitioners can intensify a family's feelings of being judged. The assessments required to ascertain service need and plan for interventions can mean that private experiences become open to a public gaze. At times these experiences are the focus of unwanted attention that is not only unhelpful but can be demeaning. Those outside the support relationship may perceive the support role as a burden and this in turn undermines the importance of this relationship and also devalues those within the relationship. What families tell us is that while the daily tasks can be challenging they are also rewarding and what is more likely to be a burden and create issues are the external factors in the support relationship, such as inadequate resources and the attitudes of others to their roles. For example, having practitioners recommend to parents that they should "take a break", but failing to support the family to seek out appropriate respite care for their child. A more helpful approach is to place value on the support relationship and to acknowledge its central role in enabling people to live in their local communities. Care relationships are part of the natural fabric of community life. Practitioners have a key role here by facilitating access to appropriate resources.

Also of significance for practitioners is developing an understanding of the nature of the care relationship. Care by family members extends beyond simple support. This kind of support can be understood as "extraordinary care" which is embedded in ordinary relationships as an everyday activity (Collings, 2009, p. 7). Family support has relational, affective and behavioural aspects and it is constituted of "labour and love" and of "activity and identity" (Collings, 2009, p. 7). Support in the family takes place in a relational context of commitment and attachment and a range of support is provided, including emotional, practical and financial (Collings, 2009, p. 7). Providing care is complex and multifaceted. Families will at times need to access the specialist skills and knowledge of medical practitioners and the nature of this will change as new needs emerge. Regardless of what needs emerge the family relationship will remain as a central relationship in a disabled person's life journey. Effective practitioners respect this and value the support families provide and acknowledge that it will be families who enable disabled children to have full and meaningful everyday experiences.

Despite medical practitioners' good intentions, families remind us that at times they fail to understand the significance of the caring role and the strengths and capacities families have developed in order to provide meaningful support to their child. In such situations practitioners need to be encouraged to think differently about family life and to understand that a focus on deficits and problems can mask the "multiple positions" families may occupy (Munford & Sanders, 2005; Sanders & Munford, 2010). While not denying the challenges and the daily struggles that families may face, families also want recognition of the diversity of family life; their experiences of disability is one aspect of family life and a focus on the other aspects can assist them to achieve a sense of coherence and meaning that helps them make sense of the daily tasks they need to achieve and the issues they need to confront.

Consistency of Support: Working with Practitioners

Families report that inconsistent and disrupted access to services can be a major challenge. Consistency of support takes many forms; a primary concern is having a consistent approach to service engagement so that there is no disruption to the quality of support provided. When there are changes in service delivery, including turnover of medical practitioners, families may face additional challenges; for example, being asked to brief new practitioners and explain their circumstances. Many families talk of having to cope with the added pressures of changes to service delivery; they recount stories about having to be flexible and prepared to learn about the latest ideas in service delivery. Some of these are very helpful and do have the potential to enhance support networks, while others require families to continually justify their entitlement to services as service specifications and thresholds change.

Families are required to understand and respond appropriately to the developmental changes in a child's life and need to negotiate services in a range of domains such as medical services, education services and specialist services (for more on providing developmentally appropriate care during the transition to adolescence see Lennon et al., this volume). Families take on multiple roles ranging from emotional to practical support. Practitioners may fail to recognise the complexity of the care role and may not acknowledge the knowledge, skills and expertise the family develops over time. While some families feel supported in their role and are acknowledged for what they have contributed, others feel that practitioners do not always recognise their skills, such as managing medication and clinical routines, developing communication skills, working on enhancing mobility, and helping the child work through identity issues. While many families would willingly have others complete these tasks, this kind of support is often unavailable so it rests on families to equip themselves with the knowledge and skills to effectively support their child. Given this experience, family caregivers should be seen as key members of the support team and not excluded from key decisions (Collings, 2009).

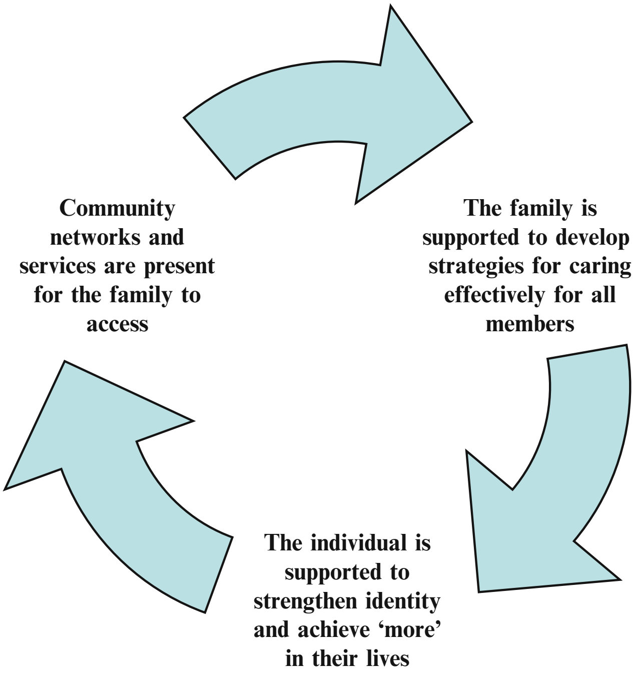
Some service systems still function to exclude disabled people and their families from decision-making processes. While it can be difficult to organise effective teams so that everyone can fully participate this needs to remain an important goal. Medical practitioners can facilitate the participation of families in key decision-making processes about service provision. This requires having skills in team work and facilitating teams in ways that enable equal participation of families and practitioners. Ideally all of those involved in providing support are viewed as an interdependent team. Here the disabled person is at the centre of an interdependent network whose members' knowledge and skills are equally valued and where all are recognised as having something positive to contribute. Families report that while medical practitioners may have discipline knowledge they are often lacking in other core skills such as facilitating teams and communication skills that enable them to effectively communicate with a diverse client population (Munford & Sanders, 2005).

This discussion has outlined a number of key themes that are present in the lives of families; these may create challenges for them as they mediate their caregiving role with other factors in their family life. The next section explores a range of strategies that contribute to building strengths and resilience in family life. These strategies are a foundation for building positive and productive relationships between medical practitioners and families and their children.

Making a Difference: What Works for Families and Children

This discussion focuses on three areas. Based on an ecological–transactional approach effective support for families and their children is perceived as an integrated system that focuses on the interaction between the family, the individual and the community, which includes both formal services, such as medical services, and informal networks, such as extended family support, and is informed by policy and societal systems and structures including the economy, political and social systems, and culture. The following diagram summarises this approach.

Building Family, Individual and Community Strengths and Resilience



The Family

Understanding Strengths and Capacities: Changing Our Perspectives

A strengths approach assists us to think differently about family life; to move from a focus on "problems" and "deficits" to thinking about what positively influences family life. A focus on strengths does not ignore risks or issues but encourages us to find solutions by seeing and thinking differently about family life (Munford et al., 2012; Munford & Sanders, 2008; Sanders & Munford, 2010). A key focus is to determine how families can be supported to develop strategies for caring effectively for all family members. Strengths approaches include the following:

- A commitment to the belief that families possess strengths and resources that can be harnessed in support processes.
- An understanding that practitioners need to invest in building effective relationships with families so that they can assist in harnessing strengths and resources.

- That labelling families as dysfunctional when they are not coping can mean that we do not learn and understand how families have survived and achieved success despite the challenges. This includes understanding the everyday lived experiences of families and the way they have mediated challenges including how they have resisted policies that have excluded them from participation in community life.
- That practitioners need to think about what it is that enables families to survive and grow and to understand that service systems can actually alienate families and make it more difficult for them to engage with services and locate support.
- That requiring formal support and access to services reinforces our interdependence as community members and should be perceived as a natural component of the fabric of community life.
- That practitioners need to be creative in assisting families to find solutions and obtain support, know how to work on multiple levels, and work collaboratively with other practitioners and service systems to ensure that both practical and emotional needs can be met.

Underpinning strengths approaches is the belief that all families have a right to an ordinary life and that it is unhelpful to perceive those who face enduring challenges as suffering human beings living tragic and sad lives that need to be “fixed” before they can participate fully in their communities. Families and their children do not want to be defined by their medical and support needs but want to be perceived as citizens who are included in the daily life of their community. Practitioners can be of significant help if they develop an understanding of the strategies that will make a real difference in the lived experience of families and their children.

Understanding Context

Understanding context includes learning how political, social, economic, religious and cultural factors influence family life and shape what it is possible for them to achieve. Taking a critical realist position it is acknowledged that there will be constraining factors in people’s environments but that there will also be opportunities for people to construct and define their situation and to create change for themselves (Guo & Tsui, 2010; Houston, 2010). Medical practitioners who fully understand the contexts of family life can assist them to find opportunities; central to this is developing an understanding of the frameworks families use to make sense of their worlds including cultural, religious and spiritual beliefs (for more on the importance of cross-cultural “resilience work” see Yi, this volume). Families can hook into these frameworks in order to learn how to gain a sense of control over their experiences and life circumstances.

Understanding context also means that practitioners challenge themselves to reflect on their own experiences and orientation to service provision and prepare themselves for working with families. This includes engaging in honest reflection on how much they know about the family's context and the communities in which they live. For example, do they understand the nature of community life and whether these communities are part of the network of support for the family or function to further marginalise and isolate families (Munford & Sanders, 2008)? Of importance is the service context and thinking about how this impacts on families. For example, do medical settings enhance or hinder interactions with families. Do service protocols support practitioners to form partnerships with families? Are the rights of families upheld by all practitioners across all services, such as the right to be treated with respect and dignity, the right to be informed about all aspects of service provision, and the right to be included in all decisions?

Harnessing Natural Supports

Families and their children are at the centre of their own lives and before they have entered into a relationship with a formal service agency they would have harnessed their own supports and developed knowledge and expertise on how to manage their situation. Families are not "blank slates" or the passive recipients of wisdom bestowed upon them by experts (Sanders & Munford, 2010, p. 38). Families know what has not worked for them in the past and they are the bearers of their own unique histories. When medical practitioners enter a family's world they must remember that they are entering a process that has already begun and they need to hook into this process, not undermine it. Their role is to assist the family to identify what it is they need and to follow through on any tasks and processes they have agreed to facilitate. At all times they must remember that they are a "visitor" in a family's life and no matter how complex issues are, it is the family who will be in charge of decision-making and the implementation of these decisions. As Gilligan (2004) asserts, practitioners need to understand that they are not the exclusive source of help. Successful work will occur when practitioners support families to harness the strengths within these contexts (Gilligan 2004, pp. 101–102). For example, medical practitioners have a key role in supporting families to identify how they can access supports in their local communities in ways that cause the least disruption to family life.

Understanding the Factors That Enhance Resilience

Building resilience and capacity will enable families to sustain support over the long term and achieve well-being for all family members. An *ecological perspective* on resilience foregrounds the interaction of key systems and their role in contributing to a family's resilience (Liebenberg & Ungar, 2009). Resilience is a function of the social ecology of an individual or family wherein environmental, cultural and social resources can create pathways for positive growth. Viewed in this way resilience is not only associated with individual attributes, but arises out of the interaction between individual factors and the social environment (Liebenberg & Ungar, 2009). Families will build resilience by being able to successfully seek out resources in their environments; to navigate to these resources and to negotiate for them in culturally meaningful ways (Liebenberg & Ungar, 2009). For example, a family who is experiencing stress can build resilience and the capacity to cope in the future by being supported to successfully find resources to help them in their support role and to negotiate for resources that match the specific needs of the family. If the family is able to successfully seek out support they will be able to build on this to address issues in the future. They cannot do this alone however as their environments have a key role in making available the resources they need to build resilience. To be effective these resources need to be available and families may need to be supported to use them effectively.

Medical practitioners have a key role in supporting families to develop resilience and enhance their capacity to cope with their care roles. Central to this is helping families work with support systems to determine their support needs and how they want services to work with them. Effective practitioners are able to support families to identify the skills they have and strengthen these. For example, families may successfully cope with the daily routines but their coping capacities can be enhanced if they are able to access respite care at certain times so that the needs of all family members can be met. Medical practitioners can also help families identify the interventions that have worked well in supporting their child and support them to ensure that these continue. This may require drawing other people into the family's network of support. Being able to clearly identify needs and have these met enables families to develop a sense of agency and control over their circumstances.

The Individual

Constructing Positive Identities

The disabled child is at the centre of service provision. Practitioners need to work to give the child opportunities to express their views about interventions and to be fully involved in decision-making. A key focus is enabling the child to construct a positive identity, to achieve a sense of coherence and be supported to achieve their goals and aspirations. The support relationship is critical in assisting the child to develop a positive and meaningful sense of self. The support provided needs to be respectful and practitioners need to understand the impact involvement in services can have on a child. For example, relying on others to assist you in daily living routines, needing to attend medical appointments, and being involved with many practitioners, can undermine self-efficacy and control over one's circumstances.

Practitioners have a key role in helping the disabled child and their family positively manage their daily tasks and interactions. They can also ensure that engagement with services is a positive experience.

Reciprocity

Positive engagement with services is achieved when relationships between practitioners and clients are based on reciprocity. Traditional conceptions of the provision of care viewed disabled people as needing protection; such a view positioned them as being passive in the support relationship, having things done to them not with them. Current thinking challenges this view and argues that practitioners need to work to make support acceptable and meaningful (O'Brien & Sullivan, 2005). Being able to build reciprocal relationships that are genuine and authentic provides a strong foundation for interventions. Reciprocity is enacted when medical practitioners work to establish rapport with the family and child and take the time to understand family life. Feeling valued by practitioners enables families and their child to fully engage with services and interventions.

Finding Possibilities: Creating "More"

Services are a valuable resource that enables families and their children to enhance their strengths and resilience. This in turn enables disabled children to achieve "more" and to realise their dreams (for more on understanding the role of hope and dreams in the lives of families who raise medically vulnerable children see Mattingly, this volume). As the preceding discussion illustrated disabled people have often been restricted in the choices they make and their aspirations have been focused on a narrow range of options. Current thinking focuses on enabling disabled people to participate in a range of experiences and for others to understand the multiple positions they may occupy. This kind of support from practitioners and other support networks is informed by "possibility thinking" or finding "more" for the person to experience (Handley et al., 2009). "Possibility thinking" provides new perspectives for understanding the complexity of social situations and it hooks into the strengths orientation of finding out what has worked for families and individuals in the past and using these to open up new possibilities for the future (Handley et al., 2009). It moves from a focus on coping with a situation to taking control of a situation; families and children build on success in addressing current issues to build strategies for dealing with issues in the future.

Medical practitioners are part of a team of people that can support "possibility thinking". Such an orientation requires them to listen for opportunities in an individual's story; attention to the small details may contain the potential to find solutions. Connected to this is the commitment to assist the family and their child to seek "more", to have big dreams and to envision different futures.

While providing appropriate support for a family and their child may be concerned with dealing with the immediate issues one must ask whether this support extends the capacity and resilience of both the disabled person and their family. Effective support can have a key role in advancing community participation and inclusion and it can extend opportunities and possibilities for growth. Medical practitioners have a key role in advocating for the removal of barriers that prevent full participation in community life. For example, facilitating access to physical resources such as equipment that extends mobility and seeking out funding that will enable a child to participate in a diverse range of community activities.

The Community: Services and Support Networks

Responsive, Flexible, Interdependent Networks of Support

The research on the provision of effective support tells us that to be successful support needs to be responsive and flexible. An important long-term goal is to develop an interdependent network of support that will enable families to seek out a range of options for support in the community via informal support networks and from formal services (Carers New Zealand & The New Zealand Carers Alliance, 2007; Merriman & Canavan, 2007). Successful service options acknowledge the diversity of family life and experiences and incorporate these into decision-making and short- and long-term planning. Families will experience conflicted feelings when seeking out services and these feelings must be recognised and acknowledged. They report that effective practitioners take the time to understand their needs and rights and that these practitioners are sensitive and respectful. Services need to be both person-centred and family-centred so that the needs of both the child and the family inform decisions about the way support will be provided (Merriman & Canavan, 2007). Those planning services need to find ways to develop collaborative partnerships with families so that their knowledge and ideas inform planning processes both in terms of what they specifically require for their family and in the design of services in general.

Relationships

Building strong relationships with practitioners are at the core of successful partnerships between families and practitioners. Relationships with services should not undermine a family's efficacy and become yet another challenge that the family are required to mediate. Practitioners can add resources and value to family life. Respecting families' expertise and competence provides a strong base upon which partnerships with medical and other practitioners can be built. Central to this is respecting the expertise that each partner brings to the relationship; for families it is knowledge of their child and for practitioners it is knowledge about impairments, effective interventions, programmes and resources. Building strong partnerships and working collaboratively aligns with approaches that are concerned with enhancing participation and citizen engagement in decision-making. Active participation of the family in decision-making about interventions is critical to their success.

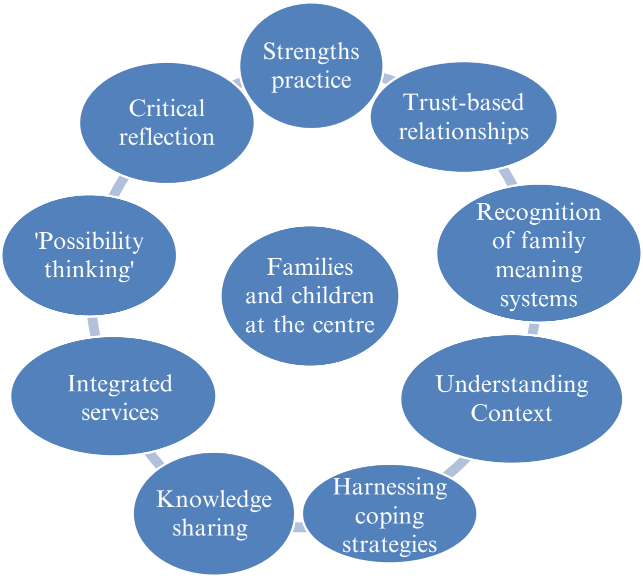
Effective practice grows from the recognition that when people have power and control over their circumstances they are more likely to be able to find positive solutions to their issues and challenges (Sanders & Munford, 2010). The next section presents a model of practice for medical practitioners who seek to build the strengths and resilience of families and their children. This approach embraces a collaborative approach to practice and places the family and disabled child at the centre of service delivery and networks of support.

Building Collaborative Partnerships Between Families and Practitioners

This final section brings together the ideas presented in the previous discussion and outlines a model for facilitating collaborative partnerships in medical services. Effective services are built around the regular and normal routines of family life. These services do not interrupt family life but respond in timely and appropriate ways and provide resources that enhance family life and well-being. Practitioners do not take over decisions for families but respect their autonomy. They work with families as equal team members and recognise that effective support is based on integrated and interdependent networks of support. By placing the person at the centre of the support system and acknowledging the diversity of family life it focuses on how support services need to be tailored to respond to the meaning systems of families so that all family members can experience well-being.

A collaborative orientation to planning for services emphasises joint agenda setting and identification of shared goals that take account of the needs and rights of all those involved. Key to this approach is recognising what families and disabled people bring to the planning table; alliances with families should be culturally responsive and respectful of differing meaning systems. Where cultural beliefs are a barrier to effective service engagement practitioners need to work sensitively and respectfully with families to support them to understand how interventions will contribute to positive outcomes for their child. Working in partnership with families enables practitioners to support families to identify what has worked for them in the past and use this knowledge to find solutions to current issues. Taking a collaborative approach means there is more considered thinking on an issue and when this is combined with attentiveness to opportunity and possibility, new and alternative strategies can be generated. This includes thinking differently about service provision and learning how to make the most of the available resources. The following diagram outlines the key elements of this approach.

Collaborative Partnerships



The following discussion summarises the key elements of collaborative partnerships between families and medical practitioners.

- The family and their child are at the centre of decision-making processes. This means they have a voice, they feel they are being heard and they are able to form positive partnerships with medical practitioners. Families have a key role in directing service provision and determining the nature of their relationship with practitioners and service systems. Their autonomy is maintained and strengths rather than “deficits” are focused on. Immediate issues are addressed but the orientation of service provision is to build the resilience of families and children in the long term.
- A family’s cultural frameworks and meaning systems are respected by medical practitioners. Generating connections with cultural and belief systems assists the family to gain a sense of control over their experiences and circumstances and enable them to seek support from those who know and understand their history and contexts. Central here is enabling families to seek out services that embrace their identities and meaning systems so that families can fully engage with services and interventions. For example, this may mean encouraging extended family members such as grandparents to be involved in interventions.
- Practitioners understand the way in which context influences family and community life. This involves understanding how political, social, economic, religious and cultural factors influence and shape what it is possible for families to achieve. Practitioners can support families to seek out resources and to engage

with positive change processes that will assist them to mediate the structural factors that function to restrict opportunities and exclude them from full participation in community life. For example, gaining access to financial support and resources that support interventions with their children.

- Medical practitioners take care not to disrupt the natural coping mechanisms that have been developed by the family and should build upon what has already been established within the family. These natural coping mechanisms promote autonomy, self-determination and enhance resilience. For example, families may have developed a strong network of support and these individuals can be encouraged to become part of the intervention and enhance their skills so they are equipped to be of the most help for the family and child.
- A key element of collaborative partnerships is the sharing of diverse knowledge. This orientation to service provision gives prominence to the idea that learning, growth and change are inherent human capacities and that all people are simultaneously learners and teachers. At the heart of practitioner and family partnerships are respectful learning relationships. This idea is closely related to the notion of reciprocity which recognises the knowledge and skills families have developed over time. Families, given their experience, can assist practitioners to learn about what constitutes effective support and practitioners are able to impart knowledge about impairments and interventions to families that is delivered respectfully and sensitively.
- Central to collaborative partnerships between practitioners and families is the provision of integrated services that enable the child and their family to enter into relationships with service systems that are themselves integrated and collaborative (for more on how the structure of medical services influence children's well-being, see Ungar, this volume). Here service systems are prepared to engage with their communities and to work in partnership to ensure that service provision is responsive and does not create barriers that disrupt the achievement of successful support relationships. This may require that medical practitioners hold their "professionalism lightly" (Munford et al., 2012, p. 71) and are prepared to be flexible and open to innovative and creative solution-finding processes that seek to enhance their relationships with families. For example, this involves welcoming families and practitioners in other services (for example, teachers) as equal team members who bring knowledge and skills to services which can be harnessed to provide more effective and responsive interventions.
- Collaborative partnerships respond to the immediate and practical needs of a child and their family and have the potential to contribute to strengthening a family's support network in the long term. These partnerships are a mechanism for opening up opportunities for inclusion and participation. The principle of "more" and "possibility thinking" constructs the support relationship as an opportunity for the disabled person and their family to engage in transformational change where visions and aspirations can be achieved. A collaborative partnership while focusing on the immediate and short term will also be future-focused as it is this thinking about what is possible that will realise the goals for citizenship, inclusion and full participation in community life. For example, providing learning

resources and managing medical routines so that a child can attend school in their local community which then enables them to create a learning pathway for realising their long-term goals.

- The realisation of collaborative partnerships requires ongoing critical reflection (Munford et al., 2012). Here the family and practitioners create mutually agreed processes that enable all partners in the relationship to reflect on the partnership. Such processes are an integral component of service relationships; it requires open-mindedness and a commitment to thinking deeply about what is working well and how practices can be improved. It is often in this space of critical reflection where thinking of "more" and "possibility thinking" is enacted.

In Conclusion

This chapter has focused on the relationships between medical practitioners and families and their disabled child. It identified the factors that build strengths and resilience and enhance well-being. It began with a discussion of the historical influences on the construction of disability and the provision of services. The discussion on philosophy highlighted how impairment has been defined and interpreted and how disability has been constructed throughout history. Dominant thinking about impairment and disability has changed over time and this thinking has determined the position of disabled people in our communities and influenced service provision. Changes to service provision have impacted on family life and the move to community-based services resulted in a change in role for families as they took on the major caregiving role and the support of their family member. To do this successfully they became experts in a range of areas and learned how to be strong advocates for their family member so they could gain access to appropriate support and services.

The second section discussed the issues for families as they worked to find effective support for their child and as they engaged with medical services. Families have become experts in "caring for" their child while maintaining other family relationships and routines. Of significance is finding appropriate resources that will enable families to sustain care over a long period while maintaining their own health and well-being.

The third section outlined a number of key factors that contribute to effective service provision and the key role for medical practitioners in supporting families. This requires a "different" way of thinking about service provision and a "different" orientation to practice with families and children. The idea of collaborative partnerships between medical practitioners and families was proposed as one approach to providing effective support as it keeps the family and the disabled person at the centre of decision-making and takes a collaborative approach to service planning and provision. Such an approach has the potential to advance the interests of the disabled child and their family by encouraging interdependence and contributing to the inclusion and participation of children in their communities. Here medical services have a key role by developing positive and nurturing relationships with families and children. These relationships are a key resource in supporting families to build strengths and resilience that enhances their health and well-being and enables their children to realise their dreams and aspirations.

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Chapter 14
The Concept of Resilience in Children's Health and Social Care Policy

Jane Noyes

Introduction

In this chapter resilience is explored in relation to children's health and social care policy in a United Kingdom (UK) historical and contemporary context. Some but not all current UK policies that mention resilience provide some explanation as to what resilience is and what being resilient looks like. Those policies that do define resilience vary in depth, but tend to use descriptors or metaphors such as enabling children and families to *cope with adversity*, *deal with stresses and stressful events and to bounce back*. As no one single explanation or definition of resilience is used in policy documents, in this chapter, Windle's definition which constitutes a theory of resilience—derived from literature review, concept analysis and expert consultation—is used as it appears to best capture the intent of policies that seek to develop or promote resilience in children and their families (Windle, 2011). According to Windle, resilience is '*the process of effectively negotiating*, *adapting to*, *or managing significant sources of stress or trauma. Assets and resources within the individual*, *their life and environment facilitate this capacity for adaptation and* '*bouncing back*' *in the face of adversity. Across the life course*, *the experience of resilience will vary*' (Windle, 2011).

J. Noyes (✉)
School of Social Sciences, Bangor University, Gwynedd, UK
e-mail: Jane.noyes@bangor.ac.uk

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Historical Context: From Institutionalisation to Self-Care, Self-Reliance and Resilience

The promotion and inclusion of resilience as an intended and desirable outcome of policy has evolved as research into resilience has grown and the intent of policy concerning disability has changed over time (Windle, Bennett, & Noyes, 2011). Over the past 50 years there have been radical changes to health and social care policy for children, especially for children with disabilities and long-term or life-threatening or limiting-conditions (Shakespeare, 2006). Around the middle of the last century, the dominant philosophy was of medical 'deficit' models of illness and psychopathology that focussed on what children could not do, and the limitations that their functional and intellectual disabilities entailed (Shakespeare, 2006). In many high-income countries such as the UK, 'disabled', 'medically fragile' or formerly 'handicapped' children were commonly considered too much of a 'burden' for their families to care for at home and right up until the 1970s and 1980s were typically sent away to live in institutions. Institutionalisation of disabled children stripped many parents of their rights and responsibilities when the State took on the role of parent. Likewise many disabled children were denied access to a family life, a high quality education and adequate access to high quality healthcare and social services support. Society broadly accepted that the life chances of disabled children were disadvantaged compared with non-disabled children. When disabled children were marginalised by the out of sight and out of mind collective psyche of an entire nation, little changed over decades to improve disabled children's lives.

From the 1970s and with increasing speed and emphasis in the 1980s, in many high-income countries (including the UK), children's health and social policy underwent one of the most radical changes in history—from institutional care to family-based care in the community with support from health and social care services. The medical 'deficit' model was superseded by the social model of disability that reconceptualised disability as socially constructed barriers that prevented children from being included in society—thereafter coined as social inclusion and exclusion in a policy context (Shakespeare, 2006). For a full account of the social model of disability, see Munford, this volume. Since then, with the passing into Law of rights-based legislation following the 1989 signing of the United Nations Convention on the Rights of the Child, in the UK disabled children are most commonly cared for at home by their families, but still overly represented in the 'looked after' system and cared for in institutional settings or by foster or adoptive parents in substitute family settings. 'Looked after' children are those for whom the State assumes responsibility, either as sole protector or jointly with parents or guardians.

At the same time as the radical change from institutional to significant investment in family-based care (or maybe partly because of it), the epidemiology and life expectancy of childhood disability and illness has changed dramatically (Noyes et al., 2013). Life expectancies extending beyond initial expectations have now become the norm as parental advocacy for treatment, new medical advances, and improvements in care have now extended disabled children's illness trajectories into adulthood, especially for childhood life-limiting conditions such as cystic fibrosis and muscular dystrophy (Noyes et al., 2013). Children with disabilities, for example, have been growing as a population over the last two decades in the UK as in other high-income countries (Perrin, 2002). New medical specialities have been created to manage new or redefined conditions, such as technology-dependency, HIV, autism, autistic spectrum disorder and attention deficit hyperactivity disorder.

In 2004, half way through a decade of economic prosperity, the UK Governments were forewarned about future unaffordable economic costs of long-term care and the potential benefits self-care and self-reliance. This wake-up call concerning unaffordability and unsustainability of health and social care services has been influential in resetting the policy agenda towards building self-caring and self-reliance, rather than emotionally and financially dependent families and children (Wanless, 2002). The end of the 2000s also witnessed an unexpected and catastrophic economic crisis in the UK banking sector followed by immediate economic recession. The subsequent rushed-through austerity measures brought in by the Government of the day meant that with increasing numbers of disabled children who required support, Governments and Non-Government Organisations who commissioned children's health and social services were having to deliver more for less whilst striving to achieve better outcomes for children and their families. There has also been a radical rethink to refocus the disabled children's research and policy agenda, from one of the rights now largely achieved in law to better understanding of the organisation and delivery of services to achieve child and patient-centred care (and not the other way round), and to developing interventions that further improve outcomes for children and their families (Chief Medical Officer, 2013). There is greater awareness that in line with medical and social advances to extend life and live at home, disabled children and their families need to be better equipped mentally to cope with the additional every day and changing challenges they face in living their lives.

Embedding Resilience as a Concept in Health and Social Care Policy

In being forced to look ahead, and having to think differently about policy and service delivery, the concept of promoting resilience in children and families within health and social care policy was seen as a way of changing the philosophy to one of developing empowerment and promoting self-reliance—with less emphasis on service receipt and professional interaction to provide a response when challenges were encountered by children (especially disabled and vulnerable children) and their families. For more on the importance of multisystemic, coordinated and continuous service provision, see Ungar, this volume. Promoting resilience was thereby conceptualised as a policy for long-term economic benefit and family stability.

One of the first reports to consider resilience in a UK policy context was published by Newman and Blackburn of Barnardos for the Scottish Executive in 2002 (Newman & Blackburn, 2002). Their report 'Transitions in the Lives of Children and Young People: Resilience Factors' outlined the emergence of *resilience as a well developed concept in psychology*, *but less developed in the fields of healthcare*, *education and social care* (Newman & Blackburn, 2002). Nonetheless, they found mention in the literature of resilience in relation to *sexual abuse*; *child maltreatment*; *the children of alcoholics*; *parenting and child care*; *child placement and children in need generally*; *children with emotional and behavioural difficulties*; *looked after children*; *family therapy*; *personal development in schools*; *adoption*; *and*, *more generally*, *as a conceptual framework for social work practice* (Newman & Blackburn, 2002).

Of particular interest to health and social care policy, Newman and Blackburn (2002) asked *why and how the promotion of resilience could help children and young people cope with the adversities that arose during periods of change and transition*, *and whether our professional preoccupation with mitigating risk in children*'*s lives was affecting their and their family*'*s ability to be more resilient*? These questions resonated with parents of children with disabilities and leading children's organisations, such as the Council for Disabled Children, who in 2004 produced guidance on managing the '*Dignity of Risk*' (Lenehan, Morrison, & Stanley, 2004) to move towards a more inclusive child-centred (and not professional-centred, risk averse and exclusionary) approach to managing risk. Several contemporary research studies reported that despite significant investment, some parents experienced the health and social care services that they received during this time as more of a burden than support, which drained them of energy and enjoyment of family life (Heaton, Noyes, Sloper, & Shah, 2005; Lewis & Noyes, 2007; Noyes & Lewis, 2005). Parents commonly described suffocating policies whereby professionals were compelled to 'risk manage' their lives and by doing so tried to eliminate risk from their disabled children's lives by restricting anything that could be considered risky lest something happen to the child for which the professional could be held accountable. Irrespective of advances in medical, health and social care, as in other high-income countries, UK health and social care services commissioned to enable more disabled children to live at home have been highly criticised by parents and children for being too inflexible, disjointed, disorganised and placing too much emphasis on what the child cannot do, rather than on what they can do if given appropriate support. Similar experiences of the negative impact of services have also been noted by leading researchers in other publically funded free at the point of access health systems (Yantzi, Rosenberg, & McKeever, 2007). Comparisons with privately funded health systems reveal similar issues concerning service coordination and disempowerment citing reasons such as lack of insurance coverage, eligibility criteria or capped benefits (Cousineau & Farias, 2009).

In a UK context, many parents said that the State inappropriately continued to act as a surrogate parent for their child and many families felt constrained or crushed by, and dependent on, the welfare payments and services they received rather than being empowered to live their lives as they decided (Lewis & Noyes, 2007). British society and communities in general have similarly been both helpful and hindering in their support for disabled children and their families. Moving children out of institutions to enjoy greater social and educational integration in families, schools and communities has generally been experienced by children and their families as a positive thing, albeit with notable exceptions when services and support are inappropriate. Many families with disabled children describe their lives as good. But at the same time, this movement from institutionalisation to integration back into society, community and family has also provided new opportunities for additional exposure to bullying by non-disabled peers, greater experience of inequality and injustice if the policy aspiration did not match the reality, and created different emotional and physical strains on child, parental and family relationships which have led to family breakdown (Heaton et al., 2005).

Newman and Blackburn (2002) concluded that known risk factors that affect children's well-being (such as bullying) can be cumulative and can heighten the probability that children will experience poor outcomes and not exhibit resilience. Whereas resilience factors operate in three dimensions (the individual, the family and the external environment) and presence of resilience factors increased the likelihood that children could resist or recover from exposure to adversities (Newman & Blackburn, 2002). Therefore health and social care policy and appropriate interventions could have a key role in promoting exposure to healthy risk and maximising development of resilience factors. In exploring resilience for a policy context, they described three groups of children who may exhibit resilience and from whom lessons could be learned:

- Children who succeeded, or did not succumb to adversities, in spite of their high risk status, for example, low birth weight babies.
- Children who exhibited maturity and coping strategies in situations of chronic stress, such as children of drug using or alcoholic parents.
- Children who had suffered extreme trauma, for example, through disasters, sudden loss of a close relative or abuse, and who had recovered and prospered (Newman & Blackburn, 2002).

The importance of considering resilience in a health and social policy context was further put into the spotlight by successive UNICEF reports (UNICEF, 2013) of child well-being in rich countries that put the UK towards the bottom of the league. Too many children were clearly not exhibiting resilience and their feelings of well-being were suffering as a result. In 2007, when the UK came bottom of the league table for child well-being across 21 industrialised countries—Professor Jonathan Bradshaw, one of the authors from York University, UK, was quoted as saying that he '*put the UK's poor ratings down to long term under-investment and a "dog-eat-dog" society*' (BBC News, 2007). Contemporary polices such as 'Sure Start' (Department for Education, 2013), 'Aiming High for Disabled Children' (HM Treasury Department for Education & Skills, 2007) and 'Getting it Right for Children' (Scottish Government, 2008) summed up the political commitment to improve well-being but did not say much about resilience. *The Children's Plan* (Department for Children & Schools & Families, 2007) was subsequently rolled out in England in 2008 with the aim of eradicating child poverty by 2020. Families were seen as partners with Government and there was an emphasis on personalisation of care and a more holistic approach in attending to children's rights. The Children's

Plan (Department for Children & Schools & Families, 2007) is clear in its strategic emphasis on building resilience in children and young people as part of this policy to improve well-being but says little about how to achieve this policy aspiration.

Case Study: Children's Policy in Scotland

In Scotland, policymakers have gone one step further by building a resilience matrix in children's policy as a framework for practice and analysing information (see Fig. 14.1) (Scottish Government, 2012).

The underpinning programme theory shown in Fig. 14.2 depicts a child at the centre with family and community providing everyday support and care; universal provision supporting development and building resilience; additional support working to overcome disadvantage and supporting learning; specialist help addressing

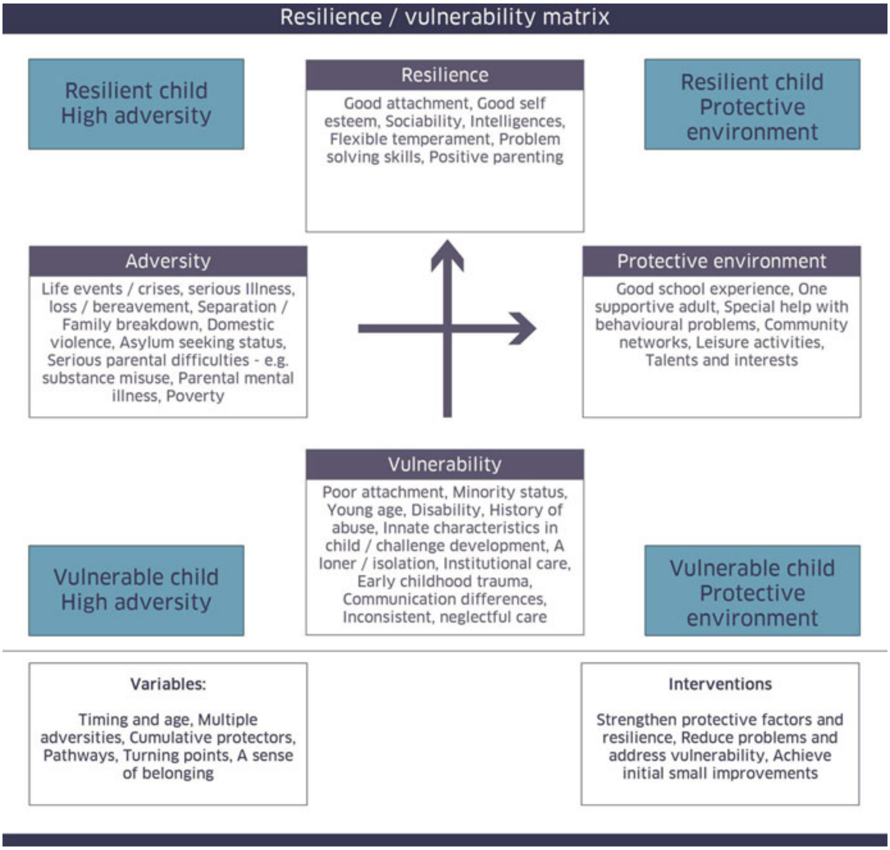


Fig. 14.1 The expanded Resilience Matrix used in Scottish Government Policy (Scottish Government, 2008, 2012). Adapted from work undertaken by the NSPCC and University of Sheffield and published as a training pack (NSPCC, Department of Health, & Sheffield, 2001)

Fig. 14.2 The Underpinning programme theory of building a network around the child to promote resilience in Scottish children (Scottish Government, 2012)

more complex needs that impact on health and well-being; compulsory intervention ensuring action to overcome adversity and risk.

The Resilience Matrix fits into the National practice model for children's policy (Fig. 14.3).

The National practice model has four main steps.

Step 1 Observing and Recording Using the 'Well-Being Wheel'

The 'Getting It Right for Every Child' Policy and implementation guidance places 'well-being' at the heart of the policy and outlines eight areas of well-being in which children and young people need to progress in order to do well now and in the future (Fig. 14.4) (Scottish Executive: Getting It Right for Every Child Team, 2010; Scottish Government, 2008). The eight indicators of well-being are: **Healthy**, **Achieving**, **Nurtured**, **Safe**, **Active**, **Respected**, **Responsible and Included**. These eight areas are set in the context of the 'four capacities' to enable every child and young person to be a **successful learner**, a **confident individual**, a **responsible citizen** and an **effective contributor**. The Well-Being Indicators are used by practitioners to record observations, events and concerns and as an aid in putting together a child's plan.

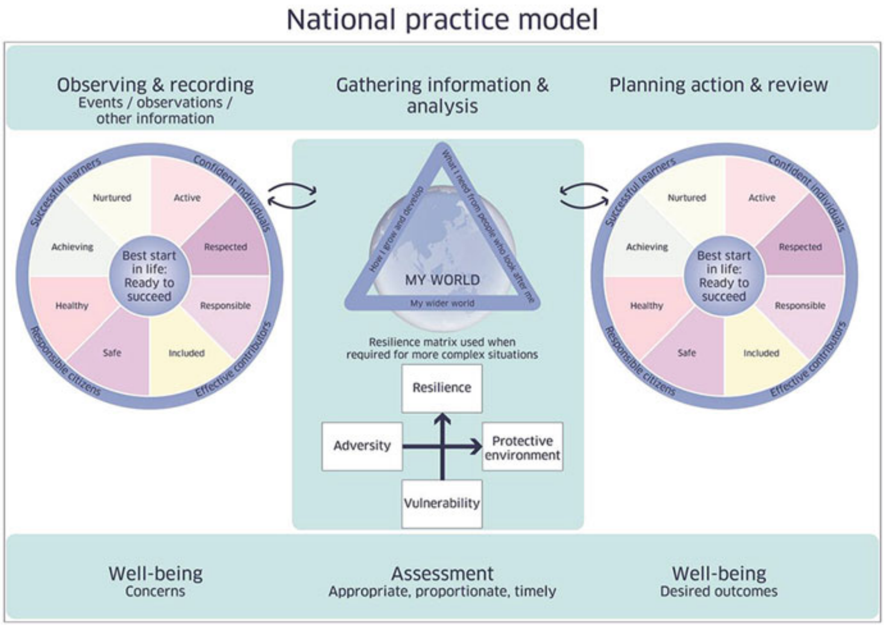


Fig. 14.3 National practice model in Scotland (Scottish Government, 2012)

Steps 2 and 3

The My World Triangle and the Resilience Matrix are used to gather, structure and help with assessing and analysing information. The ***My World Triangle*** (Fig. 14.5) is used by practitioners to better understand a child or young person's whole world.

Step 4 Planning, Action and Review Using the 'Well-Being Wheel'

Collated information on the child is then mapped against the resilience matrix shown in Fig. 14.1 and a plan is put in place to address any adversities and promote resilience.

When the child or young person's needs are clear, they can be summarised using the *well-being wheel* (Fig. 14.4) to develop a plan for action. In helping practitioners to operationalise the policy the implementation guide (Scottish Government, 2012) defines three building blocks of resilience (secure base, self-esteem and self-efficacy) accompanied by what it means to be 'resilient' in this policy context (see Fig. 14.6). These three concepts and in particular self-efficacy maps directly onto the desire by governments for people to be increasingly self-reliant and self-caring

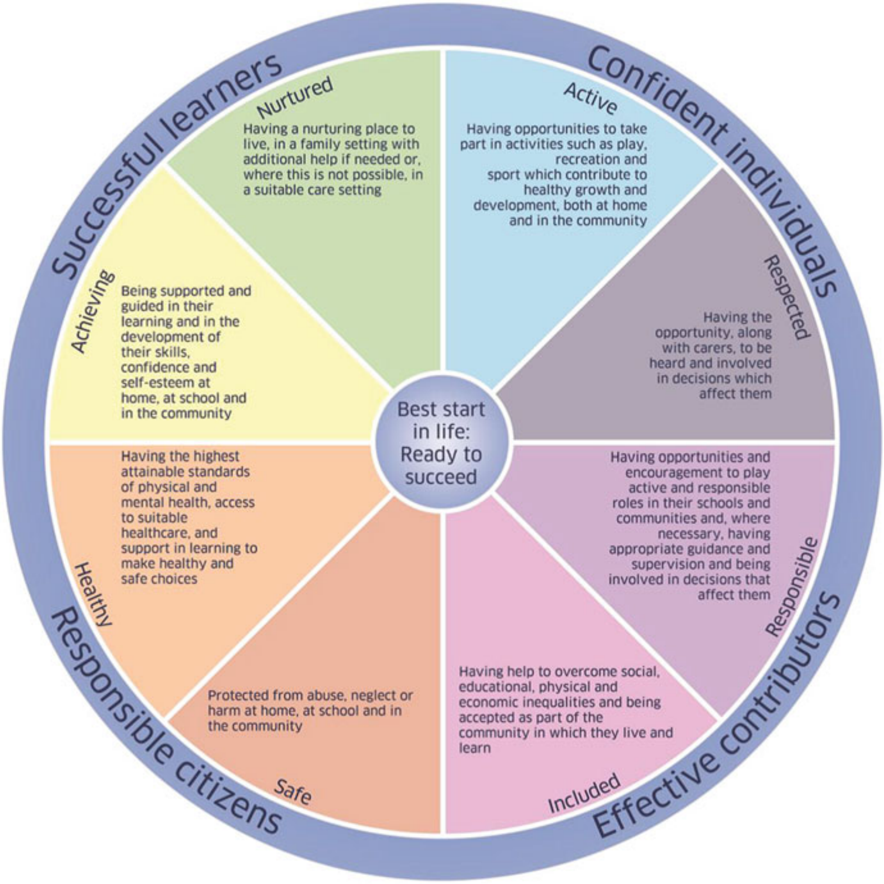


Fig. 14.4 The well-being wheel (Scottish Government, 2008)

(especially with their health and social care needs) with reduced reliance on the State. These three building blocks of resilience and attributes have been translated from Edith Grotberg's 'Three sources of resiliency: I HAVE (social and interpersonal supports), I AM (inner strengths) and I CAN (interpersonal and problem solving skills)', which were developed from the International Resilience Project (Grotberg, 1995). Following Grotberg's theory and logic, for a child to be resilient, they require more than one source of resilience and if, for example, a child has high self-esteem (I AM), but does not have people around to support them (I HAVE), and is not able to solve problems (I CAN), then they will not be resilient (Grotberg, 1995). Therefore Scottish Government children's policy is designed to focus on the I AM, I HAVE, I CAN for every child to nurture resilient children and families.

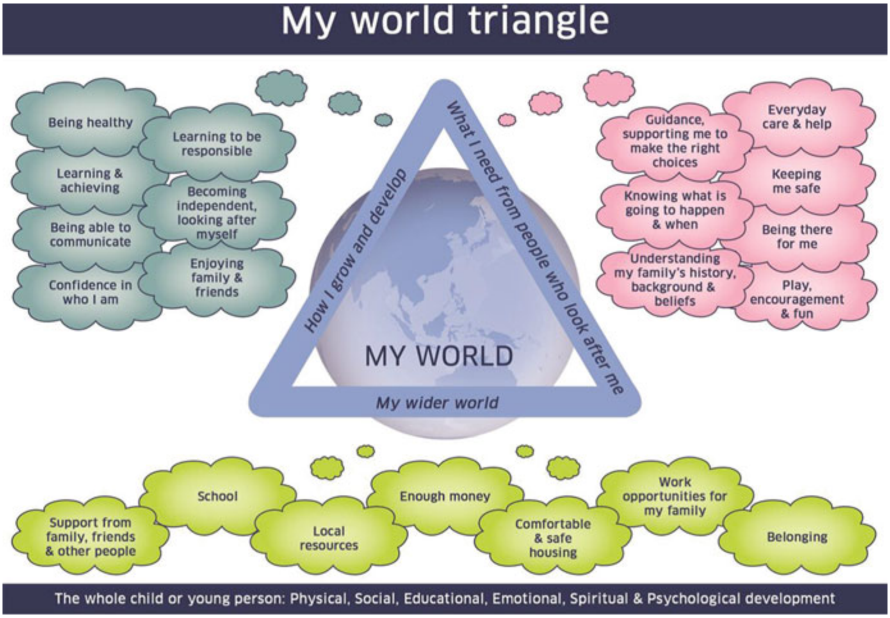
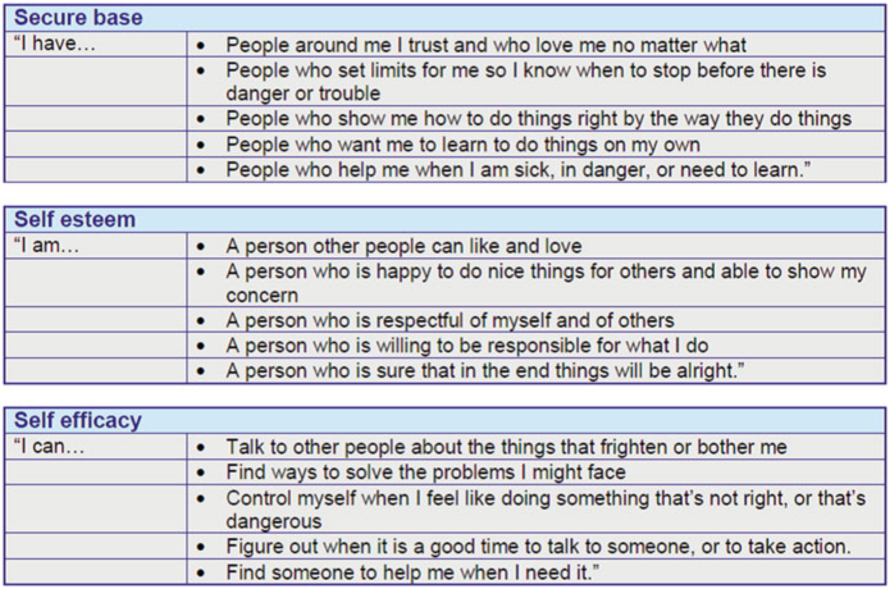


Fig. 14.5 The 'My World Triangle' from Scottish children's policy (Scottish Government, 2008, 2012)



Secure base	
"I have…	• People around me I trust and who love me no matter what
	• People who set limits for me so I know when to stop before there is danger or trouble
	• People who show me how to do things right by the way they do things
	• People who want me to learn to do things on my own
	• People who help me when I am sick, in danger, or need to learn."

Self esteem	
"I am…	• A person other people can like and love
	• A person who is happy to do nice things for others and able to show my concern
	• A person who is respectful of myself and of others
	• A person who is willing to be responsible for what I do
	• A person who is sure that in the end things will be alright."

Self efficacy	
"I can…	• Talk to other people about the things that frighten or bother me
	• Find ways to solve the problems I might face
	• Control myself when I feel like doing something that's not right, or that's dangerous
	• Figure out when it is a good time to talk to someone, or to take action.
	• Find someone to help me when I need it."

Fig. 14.6 The three building blocks of resiliency in Scottish Government policy (Scottish Government, 2008, 2012)

Summary

In summary, resilience has now become mainstream in children's policy (in England, Wales and Scotland) as demonstrated by the excellent policy briefing by Glover for Barnardos (Glover, 2009). Glover describes some of the many policies such as the Family Nurse Partnership (FNP) (Ball, Barnes, & Meadows, 2012), the Social and Emotional Aspects of Learning (SEAL) Programme (Humphrey et al., 2008) and the Local Well-Being Project including the Resilience Programme (Challen, Noden, West, & Machin, 2008), for 11–13-year-olds across 22 schools which helps children to develop assertiveness, acquire decision-making and relaxation skills, and cope with difficult situations and emotions. The Social Care Institute for Excellence (SCIE) has also produced guidance on promoting resilience in fostered children (Bostock, 2004). Most recently the Chief Medical Officer's Report (Chief Medical Officer, 2013) into the state of children's health summarised the additional value of engendering resilience in young people in addition to being healthy: '*Reducing Disease is fundamental but so too is ensuring that our young people are capable of meeting the changing requirements of life. We need to ensure that they are resilient and primed to succeed*' (*Chief Medical Officer*, 2013). Building resilience of young people is mentioned 107 times in the report and features prominently in the recommendations (Chief Medical Officer, 2013). Non-government organisations have likewise prepared policy briefings to incorporate resilience-promoting philosophies into services for looked after children and other contexts (Bostock, 2004; Glover, 2009; NCH, 2007).

The research community has also made a major contribution to policy development, for example, by enhancing understanding about building resilience in carers of children with long-term conditions and disabilities, and by providing clear examples for practitioners as to what resilience promoting interventions and aspects of services look like. See, for example, the concept analysis for nurses to use with carers of children with long-term illnesses, and examples of resilience promoting models and frameworks for social work and multidisciplinary practice (Glover, 2009; Lin, Rong, & Lee, 2013; Mitchell, 2011).

Policy Implementation and Evaluation Challenges and Questions

Resilient People Can Be Nice or Nasty

As most health and social care practitioners will testify, Glover (2009), and Newman and Blackburn (2002), remind us that '*some resilient people can also be withdrawn, defensive, confrontational—not particularly nice individuals, and that these resilient characteristics have often been developed by the young person to enable coping*'. Glover goes as far as saying that, '*research has shown that those most resistant* *to stress often have a sociopathic aspect to their personalities*' (Glover, 2009 P6; Newman & Blackburn, 2002). To some extent, this can be explained by the fact that children and their families have often battled long and hard over many years to access the care, services and opportunities that they want and changing these established behaviours is very difficult if not impossible.

Is the Promotion of Resilience the Same as Promotion of Good Parenting?

It has not escaped attention that many of the policy imperatives to promote resilience in children and families have considerable overlap and intent with previous and ongoing policies to promote good parenting practices and strong families and communities. For example, the preceding Incredible Years programme (McDaniel, Braiden, Regan, n.d.) to support parents to optimally care for their young children is primarily concerned with increasing coping, confidence and communications skills and these skills map directly onto the desired outcomes of the newer resilience promoting policies, e.g. the Children's Plan (Department for Children & Schools & Families, 2007).

Policy Implementation Strategies

Although policymakers typically rely on a diversity of evidence types when making policy (from trials to opinions), there is a dearth of research on promoting resilience that is specifically helpful in developing and implementing actual interventions to operationalise health and social care policies that promote resilience. Much of the 'resilience' research has been undertaken in educational and psychopathological contexts, and does not easily translate into interventions that can be delivered by the health and social care workforce within the context of current service delivery, or by the families themselves at home.

Health and social care policies that include reference to resilience vary in detail from policies that mention the concept and expect that the workforce will know how to successfully implement resilience promoting interventions (Chief Medical Officer, 2013), to policies that are developed using a resilience matrix as an underpinning theoretical basis and include templates and tools for implementation by the workforce to use with every child (Scottish Executive: Getting It Right for Every Child Team, 2010). The Scottish Government Implementation guide reports that professionals found that using the Resilience Matrix was the most challenging component of the national practice model (Scottish Executive: Getting It Right for Every Child Team, 2010; Scottish Government, 2008). The implementation guide was updated in 2012 to provide further clarification on the concepts and practical guidance on its use (Scottish Government, 2012).

The health and social care workforce is made up of enormous numbers of different cadres of staff from highly qualified doctors to unqualified carers in receipt of minimum training. In the UK, the health and social care workforce is the largest workforce. The National Health Service workforce alone used to be compared in number to the size of the Russian Red Army prior to the breakup of the Soviet Union. Irrespective of grade, most staff working in health and social care have not received additional orientation to resilience promoting policies and practices and many especially those that work as carers with families at home are unlikely to know of the existence of such policies. Likewise, health and social care professionals who are aware of resilience promoting policies commonly find it challenging to change, and sustain any behaviour change, when routinely interacting with children and families. Nonetheless, implementation of health and social care policy is keenly monitored and driven by leading UK children's charities who have a track record of calling those responsible to account when children's lives are negatively affected.

Evaluating Policies and Measuring Resilience as a Policy Outcome

Having established resilience in UK policy and practice, the next challenge is working out how to measure if resilience is indeed increased as a result of the strategies and programmes. For some innovative mixed methods approaches to 'measuring' resilience, see Liebenberg, this volume. Thus far there have been few robust assessments or evaluations with some notable exceptions (Finch, Hargrave, Nicholls, & van Vliet, 2014) of the impact of resilience promoting policies. Evaluation of interventions and policies designed to promote resilience, however, require reliable and valid measures (Windle et al., 2011). A systematic review of resilience measures (Windle et al., 2011) did not identify a psychometrically robust instrument that was primarily designed to measure resilience in a health and social care context. Non-Government organisations such as New Philanthropy Capital and Barnardos have either developed or provided some examples of measures and evaluation frameworks that may be helpful, but provide few details of their psychometric properties. See, for example, (Finch et al., 2014; Glover, 2009). It is, however, likely that the requirement for psychometric robustness of instruments used for evaluation of outcomes will vary between research and policy contexts.

Many children and young people with disabilities, long-term, life-threatening or life-limiting conditions also have intellectual disabilities and there is a dearth of evidence on how best to assess resilience in this heterogeneous population. It is also likely that attributing improvement in resilience solely to policy interventions is problematic in that irrespective of any exposure to population-based, community-level or individually targeted interventions, children and young people should, in theory, develop increasing resilience as they grow up.

In 2007, the UK was placed at the bottom of 21 rich countries on child well-being (BBC News, 2007). By 2011 (the report was published in 2013), the UK had moved up to 16th position out of 29 nations, below Slovenia, the Czech Republic and Portugal (UNICEF, 2012). The accompanying report by UNICEF (2012) concluded that although the UK had moved up the league table in overall child well-being, '*since 2010 the downgrading of youth policy and cuts to local government services due to the economic recession and austerity measures were having a profound negative effect on the well-being of young people age 15–19*'. In reality, it is difficult to determine the degree of impact of youth unemployment and overall economic recession on policy outcomes to build resilience and a sense of well-being in this age group, as they have as a group been most affected by the economic recession. This fluctuation over time in perceptions and experiences of well-being maps directly back onto Windle's conceptual explanation that exposure to adversity and ability to be resilient varies over the life course, and aligns with Elder's observations of life course development and the different impacts of societal events at different ages on children born in the depression of the 1920s and followed for two generations up until the 1960s (Elder, 1998; Windle, 2011). One explanation for the low sense of well-being experienced by young people age 15–19 in the UK in 2011 is actually their exposure to a prolonged period of adversity (economic recession) from which they will bounce back (i.e. demonstrate resilience) when they have found meaningful employment and can move on with their lives. Moving into meaningful employment for many young people with disabilities and those with life-limiting conditions can however be experienced as yet another adversity to overcome.

Conclusion

Resilience is now recognised as having a potential influence on the health, well-being and quality of life of all children (especially disabled children) and their families, and how they respond to the various challenges as they grow up (Windle, 2011). Building resilience in children, families, communities and nations is now central to health and social care policy in the UK, and specifically so in Scotland. Being resilient is seen as a way of becoming more self-reliant and more able to cope independently of State intervention and, as a consequence, young people will develop a greater sense of well-being. It has yet to be determined if policies actually achieve their anticipated outcomes as they vary in the degree to which they provide tools to implement resilience as a concept into health and social care services and practice. It has yet to be established if the health and social care workforce will have sufficient knowledge and skills to change their behaviours and practices in order to promote resilience within every day services and encounters with children and families without additional training. It is uncommon for measures of resilience to be used in routine practice outside of a research context, so Governments may have to rely on future UNICEF reports of child well-being as a proxy for judging the success of policies to build resilient populations of children and families who are better able to cope with adversity in childhood. Other factors such as growing up and economic recession are likely to have an impact on children's resilience over time. It is therefore highly challenging to unpack the complex causal pathway of what works, in a policy context, to improve and sustain resilience in children and their families.

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Part V
Where We Have Been, Where We Are Going

Chapter 15
Coping with Chronic Illness in Children and Their Families

Ronald T. Brown and Mary Jo Kupst

Introduction and Background

Over the past decade, substantial strides have been made in understanding factors that affect the psychological well-being of children with chronic illnesses and their ability to cope with the demands and stressful life events specific to their medical conditions (Halfon & Newacheek, 2010; Roberts & Steele, 2009). A childhood chronic illness is a health problem or medical condition that endures for an extended period of time, affects a child's functional activities, and requires extensive medical care (Compas, Jaser, Dunn, & Rodriguez, 2012). Children with chronic illnesses must cope with myriad stressors, including the possibility of slowed or altered physical development, periodic medical procedures, unexpected health crises, and school absences. Further, they must master the same developmental tasks and challenges as their healthy peers. In this chapter, we first provide an overview of the epidemiology of chronic illness in children and adolescents. We then present a review of two models that have been used by health psychologists to understand pediatric patients' ability to manage the stress of chronic illness: stress and coping models and social ecological models. We have chosen these two models as the majority of research in the field of pediatric psychology have taken elements from both models and these models have driven much of the research in the field.

It should be noted that coping focuses on individual differences while adjustment focuses on the normative as outcome. As an exemplar of the stress and coping model, we provide an overview of the coping literature among children and adolescents with cancer and their families as well as interventions designed to enhance

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R.T. Brown, Ph.D. (✉)
Department of Psychology, University of North Texas at Dallas, Dallas, TX, USA
e-mail: RTBrown@untdallas.edu

M.J. Kupst, Ph.D.
Department of Psychology, Medical College of Wisconsin, Milwaukee, WI, USA
e-mail: mkupst@mcw.edu

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coping in children and their families. Finally, we highlight some of the methodological issues associated with coping and define an agenda for future research in this area. In the context of this chapter, coping with a chronic illness among children and their families is considered from the perspective of pediatric psychology, a scientific discipline at the interface among clinical psychology, developmental psychology, and health psychology that applies psychological theory for the purpose of promoting adjustment and well-being as an ultimate outcome.

Definition of Chronic Illness

Chronic illness has been defined as a condition lasting 3 or more months that creates a functional impairment or medical needs greater than would be expected for a child of that age. More recently, Van Cleave, Gortmarker, and Perrin (2010) have defined childhood chronic illness as any physical, emotional, or mental condition that prevents a child from attending school, doing schoolwork, or participating in regular activities, and that necessitates the regular use of medical or special equipment.

Epidemiology

Estimates of the prevalence of childhood chronic illness vary widely, depending on how the term "chronic illness" is operationalized and on which methods are employed for ascertainment of cases. van der Lee, Mokkink, Grootenhuis, Heymans, and Offringa (2007) have found that as many as one in four children ranging from birth to 18 years may have a chronic health condition. Prevalence rates have ranged from 3.5 % for young children to 35 % among adolescents. In addition, child gender, family income, and family structure, with boys, children from low income families and children from single parent families being at highest risk for chronic health problems (Newacheck & Halfon, 1998). The prevalence and incidence rates for various childhood chronic conditions also vary considerably. For example, the incidence for Type 1 diabetes mellitus (T1DM) in youth ages 0–18 in the United States is 15,600 cases per year (National Institute of Diabetes and Digestive and Kidney Diseases, 2011), while the incidence of hemophilia is only 5000 cases per year (National Heart Lung and Blood Institute, 2013).

Also of interest is the fact that the prevalence of childhood chronic illnesses has been increasing over the course of time (Newacheck, Rising, & Kim, 2006). This increase is likely due to a number of factors, including the increasing rates of certain conditions (e.g., asthma, T1DM); enhanced detection and identification of certain disorders through improved screening (e.g., sickle cell disease); and improved availability and efficacy of treatments, leading to longer life span and/or to cure (e.g., cystic fibrosis, acute lymphocytic leukemia). It has been estimated that more than 90 % of children with significant chronic conditions now survive well into adulthood. Thus, an understanding of the factors that affect long-term psychological health and well-being in this population is of prime importance.

Adjustment and Adaptation of Chronically Ill Children and Adolescents

Given the number of stressors faced by children and adolescents with chronic illnesses and their families, over the past several years studies have sought to determine the impact of chronic health conditions on children's mental health and psychological well-being. Earlier research had suggested that children with chronic health conditions do suffer from a number of adjustment and mental health difficulties. We define adjustment as the absence of psychopathology or negative outcomes (for review see Masten, 2014). Measures of adjustment typically reflect greater or fewer levels of symptoms related to psychopathology (e.g., externalizing behavior problems, internalizing problems). However, these studies were typically characterized by small sample sizes, methodological difficulties, and assessments that overestimated the risk for psychopathology in this population due to dependent measures that inquired about somatic (physical) symptoms (Drotar, Stein, & Perrin, 1995; Friedman, Bryant, & Holmbeck, 2007).

More recently, meta-analyses, which minimize the effects of sampling bias, have been employed for the purpose of investigating the epidemiology of mental health conditions in children with chronic illnesses. Lavigne and Faier-Routman, (1992) conducted a meta-analysis in which they examined psychological adjustment in chronically ill children from over 80 studies. Conclusions from this analysis were that with the exception of chronic health conditions impacting the brain and sensory disorders, chronically ill children were only at moderately increased risk for psychological adjustment difficulties relative to their healthy peers. The risk for internalizing problems (anxiety, depression) was found to be relatively higher than the risk for externalizing (conduct disorder, attention-deficit/hyperactivity disorder, oppositional defiant disorder) problems. In fact, these findings were recently replicated in a meta-analysis of 569 studies of children with chronic illnesses (Pinquart & Sehn, 2011), although the effects of chronic illness on psychological adjustment and adaptation were weaker when youth ratings were considered relative to parent ratings. It should be noted that adjustment and adaptation are frequently used interchangeably by many researchers and we use these terms interchangeably in this chapter. Wallander and Varni (2003) have noted that successful adaptation is reflective of positive mental health, social functioning, and physical health. Successful adaptation to a stressful situation typically involves cognitive understanding of the problem and potential ways to cope with the problem by means of emotional regulation and appropriate behavior. Thus, the individual is able to deal with the problem given individual and environmental demands and simultaneously achieve some sense of mastery or well-being. Successful adaptation to a stressful situation typically involves cognitive understanding of the problem and a potential means of coping with it including emotional regulation and behavior in response to environmental demands. The end result is a positive set of outcomes in response to a particular stressor. It should be noted that coping is focused on individual differences while adjustment focuses on the normative as the outcome (Wallander & Varni, 2003).

There also is some evidence that chronically ill children with specific illnesses are at slightly heightened risk for psychopathology. In a meta-analysis of 21 studies of psychological adjustment in children with chronic arthritis, LeBovidge, Lavigne, Donenberg, and Miller (2003) found that although there was a significant difference in the adjustment between children with arthritis and their healthy peers, the overall effect was small. However, a higher risk of adjustment difficulties was found for internalizing disorders than for externalizing disorders. For youth with irritable bowel disorder, Neff et al. (2010) demonstrated higher rates of depressive symptoms among these youth compared to healthy controls as revealed by parental reports. Nonetheless, no differences were found in depressive symptoms when youth self-reports were employed. Similarly, for a meta-analysis among children with T1DM, Reynolds and Helgeson (2011) obtained generally small to medium effect sizes for depressive symptoms when compared to a comparison control group. Taken together, the literature suggests that chronically ill children are an at-risk group for psychopathology but that risk will result in significant psychopathology only as the result of a complex interplay between chronic illness parameters and additional risk and resilience factors. Resilience is defined as outcomes for which competence and coping have been effectively put into action in response to stress and adversity (Compas et al., 2001). In general the construct of resilience refers to being able to withstand or recover from stress and adversity and make the individual stronger as a result. It is conceptualized as a positive outcome despite exposure to potentially traumatic events (Bonanno, 2012). Wallander and Varni (2003) have conceptualized resilience factors to include interpersonal factors (e.g., temperament), social ecological factors (e.g., family, social support, resources), and stress processing factors (e.g., appraisal of stress, coping).

Finally, adjustment and adaptation to childhood chronic illness also has been investigated from the perspective of successful transition to adulthood. More specifically, this research has sought to examine whether children with chronic conditions are able to master adult roles, including living independently, holding employment, and sustaining successful relationships. In a secondary analysis of data from the National Longitudinal Study of Adolescent Health, Maslow, Haydon, McRee, Ford, and Halpern (2011) compared outcomes for over 13,000 individuals who ranged in age from 18 to 28 years with and without a chronic illness that was diagnosed in adolescence or earlier. Findings revealed that young adults with a childhood chronic condition were as likely as those without such an illness to report satisfying romantic relationships, to be married, to have children, and to be living independently. Of interest is the finding, however, that even after controlling for social class, young adults with a childhood chronic illness were less likely to have graduated from college or to be employed. They also had lower mean incomes than their healthy peers. These data suggest that although the presence of psychopathology is not common, childhood chronic illnesses may have more subtle effects on psychological well-being that are not necessarily captured by gross measurement of psychopathology, and that may affect well-being and educational and occupational attainment in childhood.

Risk and Protective Factors

The earlier research on those factors affecting the psychological adaptation of children with chronic illness employed a categorical, or illness-specific, approach and focused primarily on how disease-specific factors (e.g., duration, severity) impacted outcomes (Perrin, Newacheck, & Pless, 1993; van der Lee et al., 2007). A short coming with this approach is that these constructs inconsistently explained the variance in child psychological outcomes either cross-sectionally or longitudinally (Stein & Jessup, 1984; Wallander, Varni, Babani, Banis, & Wilcox, 1989). These findings, coupled with trends in the coping literature toward the use of integrative models that are inclusive rather than reductionistic (Snell & DeMaso, 2010), have led to the present focus on the use of noncategorical models of adaptation. These noncategorical models propose that children with chronic illness face common stressors and challenges (Garstein, Short, Vannatta, & Noll, 1999), and that psychological outcomes are dependent on developmental and psychosocial processes superseding illness-specific factors. We review two sets of noncategorical approaches to the prediction of psychological outcomes in childhood chronic illness below: stress and coping models and social-ecological models.

Coping

There is no doubt that the diagnosis, treatment, and management of a chronic illness in children and adolescents is a source of stress for both children and their families. There also is a body of literature to suggest that the onset and the course of the illness may be impacted by these stressors. Such stressors are frequently related to daily activities of living (e.g., attending school, engaging in peer activities), stress associated with various treatments and the disease itself (e.g., pain), and stress associated with the ambiguity of the illness and the outcome (Compas et al., 2012). Coping is conceptualized as a process that unfolds in the context of a situation that is assessed as personally significant and involves both behavioral and cognitive efforts to manage external and internal demands that exceed the resources of the individual (Folkman & Moskowitz, 2004; Lazarus & Folkman, 1984). Thus, coping serves as an effort to regulate physiology, cognition, emotions, behavior, and the interactions with others in response to a stressful life event (Compas et al., 2012). Various definitions and conceptualizations for coping have been offered in the extant literature. For example, Compas et al. (2001) has defined coping as, "conscious and volitional efforts to regulate emotion, cognition, behavior, physiology, and the environment in response to stressful events or circumstances" (p. 89). We define coping as the process by which resilience actually occurs. Similarly, Skinner and Zimmer-Gembeck (2007) have defined coping as the study of how individuals manage actual stressors in real-life contexts and how the effects of these stressful episodes actually accumulate during the course of development for the individual. These definitions are important since as Compas et al. (2012) have argued the definitions reflect important links between coping and the regulation of psychological and physiological processes that include emotion, behavior, and cognition. Common means of coping include instrumental action, problem-solving, support-seeking, distraction, escape opposition, and social withdrawal (Spirito, Stark, & Knapp, 1992).

Skinner and Zimmer-Gembeck (2007) have discussed a dual-process model of coping where coping is posited to incorporate stress reactions and action regulation. Stress reactions include immediate and automatic responses to stressful situations while action regulation includes efforts to mobilize, manage, and direct physiology, emotion, attention, behavior, and cognition in response to stress (Skinner & Zimmer-Gembeck, 2007). It should be noted that there has been some controversy in the literature with some experts suggesting that immediate and automatic responses are not really coping strategies and that coping only includes voluntary efforts (Folkman & Moskowitz, 2004).

Compas et al. (2012) have conceptualized primary control coping or specific efforts to change a stressor such as problem-solving or an individual's emotional reactions to a specific stressor (e.g., emotional expression). Secondary control coping refers to efforts to adapt oneself to a stressor by the use of such strategies that include cognitive reappraisal, positive thinking, acceptance, and distraction (Compas et al., 2012). Finally, disengagement coping refers to those efforts to orient away from a particular stressor or an individual's reaction to a specific stressor (e.g., avoidance, denial). In a meticulous review of the pediatric coping literature, Compas et al. (2012) provide evidence that disengagement or passive coping is associated with poorer adjustment or adaptation. However, for primary control or active coping, the data are less consistent. Based on these findings, Compas et al. (2012) have argued that secondary control coping is an appropriate match with the frequently uncontrollable aspects of a childhood chronic illness. As Compas et al. (2012) have observed, the use of avoidance, denial and wishful thinking fails to facilitate the regulation of emotional distress and may further impede engagement or active coping strategies that may serve to regulate uncontrollable stress. Finally, active or primary control coping such as problem-solving may represent an appropriate fit for response to specific types of stressors and a potentially poor fit for negotiating other types of stressors. Thus, while the use of disengagement coping including avoidance and denial is generally associated with poor adaptation to chronic illness, there is substantial evidence that secondary control coping is associated with better adaptation among children and adolescents with chronic conditions

(Compas et al., 2012). Clearly, the efficacy of coping strategies is contingent on the actual match between the specific stressor and the individual's specific coping responses, especially the controllability of the stressor. Where the individual is unable to exert control, there must be reliance on secondary control or emotion focused strategies.

In support of a potential match between a specific stressor and the individual's coping response, a meta-analysis by Aldridge and Roesch (2007) assessed the efficacy of coping strategies on psychological and physical adjustment in 1230 children diagnosed with cancer. Their findings suggest that using different coping strategies during various times of the cancer experience may represent successful adaptation to the disease. Of most importance is that the use of avoidant-emotion focused coping following the cancer diagnosis may actually be related to positive adaptation, while problem-solving types of coping may be more adaptive following the initial diagnosis. In addition, the investigators note that specific coping interventions are apt to be most appropriate with specific medical procedures following the initial diagnosis.

Development of coping. It is important to note that the coping process available to children will change as they grow and mature. There are actually differences in coping that exist from early childhood to early adulthood and as Skinner and Zimmer-Gembeck (2007) have noted, it remains the task of future research to identify specific chronological ages during which coping might actually demonstrate developmental shifts or key critical periods for the development of coping. Skinner and Zimmer-Gembeck (2007) have traced the developmental trajectories of coping that begin during the neonatal period and are primarily reflexive, through infancy, preschool middle childhood, and adolescence. Coping during infancy occurs by means of action schemes and is supplemented to direct action during the preschool years. Cognition assumes a more salient role during middle childhood and meta-cognitive processes are employed most frequently by adolescence. During infancy and early childhood temperament, socialization and typical development are believed to shape coping and coping also is mediated by caregivers as they detect threats, protect and remove stressors and sooth and comfort children as they negotiate the stressors of the environment. Given these differences, it is appropriate for pediatric coping supports to be targeted to the child's developmental capabilities.

Stress and Coping Models

The Wallander and Varni (1992, 1997) disability-stress-coping model is particularly useful for understanding the coping processes of children with chronic illness. In this particular model, pediatric chronic illness is viewed as an ongoing chronic strain for children and their caregivers, since the chronic illness is viewed as exposing children to negative life events. Risk factors that affect adjustment include disease/disability parameters (e.g., condition visibility, disease severity, degree of cognitive impairment), with their implications for functional independence, and psychosocial stressors (e.g., illness-related problems, life events, daily hassles). Resilience factors include child intrapersonal factors (e.g., temperament, problem-solving ability, self-efficacy), ecological factors (e.g., social support, family resources), and stress-processing factors (e.g., cognitive appraisal, coping strategies). Thompson and Gustafson's (1996) transactional model of stress and coping is similar to the model proposed by Wallander and Varni, in that childhood chronic illness is conceptualized as a stressor to which the child must adapt. Risk and resilience factors that moderate and/or mediate child outcome include illness parameters, demographic parameters (such as child age), family functioning, parental adjustment, and methods of coping. Tests of both of these models have generated support for various model components, but neither model has been comprehensively tested (Drotar, 2006).

Social-Ecological Models

In an effort to more thoroughly characterize the impact of the environment on a child's adaptation over the course of time, Bronfenbrenner (1979, 2006) proposed a social-ecological model of contextual human development. The model has subsequently been employed to comprehend the psychological and health outcomes in children with chronic illness (Brown, 2002). This model depicts the process of human development as a reciprocal interchange between the individual and nested, concentric structures that mutually influence one another at the level of the microsystem (family, school, peers), exosystem (parental workplace, school system, health care system community resources), and macrosystem (culture, laws); later versions of the model added the chronosystem that considers how structures develop and change over time. Extrafamilial systems are viewed as interconnected with the child and his/her family. Problem behavior such as poor adjustment to illness may be a function of difficulty within any of these systems, or may be due to difficulties that characterize the interface between these systems (e.g., family-health care provider relations, family-school relations, child-peer relations). In contrast to stress and coping models, the social-ecological model places greater emphasis on understanding the influence of more distal contextual factors on childhood adjustment and adaptation, such as the influence of neighborhood, community, and health care systems. In addition, because of the focus on interactions between risk and resilience factors situated at multiple levels from the microsystem to the macrosystem, social ecological models are multiplicative rather than additive in terms of predicting a child's level of adaptation (Schneider & Stokols, 2009).

Variants of the social-ecological model have been applied to several different childhood health problems, including obesity (Davison & Birch, 2001) and severe nonadherence to medication regimens (Naar-King, Podolski, Ellis, Frey, & Templin, 2006). Nonetheless and similar to the stress and coping models, tests of multiple model components have rarely been undertaken primarily due to feasibility constraints. In an effort to overcome these obstacles, The National Institute of Child Health and Human Development, together with other US government agencies, has funded the National Children's Study (www.niehs.nih.gov/research/programs/children-study), which will follow a cohort of 100,000 children from birth to 21 years of age; the study will include children with chronic illnesses such as asthma and diabetes. This study should thoroughly evaluate social-ecological models of psychological adaptation, as data will be collected on a wide array of multisystemic factors influencing psychological health (Georgopoulos et al., 2014). We now provide a brief review of the literature on family, peer, and broader system influences on psychological adaptation among chronically ill children.

Impact of Various Systems on Child and Family Psychological Adjustment

The earlier literature of family influences on child adaptation among children with chronic illness focused on specific family processes such as cohesion and conflict. These early studies were limited by their cross-sectional nature and problems associated with shared informant biases since caregivers frequently provided data on child adjustment and family climate (Drotar, 1997). Subsequent longitudinal investigations of families of children with chronic illnesses have supported the earlier cross-sectional studies by suggesting that the presence of persistent behavioral problems was significantly associated with baseline family conflict. In general, these findings appear to be nonspecific to the chronic illness. In fact, children who are chronically ill may not manifest any more behavioral problems than the general population.

In recent years, the relationship between parenting specific behaviors and child adjustment has been of increased interest as researchers have attempted to identify the particular family interactional patterns that are most highly associated with psychological risk in children with chronic conditions. In the general child development literature, parenting styles characterized by high levels of warmth/support, high levels of behavioral control (e.g., limit setting and supervision), and low levels of psychological control have generally been found to promote good child adjustment (Barber, Stolz, & Olsen, 2005).

Parenting behaviors that have been associated with positive developmental outcomes for healthy children also have been found to serve as protective factors and to predict psychological well-being among chronically ill youth (Watson et al., 2014). In addition, risk for psychopathology among children and adolescents with chronic conditions has been associated with parental under-involvement (Wiebe et al., 2005) thereby supporting the notion that limit setting and supervision promote healthy adaptation to chronic illness.

Of considerable interest has been the effect of family stress on child adjustment. Studies evaluating the effects of family stress that is directly associated with childhood chronic illness have generally demonstrated that higher levels of illness-related family stress are associated with poorer child adjustment (Stein & Jessop, 2003). In an investigation of caregiver challenges in families of 40,000 children with special health care needs, Kuo, Cohen, Agrawal, Berry, and Casey (2011) found that caregivers of children with complex health care needs reported spending a median of 2 h per week on health care coordination and 11–20 h per week on direct home care of their child. More than half of families (58.8 %) reported financial problems, and 54.1 % reported that a family member had stopped working because of a child's health. Studies also suggest that non-illness-specific family stress, such as the occurrence of negative life events, may have an impact on the adjustment of chronically ill children (von Weiss et al., 2002). In a meta-analysis of studies assessing psychosocial correlates of children's adjustment to chronic illness, Lavigne and Fraier-Routman (1993) found that levels of life stress were more potent predictors of child adjustment than disease factors or socioeconomic status.

As Compas et al. (2012) have argued, it will be important for future investigations to examine sources of support and those factors that impede effective coping among chronically ill children and adolescents. As Compas et al. (2012) observe, the role of parents' coping may be important at several levels since caregivers may serve as a resource to support and model children's effective coping in response to the stressors associated with a chronic illness.

Peers

Peers may provide an important source of coping and support for children with chronic illnesses, particularly during adolescence. Earlier cross-sectional studies of the relationships between peer relationships and psychological adjustment have suggested that positive peer relationships were predictive of better psychological adjustment in children with diabetes (Varni, Babani, Wallander, Roc, & Frasier, 1989), congenital limb deficiencies (Varni, Setoguchi, Rappaport, & Talbot, 1992), and cancer (Varni, Katz, Colegrove, & Dolgin, 1994). However, adjustment difficulties also may result in problematic peer relations, and subsequent longitudinal studies have not always supported a protective effect of positive peer relations. For example, in a longitudinal study of childhood cancer survivors, Thompson, Herhardt, Miller, Vannatta, and Noll (2009) found that measures of peer relationships in middle childhood did not predict externalizing behavior problems during late adolescence and early adulthood. Finally, in one investigation, Helgeson, Lopez, and Karmarck (2009) combined the use of self-report and ecological momentary analysis to evaluate the association between friend relationships and mood among adolescents with diabetes. Findings revealed that conflict with friends was associated with greater depressive symptoms. Further, friend conflict was more strongly associated with poor psychological well-being for girls than for boys.

Broader Contextual Factors

There has been a dearth of studies that have investigated the effects of broader contextual factors (e.g., schools, neighborhood, health system quality) as well as meso- and exosystems (institutions and their interaction) on the psychological adaptation of children with chronic health conditions. Studies of healthy children clearly suggest that such contextual variables are important in understanding the adjustment of chronically ill children, since contextual variables are markers of exposures to particular stressors that may exacerbate poor health and mental health outcomes (Blair & Raver, 2012). Such factors are indirectly implicated as risk or resilience factors for psychological adjustment by studies demonstrating that chronically ill children of lower socioeconomic status have poorer mental health outcomes than those from more affluent backgrounds (Fedele et al., 1997). Further research examining contextual factors on the psychological adjustment and adaptation among children with chronic illness is sorely needed. Finally, there has been a dearth of research examining contextual factors as mediators of the association between parenting variables and health outcomes. Recent research has examined the effects of specific genes on the relationship between parenting and health outcomes (Brody et al., 2014). This research will be especially important in understanding the genetics of disease adjustment and adaptation. Clearly broader contextual factors offer significant promise in providing a noncategorical approach to understanding resilience in children with chronic illness from a social ecological framework.

Coping with Cancer

Since much of our understanding of coping with chronic illness has emerged from studies of children with pediatric cancer and their families we will devote the second half of this chapter to an overview of the coping literature among children and adolescents with cancer and their families as well as interventions designed to enhance coping in this population. When pediatric cancer was a universally fatal disease, the psychological focus was on preparing parents for the death of their child (Binger et al., 1969; Bozeman, Orbach, & Sutherland, 1955; Natterson & Knudson, 1960). These clinical observations and interviews, generally using a psychoanalytic framework, described reactions, such as initial intense distress, disbelief or denial, guilt, anger, anxiety, and in some, continued disruption of psychological functioning, such as severe depression or even psychosis. However, some clinicians and investigators found that parents were not overwhelmed by their intense distress, but in fact, tended to function adequately, and do what was necessary for their child during treatment. Researchers began to study "adaptational techniques and coping strategies" of parents whose children had been diagnosed with cancer (Chodoff, Friedman, & Hamburg, 1964). They described a "natural history of adaptation": an initial stun reaction or feeling of unreality in response to the diagnosis, intellectual acceptance as treatment began, and, later, more emotional acceptance to the reality of the child's impending death. The way people were able to adapt was through coping, described as "the sum total of all the strategies employed by an individual to deal with a significant threat to his stability" (Chodoff et al., 1964). Coping was seen as having an externally directed aspect (e.g., being able to care for the child and fulfill other responsibilities), and an internally directed aspect (e.g., being able to manage anxiety and other emotional reactions) (similar to the concepts of problem- and emotion-focused coping later described by Lazarus, 1991), and primary and secondary coping (Compas et al., 2012; Rudolph, Dennig, & Weisz, 1995).

During the 1950s and 1960s, most attention was paid to the parents of children with cancer, particularly mothers. In fact, it was common that children were not told that they had cancer, much less that they were going to die, with resulting unresolved uncertainty and fear (Natterson & Knudson, 1960). While some of these early studies acknowledged that, although they were not informed about their diagnosis and death, children often guessed what was happening. It was left to later investigators to demonstrate children's awareness of impending death and ways they behaved to demonstrate that awareness (e.g., increased distance from caregivers, Spinetta, 1974; Waechter, 1971).

Even when the prognosis was still dire, some investigators, finding that serious psychopathology was rare, chose to focus on coping and adaptation rather than on defense or pathology (Futterman & Hoffman, 1971). They described the primary coping tasks as anticipatory mourning, maintenance of confidence (including mastery operations such as searching for information, locating resources, and participation in care of the child), and maintenance of equilibrium (emotional regulation, adherence to routines, seeking social and emotional supports). In a similar focus, some clinicians and investigators began to focus on resilience in the face of tragedy (Schulman, 1976), focusing on factors that made them "good copers," such as affirming life rather than denying death (similar to what we now call cognitive reappraisal), current focus (living 1 day at a time), maintaining or developing strong self-concept, mutual support, honest communication, and normal treatment of the child.

As advances in treatment progressed and with increased survival, in the 1970s and 1980s, much more attention was paid to studying coping and adaptation to pediatric cancer, including increased funding from the National Cancer Institute to better understand the psychological aspects of cancer. Studies from this period provided a wealth of knowledge about the psychosocial functioning of children and families and their adjustment to cancer and its treatment. In particular, more attention was paid to the child and adolescent with cancer (Kellerman, 1980; Spinetta & Deasy-Spinetta, 1981). More systematic behavioral observational studies contributed to our understanding of children's coping with painful procedures (Dahlquist, 1992; Jay, Elliott, Ozolins, Olson, & Pruitt, 1985; Katz, Kellerman, & Siegel, 1980). A series of studies began to examine survivors of cancer (Kazak & Meadows, 1989; Koocher & O'Malley, 1981) with findings indicating that physical and psychological effects continued beyond treatment and that there was a need for further study of how these children and families adapted to a still potentially fatal but more likely a chronic illness.

Coping per se in pediatric cancer was still a poorly understood construct, sometimes referring to style, trait, strategy, behavior (what people did), at other times referring to coping "adequacy" (how well people managed), similar to adjustment or adaptation. One attempt to study this further was a longitudinal investigation of child and family coping with leukemia over time [from diagnosis through 10 years after treatment (Kupst et al., 1995; Kupst & Schulman, 1988)]. Ways of assessing coping included self-reports, observation, perspectives of medical, nursing, and psychosocial staff, and the use of existing measures, some of which would be considered primitive by today's standards. Using the theoretical framework of Richard Lazarus, (Lazarus & Folkman, 1984) the definition of coping included, "conscious thoughts and behaviors, capable of change, without value judgments of good or bad, contextually related." Lazarus and Folkman also emphasized the role of appraisal, the meaning of the stressor to the person, whether stressful or not, whether changeable or not which would help to determine the response (strategy) to cope with the stressor. In summary, most parents and children, despite intense distress and continuing stressors, were able to adapt remarkably well over time based on multiple indicators and informants. Factors that were related to positive adaptation early in treatment were: previous coping with stresses, family and social support, coping of other family members, few concurrent stresses, and early psychological intervention (mothers). Most of these factors continued to be related to adaptation in later phases. Among the reported effective coping strategies were: normal treatment of children, living in the present, maintaining open communication within the family, family and social support, but there was significant variability within and across individuals, and thus, no one strategy was found to be a strong predictor of adjustment.

The review by Patenaude and Kupst (2005) revealed that many studies of children with cancer and their families revealed a lack of serious psychological problems, with some studies showing positive outcomes. More research was being conducted to examine coping strategies (Compas, Worsham, & Ey, 1992; Spirito et al., 1992) although the results were mixed when strategies were linked to adjustment and other outcomes. The conclusion was that the adaptiveness or effectiveness of a coping strategy depended on the characteristic of the person, existing resources, and the specific demands of the situation. At that time, little had been done to examine the specific demands placed upon children with cancer and families. However, more recently, specific stressors over phases of treatment as well as developmental aspects have been described in several pediatric cancer reviews (Compas et al., 2012; Kupst & Bingen, 2006; Long & Marsland, 2011; Patenaude & Kupst, 2011).

How one copes with a stressor depends upon one's appraisal of the significance and controllability of these stressors (Compas et al., 2012; Folkman & Moskowitz, 2004; Rudolph et al., 1995). While there are numerous groupings of coping strategies (see reviews by Aldridge & Roesch, 2007; Skinner & Zimmer-Gembeck, 2007), in general, coping strategies are classified according to whether they can affect the stressor (problem-focusing coping, approach coping, primary control coping) or whether one must adapt to an unchangeable stressor (emotion focused coping, secondary control coping).

While a number of studies have focused on determining different strategies, few have been able to link them to adjustment or other psychological indicators. Haase's work on coping and resilience in adolescents with cancer (Haase, 2004) found that defensive coping, such as evasive coping can be adaptive to protect oneself when one is faced with a threatening situation but if sustained, can be maladaptive. Alternatively, positive coping, such as confrontive, optimistic, and supportive coping, can lead to better adaptation. The recent work of Compas et al. (2014), using classification into primary control, secondary control, and disengagement coping, found that use of secondary control strategies, such as acceptance and cognitive reappraisal (especially in situations not in one's control), as well as cognitive-behavioral distraction strategies early in treatment were associated with lower anxiety and depression. Another review (Vrijmoet-Wiersma et al., 2008), viewing coping strategies as protective factors in pediatric cancer, found that avoidant strategies could be effective early in treatment, but not necessarily in later phases when it is necessary to become more involved and active. Active problem-focused strategies tended to be more effective in lowering anxiety and depressive symptoms. Much more research needs to be conducted to examine the role of situational, personal, environmental, and medically related characteristics and their relationship to specific coping strategies, as well as to improve the measurement of coping.

Coping has sometimes involved the study of styles, often with a similar conceptual framework as coping strategies—where one either actively involves the stressor or moves away from it (Aldridge & Roesch, 2007; Skinner & Zimmer-Gembeck, 2007). Styles such as monitoring-blunting (Miller, 1995) and repressive adaptational style have been studied in relation to outcomes in pediatric cancer (Phipps, Steele, Hall, & Leigh, 2001). Very recently, Harper et al. (2014) examined the role of effortful control (ability to shift attention and inhibit emotional responses regarding a stressor) and ego-resilience (ability to effectively use coping strategies) on quality of life and emotional adjustment, finding that both coping styles play an important role in these outcomes. Knowing a person's typical coping style or disposition can be useful, but it is important to remember that it may not predict how a person will respond in every situation.

The process of coping is expected to lead to adaptation. What this means can vary according to one's theoretical orientation. In pediatric cancer, one model posits that cancer is a trauma (Kazak et al., 2006), in which cancer is viewed as a series of potentially traumatic events in which people can experience post-traumatic stress reactions to the stresses of the disease and treatment (see review by Bruce, 2006). Others do not define cancer as a trauma, and in fact, cite a "focusing effect" (Phipps et al., 2014) when it is defined as a trauma for people that can affect the way they respond and are viewed. A third model, the *Pediatric Preventative Health Model* (Kazak et al., 2006), takes the view that most children with cancer and their families do not exhibit serious psychological problems, and that a public health approach may be more useful in focusing on levels of need or risk. There has been considerable discussion about these models, but it is important to note that they have much in common.

First, regardless of the model, research has found that most children, adolescents, and young adults do not exhibit serious psychological reactions over time that require intensive intervention (Abrams, Hazen, & Penson, 2007; Kazak et al., 2007; Noll & Kupst, 2007; Phipps et al., 2014). Second, research has consistently found that a subset of children and parents (about 20–30 %) (Alderfer et al., 2010; Boman & Bodegard, 2000; Compas et al., 2014; Long & Marsland, 2011; Patenaude & Kupst, 2005) evidence the need to try to determine early who may be most at risk and may be in need of more intensive intervention. Third, there is agreement that, while pediatric cancer involves significant distress, people also can experience growth (or post-traumatic growth) and benefit long-term from the cancer experience (Long & Marsland, 2011; Phipps et al., 2014).

Resilience. Resilience is a concept often associated with coping and suggests that people may experience adverse potentially traumatic situations, with minimal distress and disruption in functioning (Bonnano & Diminich, 2013; Rosenberg, Baker, Syrjala, Back, & Wolfe, 2013). Resilient children with cancer are those who recover, adapt, and become stronger despite experiences of suffering and at times presentations of maladjustment outcomes (Wechsler & Sanchez-Iglesias, 2013). The failure to find significant effects of interventions is sometimes due to the fact that most children are functioning within the normal range, and that the "natural tendency of families to adapt to adverse events" can minimize the impact of these interventions (Barrera et al., 2014). A notable model of resilience in pediatric cancer is that of Haase, Kintern, Monhan, and Robb (2014) whose *Adolescent Resilience Model*, now *Resilience in Illness Model*, was developed through meticulous qualitative and quantitative research. Resilience, defined as confidence/mastery, self-transcendence, and self-esteem, was the desired outcome. Risk and protective factors were identified, with a model for intervention developed and implemented (Haase et al., 2014). Research using all of these models is ongoing.

Outcomes such as resilience, quality of life, and adjustment have been studied at length in pediatric cancer. More interesting than scores on measures of these outcomes are studies that have examined correlates and predictors of coping. With regard to quality of life, Klassen's review (2011) provides evidence to suggest that type of cancer, prognosis, treatment intensity, type of treatment, time since diagnosis, and late effects of treatment are significantly related to quality of life. In addition, family factors, such as parental health and well-being, anxiety, depression, and distress were associated with the child's quality of life, with mixed results for socioeconomic factors. As noted previously, personality and temperament in children with cancer and their parents have begun to be studied in relation to quality of life and emotional functioning (Harper et al., 2014). Recent reviews (Long & Marsland, 2011) have revealed social-environmental risk factors such as cumulative life stressors (Okado, Long, & Phipps, 2014), past traumatic events (Vrijmoet-Wiersma et al. 2008), demographics, such as low educational level, low SES, and poor financial resources; and for children, parental emotional functioning (Okado et al., 2014). Personal risk factors include preexisting psychological problems, and level of emotional functioning at diagnosis and early in treatment. Protective factors include good family functioning, social support, and adaptive coping strategies.

The assessment of coping especially in children has been fraught with many methodological and conceptual issues, and pediatric cancer is no exception (Aldridge & Roesch, 2007; Compas et al., 2012). Blount et al., (2008) presented the results of a workgroup to evaluate existing measures of stress and coping in pediatric populations, which continues to be useful. Since that time other measures and methods of assessing coping have also been developed, and with pediatric conditions. While there are several reasonably reliable and valid measures of coping for pediatric populations, there is no "gold standard" measure that exists for children. Paper and pencil measures can be useful in pediatric cancer, but given the myriad of stressful situations over time, and the fact that coping changes over time, it is sometimes more useful to employ qualitative methods, such as interviews or simple vignettes. To see what the child actually does, observational methods have been established (see Blount et al., 2008), especially in the area of pain and procedural distress, and can add to the validity of paper and pencil or interview methods, but they require training and continued reliability assessment. It is important to note that a one-time "snapshot" of coping may be valid for a given situation and time, but may not be the way the child copes in the next situation, and thus it is important to follow children through the stresses of pediatric cancer. In addition to measures of coping, with the demonstrated importance of early functioning as a predictor of later functioning, as well as the impact of other stressors, a screening measure for families of children with cancer (and now other pediatric conditions), the Psychosocial Assessment Tool (PAT) was developed, with several revisions (Kazak, Barakat, Didonato et al., 2011) and has become increasingly employed both clinically and in research settings.

Interventions to help children and families cope with pediatric cancer have emerged over the past decade. While most do not specifically call themselves coping interventions, their methods indicate that they are designed to do so. As a great deal of research in pediatric cancer has found that parental functioning has a strong impact on the child's distress and adjustment, several interventions have focused on enhancing or improving parents, especially mothers' adaptation to pediatric cancer. The *Surviving Cancer Competently Intervention Program* (SCCIP) was developed using the targeted approach of the preventive health model (Kazak et al., 2007), and the randomized study showed promising results for parents of children newly diagnosed with cancer (Kazak, Simms, Alderfer et al., 2005) in terms of reduced anxiety and post-traumatic stress symptoms in the intervention group. A later study (Stehl et al., 2009) found positive results in terms of participant completion and feedback, but noted the methodological issues in conducting randomized clinical trials shortly after diagnosis. One well-designed program of research has been the large-scale randomized study of problem-solving skills training (PSST) (Sahler et al., 2005). This 8 session intervention involved teaching active problem-solving strategies to mothers of newly diagnosed children to help them cope with the stresses of pediatric cancer, with strong evidence for its effectiveness in reducing maternal distress and problems in adjustment to pediatric cancer. A recent study (Sahler et al., 2013) examined specificity of the intervention and compared the PSST intervention with a nondirective support intervention. While results were similar for both groups at the end of the intervention, gains in problem-solving skills and reduced negative affectivity continued only for the PSST group. Similarly, a randomized interdisciplinary (psychologist and nurse interventionist) clinic-based intervention of mothers of newly diagnosed children with cancer (Mullins et al., 2012) focused on helping mothers identify and modify their appraisals of the disease and treatment, as well as using cognitive reframing, communication skills, and use of social support. The initial pilot study found that the intervention group significantly reduced children's post-traumatic stress symptoms and distress but the usual treatment group did not experience these changes. A subsequent investigation (Fedele et al., 2013) found that early maternal distress predicted later child internalizing symptoms, but that the intervention significantly reduced internalizing symptoms over time, at the end of treatment and at follow-up assessment.

Interventions also have been developed for children, adolescents, and young adults with cancer (Pai, Drotar, Zebracki, Moore, & Youngstrom, 2006). Much of the earlier work centered on helping children deal with the stresses of procedural pain and aversive treatments (see reviews by Dahlquist, 1992; Patenaude & Kupst, 2005). Most of these interventions involved cognitive-behavioral coping skills training (deep breathing, distraction, relaxation, imagery) as well as modeling. Dahlquist (1992) emphasized the importance of considering the child's typical coping style in selecting appropriate strategies. As with parents, the SCCIP was developed for survivors of pediatric cancer—a weekend group intervention for survivors and their families, with results indicating a reduction in post-traumatic symptoms for cancer survivors. In part, because access to psychosocial services varies widely and unevenly across medical centers, internet based interventions have begun to be studied in young adult survivors (Seitz et al., 2014) and for parents of children undergoing bone marrow transplantation (Mayer et al., 2010). It is actually too early to determine how these interventions can best be integrated into pediatric cancer psychosocial care, but they offer promise in providing supplemental support and increased access to information.

Methodological Issues

Within the pediatric psychology literature, much of the research has relied on assessment approaches that include the use of multiple informants (child, parents, teachers) across multiple settings (e.g., home, school) (Compas et al., 2012). However, much of the existing literature in the area of coping has been based on single sources of informants (e.g., child or parent self-reports), thereby making it unclear as to whether the findings are a function of a specific informant (Compas et al., 2012). Thus, as Compas et al. (2012) has recommended, it will be necessary for future studies to employ multiple sources of informants (e.g., caregivers, children, teachers) across multiple settings (home, school) within the assessment batteries. It is anticipated that such an approach would serve to integrate the stress and coping and the social ecological models that have been addressed in this chapter. In addition, the majority of investigations in the extant coping literature have relied on correlational studies, thereby precluding an investigation of the temporal relationship between coping and other variables of disease adaptation (Compas et al., 2012). For this reason, Compas et al. (2012) have recommended that future investigations employ longitudinal designs whereby coping is assessed across time and also used to predict other variables of disease adaptation over the course of time. Recent research in the field of pediatric psychology has made extensive use of biomarkers of various chronic diseases such as hemoglobin for sickle cell disease, peak expiratory flow rate for children with asthma, and glycemic control (HgbA1C) for children and adolescents with T1DM. The inclusion of these biomarkers for future coping studies will be important so as to predict the influence of coping on these various biological dependent measures. Additionally, it will be the task of future research to address how children's and parents' coping reciprocally influence each other so as to understand children's adaptation to illness within a systemic family context (Compas et al., 2012). Finally, the development of coping interventions will be important in validating much of the correlational research that has been conducted to date. To date, there has been a dearth of research that has examined the impact of various interventions on children's and families' coping with a chronic condition in a child. We next turn our discussion to promising interventions designed to enhance coping in children and their families.

Interventions Designed to Enhance Coping

Much of the pediatric psychology literature over the past decade has turned to clinical trials and intervention programs in an effort to validate empirically much of the correlational research that has been conducted over the past several decades. Clearly, within the pediatric coping literature, there has been a dearth of intervention research designed to enhance coping. While much more research is needed, the extant literature has revealed two promising coping-based intervention studies. Grey et al. (2000) developed a coping skills training program designed to teach skills such as assertive communication, conflict resolution, stress management, and positive thinking among youth with T1DM. The findings have been encouraging as the intervention has been compared with a treatment as usual condition, plus an information sheet about depression, without therapist contact. The coping intervention group (PASCET-PI) demonstrated significantly greater improvement than the comparison group on children's and parents' reports of depressive symptoms, children's global functioning, and increased perceptions of control at the posttreatment assessment. The program also has been demonstrated to have positive effects on quality of life as well as disease specific measures including metabolic control. Similarly, Szigethy et al. (2004) investigated both the efficacy and feasibility of a manualized-based cognitive therapy approach in reducing depressive symptoms among adolescents with inflammatory bowel disease. That the intervention program was so efficacious among children with one chronic illness suggests its potential efficacy with children with various other chronic conditions. Much more research needs to be conducted so as to assess its potential usefulness among other children with chronic diseases.

Summary and Conclusions

Due to technological advances in health care, children and adolescents are increasingly surviving numerous chronic illnesses that several decades ago were considered to have a very guarded prognosis. There has been mounting research to suggest that these youth are at significant risk for adjustment difficulties, psychopathology, and post-traumatic stress. In this chapter we use cancer as the prototype of understanding coping in children and their families. In general the pediatric oncology literature has demonstrated that children with cancer and their families actually demonstrate a lack of serious psychological problems with many investigations demonstrating positive outcomes (Patenaude & Kupst, 2005). Positive coping such as confrontive, optimistic, and supportive coping have been demonstrated to be associated with better adaptation to the cancer experience. Nonetheless, how an individual copes with a stressor is dependent upon one's appraisal of the significance and controllability of these stressors. Appropriate coping and eventual adaptation to the cancer experience and its associated stressors results in resilience suggesting that children and their families may experience adverse potentially traumatic experiences, with minimal distress and disruption in daily functioning.

The assessment of coping in children and their families has been a formidable task and fraught with myriad methodological and conceptual issues. Clearly, there is no gold standard that exists for children and adolescents and one particular "snapshot" of coping may not be sufficient to capture children's adaptation to the entire cancer experience. Assessment of coping also should include multiple informants (child, parents, teachers) across settings (home, school, play). Compas et al., (2012) has recommended that future studies of coping employ longitudinal designs where coping is assessed across time and whereby various biomarkers are employed in future investigations so as to predict how coping influences the disease process as well as children's and families adaptation to the disease process and how this may be mediated or moderated by biological markers.

Perhaps the most promising research in the area of coping are randomized clinical trials designed to test intervention programs to assist children and families in coping with various chronic illnesses. In the area of cancer specifically, the *Surviving Cancer Competently Intervention Program* (SCCIP) has demonstrated particular promise in reducing anxiety and post-traumatic distress (Kazak et al., 2005). Further, the 8 session problem-solving intervention designed to assist mothers of newly diagnosed children with cancer also has demonstrated particular promise in reducing maternal distress and problems in adjustment to pediatric cancer. Similar interventions have been developed for children and adolescents with other chronic diseases including diabetes and inflammatory bowel disease. For example, a coping skills program that taught children with diabetes assertive communication, conflict resolution, stress management, and positive thinking has been demonstrated to have positive effects on quality of life for these youth and to impact metabolic control, thus suggesting that it had influence on the disease itself (Grey et al., 2000). Much more research needs to be accomplished in this area including the identification of specific interventions that are apt to be most efficacious for specific diseases and for the types of children and families that are most apt to benefit from such intervention programs.

Clearly, research efforts in the area of coping and particularly how coping impacts disease adaptation, adjustment as well as biological markers of specific diseases is an important new direction in this program of research. Intervention research also will be important in validating predictive models that have been posited to date and enhancing quality of life for children and their families as they survive diseases that in previous years were deemed to have a very guarded prognosis.

While these aforementioned studies are encouraging and offer the promise of reducing stress and enhancing coping for children with various chronic diseases, future research will need to tailor specific interventions for specific chronic conditions (Compas et al., 2012). Further, we need to understand how such interventions are effective and for whom they may be efficacious (Compas et al., 2012). Thus, it will be important to test various mediators and moderators of such coping interventions on a range of dependent measures including biomarkers of disease, particularly among high risk populations.

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Chapter 16
Researching Resilience in a Medical Context: Understanding Social Ecologies Using Mixed Methods

Linda Liebenberg

Its relatively short history aside, most resilience research has focused on the characteristics and processes that facilitate better than expected outcomes for children living predominantly in contexts of chronic social adversity. More recently, the interest in these processes has expanded beyond these social contexts. Emerging initially from disciplines such as developmental and educational psychology as well as social work, members of other disciplines, such as geography, architecture, and medicine, are increasingly starting to explore the characteristics and processes that facilitate positive outcomes for diverse populations facing disparate risks. As theoretical approaches evolve and change across disciplines, it is important to take stock of the methodologies that have been developed to investigate and understand resilience in diverse contexts and the lessons learned from them.

This chapter reviews some of these lessons, using a mixed methods approach that centres around youth voice, that have emerged from a sociological perspective primarily based on Bronfenbrenner's (1979) ecological framework of human development that emphasises the importance of personal capacities, resources within the person's context, and the interactions between these various components, in understanding how people develop and their related outcomes. The chapter begins with an explanation of social ecological understandings of resilience, elucidating the relevance of this model of resilience to a medical context. I then review approaches to exploring the resilience processes that bolster children's outcomes when confronted by health risks and adversities. Specifically, I discuss an iterative mixed methods approach followed by a review of qualitative and quantitative approaches to data collection when working with children and youth. Recommendations for data gathering at each stage are also provided. In this way an introduction to mixed methods

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L. Liebenberg, Ph.D. (✉)
Faculty of Graduate Studies, Dalhousie University,
PO Box 15000, Halifax, NS, Canada, B3H 4R2
e-mail: Linda.Liebenberg@dal.ca

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explorations of resilience within medical contexts is presented from which the reader is able to develop independent research projects.

It should be noted that while mixed methods research designs are not uncommon in the field of health research (see, for example, Bergman, 2011; Morse & Niehaus, 2009), the caveats of this chapter are intended to highlight critical components that should be accounted for specifically in resilience focused health research.

What Is a Social Ecological Model of Resilience and Why Is It Relevant to Medical Contexts?

Currently in its fourth wave, resilience is now widely accepted as a set of interactive processes where individuals draw on personal skills together with contextual resources to achieve better than expected outcomes in contexts of adversity (Bottrell, 2009; Felner, 2006; Greene & Livingston, 2001; Lerner, 2006; Masten, 2001; Rutter, 2006; Wright & Masten, 2006).

Key resilience studies have consistently identified core components of the processes that facilitate positive outcomes for children and youth in the face of adversity. These components include both personal capacities and resources embedded in relationships and social context. Personal capacities include, for example, the capacity to form attachments, the capacity to self-regulate, cognitive skills, and personality or temperament. Relational resources include bonds with family, friends, and broader peer groups, as well as the ability to interact in socially appropriate ways with members of the broader community. Contextual resources include the availability of community resources (such as recreational resources, libraries, and so forth) and opportunities situated in the social context (including formal services, such as health services) (Luthar, 2006; Masten, 1999; Ungar, Liebenberg, Armstrong, Dudding, & Van de Vijver, 2013).

These characteristics echo findings in the literature pertaining to children with chronic illness and the non-medical agents that support their pathways to health. The use of healing environments, such as gardens, for example, has been promoted for hundreds of years. Van de Riet, Jitsacorn, Junlapeeya, Dedkhard, and Thursby (2014), in their study of the effects of a "Fairy Garden" on children with chronic illness at a hospital in northern Thailand, trace some of this long history. They comment on the use of gardens in European monasteries during the middle ages, through to Florence Nightingale's assertion of the need for healing spaces that include fresh air and sunlight, and to contemporary studies that demonstrate the substantial contribution of gardens to health-based resilience processes. Their own qualitative study also highlights the importance of the physical environment in the health outcomes of children and youth. In particular, their study shows how an available and accessible space, that holds cultural relevance related to relaxation, socialisation, and spirituality, supports children's adherence to treatment plans, fosters social support for parents (as parents find a common space to interact and engage with one another), and facilitates improved communication between children, nurses, and families. In this way, their study also points to the ways in which resilience fostering components (including social actors, communication, and contextual resources) are interrelated.

Halim, Yoshikawa and Amodio's (2013) quantitative study of the impact of immigrant mothers' experiences of discrimination on their children's health highlights the complex interaction of immediate and more distal relationships on children's health outcomes. Drawing on data from 98 Dominican and Mexican mothers living in the USA, their findings show that increased experiences of discrimination by mothers are indeed a strong predictor of increased reported experiences of illness with their children. Their study also showed however, that mothers' identification with their ethnic culture attenuates the impact of mothers' experiences of discrimination on their children's health. In these instances, children's reported experiences of illness are reduced. Put differently, where mothers had stronger identification with their culture, the reported incidence of children's illness was lower despite experiences of discrimination. While Hallim et al.'s study was risk focused, it does underscore the importance of relationships in resilience process of children related to physical illness and health. Importantly, this type of discrimination is not limited to immigrant families, but is also present in clinician's stigmatisation of children with Sickle Cell Disease and their families (see Salamon, Schwartz and Barakat, this volume).

Research is deepening our understanding of the ways in which youth navigate to resources they feel are required to achieve healthy outcomes, as well as the ways in which children and youth negotiate for these resources to be provided in ways that are meaningful to them and relevant to their context (Ungar et al., 2007). This work has informed research of the ways in which formal services can better augment these processes (Liebenberg, Ikeda, & Ungar, 2014; Sanders, Munford, Liebenberg, & Ungar, 2014; Stevens, Munford, Sanders, Liebenberg, & Ungar, 2014; Ungar et al., 2013). Importantly however, international research is also demonstrating the heterogeneity in how youth draw on various resources and the pathways they navigate to achieve healthy outcomes (see, for example, Ungar & Liebenberg, 2011; and the special edition of the Journal of Child Psychology and Psychiatry, edited by Panter-Brick & Leckman, 2013). These findings underscore the need to continue our efforts of expanding our understanding of resilience across contexts.

Research that delves into self-identified and self-reported understandings of pathways to health can inform the effectiveness of formal service provision in important ways. As with many other services, medical institutions are embedded and operate in social contexts that can vary tremendously. Simultaneously, clients of these services are navigating medical systems against the backdrop of their own social ecology. Their choices and decisions may therefore be predominantly informed, motivated, or constrained by the resources available or absent in these ecologies; as well as the social and cultural norms that frame their perception and understanding of life (Rich, Patachnick, & Chalfen, 2002).

In their study of young people's understanding and experiences of asthma, for example, Rich et al. (2002) found that while participants understood their illness, its aetiology and management, participants' "sense of 'fatedness'" (p. 450) meant they often inadvertently exposed themselves to triggers of their asthmatic attacks as they "take their chances with asthma and live their lives" (p. 450). Qualitative data gathered from 20 children and youth (8–25 years old) showed that the asthma education young people received was effective in informing their understanding of the illness itself. Importantly, the data also showed how the parallel frameworks informing young people's management of the illness was shaped not by formal asthma education but rather "by anecdote, cultural beliefs and incomplete understandings of personal and family experiences … governed by fear, distrust of the medical paradigm, and a sense of helplessness" (p. 450). This insight into the contradictions between the young people's formal knowledge and their seemingly poor health behaviour choices related to the management of their illness, are critical to helping clinicians provide effective support to their young clients.

Collectively then, there are strong parallels between our current understandings of the resilience processes that support children in challenging socioecological contexts and those that support children facing health challenges. Intuitively, a social ecological understanding of resilience seems well aligned with both of these contexts of adversity. Lessons learned from the investigation of resilience in the former context may lend support to studies in the latter.

Approaches to Understanding Children's Interactions with Their Social Ecologies

The value of mixed methods designs in resilience research as well as research in health and medical contexts is now well established (Creswell, Fetters, & Ivankova, 2004; Morgan, 1998; Morse & Niehaus, 2009; Sandelowski, 2014; Steckler, McLeroy, Goodman, Bird, & McCormick, 1992). Judiciously integrating qualitative and quantitative approaches into a research study broadens the scope of investigative approaches available to researchers (Jones & Sumner, 2009), enhances the reliability and validity of research findings (Barton, 2005; Richardson & St. Pierre, 2005), provides a more complete research account of the phenomenon under investigation (Creswell, Plano Clark, Gutmann, & Hanson, 2003; Johnson & Onwuegbuzie, 2004), and provides the flexibility researchers require to account for the complexity of the phenomenon of resilience (Glantz & Sloboda, 1999; Jones & Sumner, 2009; Ungar & Liebenberg, 2011).

Given the challenges posed by resilience research, these strengths position mixed methods as a viable research approach irrespective of context. As argued elsewhere (Liebenberg & Ungar, 2009), studying the resilience processes is not the same as studying risks. While risks and/or challenges need to be accounted for in the research processes (given that this is a core component of how we understand resilience), the central focus of our investigations need to be (a) the positive outcomes that characterise our immediate research context and (b) the resources and processes of children and youth that facilitate their attainment of these outcomes. Iterative mixed methods approaches, where the findings of previous or earlier research phases inform the design and focus of successive phases, are particularly well positioned to respond to this shift in focus (Liebenberg & Ungar, 2014).

Used during initial phases of knowledge development, qualitative methods allow for the exploration of previously unconsidered topics, highlighting potential features or components of pathways that should be further explored. Following on large scale surveys, qualitative data can facilitate a deeper understanding of findings, providing detailed explanations of how processes work (or don't work), or descriptions of identified components of support and why it is that these particular characteristics foster healthy outcomes. Likewise, beginning research with a quantitative approach provides important information on the prevalence or lack of resources, risks of key concern to the target population, and potential pathways or mediating events/actions that are key to understanding resilience within the research context pointing to important features and processes that should be understood in greater depth. Positioned after qualitative components, quantitative applications again serve to highlight the extent to which resources are available and processes are occurring within and across various communities; and the differences in the prevalence and use of resources across populations affirming initial qualitative findings.

Put differently, our capacity as researchers to account for and measure risk is far more profoundly established, than our capacity to account for and measure resilience processes and functional or healthy outcomes. This is the case particularly with regard to our knowledge of contextually relevant protective processes and resources. Findings from initial qualitative studies can highlight contextually relevant components of resilience contributing to the validity of the variables we then include in later surveys or experiments.

Used in isolation, large scale quantitative surveys may highlight the prevalence of resources (e.g. supportive and compassionate doctor/client interaction) or certain interactive processes that facilitate particular outcomes (a collective of single-site services focused on paediatric care), but these data do not necessarily hold the capacity to help us understand the dynamics or characteristics of meaningful resources (e.g. what does supportive and compassionate doctor/client interaction look like in a particular social context) and what are the characteristics and mechanisms that results in successful interactive processes (e.g. what services, provided how and when, and to whom?). Following up with participants using qualitative interviews and focus groups expands on our understanding of quantitative findings.

Similarly, qualitative approaches produce rich understandings of the ways in which children and their families navigate health challenges the services designed to support them. Without confirmation from statistically representative samples, the impact of these findings is often limited. In addition to a mixed methods approach to data gathering, a social ecological model also necessitates a decentred approach to research (Liebenberg & Ungar, 2009; Ungar & Liebenberg, 2011), attained by including multiple perspectives. These perspectives should hold the experiences of children and youth at the centre, but not to the exclusion of other important people who surround them. Children and youth, as primary service users, and the individuals managing their illness, bring a core understanding to the experience of both illness and what is required from their physical and social ecologies to better support a positive prognosis. Without their insights at the centre of our research, we may omit key components of young people's experiences of risk and recovery.

Primary caregivers, service providing staff, and policy makers may not be able to accurately comment on the perspectives and lived experiences of children and youth themselves, but as experts, gatekeepers and advocates for young clients, their perspectives are critical in fully understanding how they perceive the context and needs of children in relation to their adult understanding of the risks children are facing. Their perspective on the risks and resources they feel are of most relevance to the prognosis of young clients shapes their own responses to young people's needs, the resources they will provide access to or advocate for, and importantly the ways in which they themselves are or are not forms of support. Finally, they bring insight into the functioning of systems and communities, what is available and accessible, and of course what is lacking and needed. Their perspectives and experiences can be integrated through the use of surveys and interviews. Document reviews, for example, of service files, patient or client files, and school records are another key source of data that augments data gathered from various participants. Through the integration of these various perspectives, researchers are better able to account for the contexts in which children navigate and negotiate for health promoting resources; as well as the variations that occur in terms of these resources and pathways, across various contexts.

A Mixed Methods Approach to Understanding Resilience Processes

As Guest (2013) highlights, numerous typologies of mixed methods have been set out by leaders in the field. Cresswell and Plano Clark (2007), for example, have identified four major types of designs, namely the embedded design, the triangulation design, the explanatory design, and the exploratory design. The latter three of these have perhaps proved most relevant for the field of resilience research. The triangulation design tends to include concurrent qualitative and quantitative data collection that scaffolds validity of findings through the integration of analysis and finding stages. The explanatory design is ordinarily characterised by initial quantitative stages that are followed up with qualitative data gathering that elucidates quantitative findings. And finally, the exploratory design is usually one in which findings from an initial qualitative data collection phase provides the framework or focus of a larger quantitative exploration.

In instances where components of resilience processes are less well known or indicators of positive and healthy outcomes are more ambiguous, beginning the research with a qualitative component is essential to inform the content of later quantitative measures. Likewise, once findings regarding pathways to healthy outcomes are identified, successive qualitative enquiry can provide greater understanding of why it is that particular components and/or processes work together the way they do; and why it is that these processes and/or components facilitate particular outcomes. The triangulation approach allows for the integration of multiple data sources (qualitative and quantitative), perhaps even from multiple perspectives (children, parents, teachers, and document reviews), that once brought together, add credence to emerging findings.

However, within a developing field such as resilience (Masten & O'Dougherty Wright, 2010; Panter-Brick & Leckman, 2013) these three broad designs can easily become conflated. Furthermore, posed with a design question focused on sequencing rather than the most optimum approach to developing knowledge, researchers may often find themselves lost in a maze of typology. In response to this concern, Guest (2013) has proposed a shift in focus, from classifications based on the sequencing of data collection, to one that focuses on "the point of interface" (p. 141), giving emphasis to "the timing and purpose of data integration" (p. 141). He points out that the emphasis of our focus when designing mixed methods studies needs to shift more from the need for a simplistic typology of the process, to an understanding of how the integration of various research approaches can enhance our study, and to be clear on the moments where data and various approaches to fieldwork connect, integrate, inform, or explain one another. He goes on to argue that such a shift would enhance the quality of research designs. Specifically, he explains that, "[i]f the points of interface are appropriately justified, well executed, and adequately described, the foundation for a solid mixed methods research study will be laid …. [Focusing on] the point-of-interface level forces researchers to think, plan, and write more explicitly about how and why they are going to connect the pieces within a research study" (p. 149). Using this as a point of departure, I present three examples of mixed methods research, with conflated typologies, but with clear points of interface. Each example is presented using an adaptation of Guest's (2013) framework where a justification for points of interface is set out, and then used to explain how this informed the data collection type and sequencing, as well as the data analysis approach.

The International Resilience Project

The International Resilience Project (IRP) was a 14 site, 11 country study aimed at (1) developing an understanding of resilience that held relevance across cultures and contexts and (2) developing a cross culturally valid measure of resilience (Ungar & Liebenberg, 2011). Given that much of the resilience research that preceded the study was limited to contexts within the minority world—a term promoted by the Bangladeshi photographer Shahidul Alam, and used in preference to terms such as "developing countries", "third world", and the "South"—the study had to begin with an *exploratory* phase that would allow for a better understanding of what doing well looks like across different cultures, given context specific risks. This initial exploratory stage of research could then be followed up with a large scale investigation that could *affirm* the initial results. Specifically, information gleaned during the exploratory phase could be used to frame qualitative interviews and inform the contents of a quantitative survey, both of which would form the second stage of the research. The two different types of data from stage two (qualitative and quantitative) used in combination with commentary from Local Advisory Committees (LACs) could then be used to affirm and strengthen findings in this *triangulated* phase of the study.

With these goals in mind, the initial exploratory stage consisted of focus group interviews at each of the 14 sites (see Ungar & Liebenberg, 2011 for a full list). Given the need to understand risks and resilience across cultures, sites were diverse from one another both in terms of culture and risks. Local literature reviews of what it means to grow up well despite facing risks were used to contextualise the study at each site. In addition to the literature reviews, focus groups were held with adults who the local research team and LAC who had extensive knowledge of the risks young people face in their community. People interviewed included parents, teachers, and other professionals working with youth in the community, as well as adults who themselves were considered to have grown up well despite facing heightened adversity. Focus groups were also held with children who LACs felt were confronted by chronic adversity, yet were doing well despite this. At each site, findings from a content analysis of the local data were grouped according to Bronfenbrenner's (1979) ecological model. This framework was then used to identify similarities and differences across the 14 research sites. Where there was convergence, this data was used to generate 58 items for inclusion in a resilience measure.

During the second phase of the study at least 60 youth at each site completed the 58-item quantitative measure. This data allowed us to confirm and assess the relevance of these items at each site. To add depth to our understanding of how these features of resilience are relevant to children's lives, at least two qualitative interviews were conducted with one boy and one girl at each site. Data from all sites was amalgamated into two data sets (one qualitative and one quantitative) and analysis was conducted separately but simultaneously. Quantitative data was analysed using a repeated process of principle components analysis (Ungar et al., 2008) and qualitative data was analysed using thematic analysis (Ungar et al., 2007). Results from each were again compared for points of convergence, and demonstrated that while identified resilience processes were of relevance to all youth across all settings, the importance of these processes was relative to the context, culture, and gender of youth as well as the risks they face in their community. Consequently, the ways in which children drew on these processes differed across these groups (Ungar & Liebenberg, 2011).

Within a medical context, the process of iterative qualitative-quantitative-qualitative phases of data gathering could prove extremely beneficial to understanding the resilience processes involved in how people manage a specific medical concern. Initial focus groups enable the identification of themes relevant to the identified medical issue. This data can then be used to inform the construction of a survey measure either by constructing items directly from these themes as in the case of the CYRM or by integrating existing validated scales and sub-scales that reflect the emergent themes. Larger groups of participants can then complete the surveys adding generalisability to the themes identified in the initial focus groups. More in-depth individual interviews elucidate the dominant patterns confirmed through the quantitative data.

Pathways to Resilience

Pathways to Resilience was an international study of the pathways young people travel through formal services to achieve positive psychosocial outcomes, and the informal supports and relational resources that support this process. While numerous studies have been conducted of the pathways young people travel through a single service provider (such as justice, or mental health), at the time of design, no other study had considered how children travel through multiple services simultaneously. Given the evidence that young clients are being failed by services as a result of the gaps between service silos (Bovan, Harland, & Grace, 2011; Chuang & Wells, 2010; Horwath & Morrison, 2011), this study sought to learn from the ways in which young people are managing to successfully navigate across multiple formal supports, drawing on these lessons to inform service provision. Given the variation in formal service provision and informal supports across various cultures as well as political and economic contexts, an international perspective would broaden the relevance of findings. As such, the study took place in five countries (Canada, China, Colombia, New Zealand, and South Africa) and used an *explanatory* mixed methods design.

Existing knowledge of risks, resources, resilience, and outcomes of young people who are exposed to violence, poverty, marginalisation, and family-related stressors was used to inform the development of the Pathways to Resilience Youth Measure (PRYM)—a compendium of validated scales reflecting these four areas of young people's lives. The PRYM also contained an extensive review of service use history and service use experience (see Ungar et al., 2013). At each site, data was gathered from three groups of youth: (1) those with high rates of engagement with formal services (i.e. justice, mental health, child and family services, and educational supports) relative to their context; (2) youth not engaged with formal resources but whom local advisory committee members felt were doing well despite their exposure to chronic risks; and (3) a comparison group of youth from the same or similar socio-economic contexts who had not been engaged with any formal services for at least 6 months prior to the study. Scale scores within the quantitative data were then used to purposefully select youth who were invited to participate in qualitative interviews. Specifically, at each site and within each sample group, the resilience scores of participants who score above the median for risk are reviewed. Participants within this "higher risk" group and who scored highest on a resilience measure were invited to participate in a qualitative component of the study, as were participants who also score within this “higher risk” but lowest on the resilience measure. At each site, qualitative data was gathered in ways that are culturally and contextually relevant (see, for example, Liebenberg & Theron, 2015). This data is being used to elucidate findings emerging from the quantitative data (see, for example, Liebenberg, Ikeda, & Wood, 2015; Munford & Sanders, 2015; Theron, Liebenberg, & Malinidi, 2014).

In two of the sites, additional quantitative data was gathered from a youth nominated Person Most Knowledgeable (PMK). PMKs are asked to complete a companion version of the PRYM. By including the same measures, but asking about the young person’s experiences from the perspective of a knowledgeable adult, information is gained of the perspective of key adults in the lives of youth regarding the challenges youth face and the resources available to them to manage these risks (see for example Li, Liebenberg, & Ungar, 2015). At these same two sites, the service files of those youth who participated in the qualitative interviews have also been reviewed. Using a review grid (see Image 1) the who, when, where, why, and what of a participant’s experiences at each service they report using has been gathered. Once all files related to a participant have been reviewed, this data has been merged into a single story that shows a clear road map of the ways in which services respond to young clients and their needs. This qualitative data is intended to augment the experiences reported by young people and their PMKs. Both the quantitative PMK data and the qualitative file review data was used as a source of triangulation with data gathered from young people themselves (see, for example, Ungar, Liebenberg, Landry, & Ikeda, 2012).

As questions are asked of this data set, qualitative and quantitative components are drawn on in ways that are best suited to answering these questions. Similarly, data is drawn on within countries and across countries, as well as within sample groups and across sample groups. In this way, the design becomes exploratory, explanatory, and triangulating.

Used in medical settings, this comprehensive approach to data gathering ensures inclusion of multiple perspectives and sources of data in understanding how patients navigate the medical system and draw on other informal resources and supports as they manage a particular illness. Findings would be instrumental in shaping how medical services are provided to patients and how medical staff can better to draw on informal resources and supports in treatment plans. Situating resilience processes related to a particular medical issue alongside patient identified risks to engagement in treatment and or positive lifestyle choices allows for a more complete understanding of the interaction of pathways to positive outcomes in relation to related risks or barriers to these outcomes. By gathering this data both quantitatively and qualitatively ensures that findings are both generalisable and understood in more depth. And finally, including multiple perspectives (i.e. through focus groups with medical staff, family and other key supports in the lives of patients, as well as file reviews) furthers this comprehensive understanding of patient pathways ensuring that key voices of their social ecology are included in the final analysis.

RES-360

The RES-360 is a component of the Education Resilience Approaches, RES-Research modules developed by the Education Sector of the Human Development Network of the World Bank (World Bank, 2013a). The module is designed to identify the ways in which education systems can better support the resilience processes of children and youth in fragile and conflict affected states. Recognising the heterogeneity of both risks and resources that characterise these states, the RES-360 is intended to provide a rapid assessment of both these components, providing a foundation from which to enhance supports available for students. As such, the module uses an exploratory and triangulating mixed methods approach.

Beginning with a qualitative phase, the RES-360 incorporates a review of national literature (e.g. national statistics and reports on the risks the population of the state, and children and youth in particular face) and focus group interviews. The focus group interviews are intended to incorporate multiple perspectives regarding risks and resources at various levels of local society: the ministry of education, school and community administrators, teachers and parents, as well as children and youth.

Findings gleaned from these focus groups are converted into items for inclusion on a survey. The survey assesses the presence of risks and resources together with the prevalence of risks and relevance of resources to students in the community. The survey is then administered to participants representing these various levels of the service providing system (ministerial, administrative, front line, and clients). A simple analysis using descriptive statistics (frequencies, means, and standard deviations) provides a comprehensive overview of how gatekeepers of resources (ministers and administrators) perceive risks and related need for, or availability of, resources; as well as how advocates for resources (i.e. teachers and parents) perceive risks and relevant resources; and finally, how clients (i.e. students) experience the risks in their community and what they believe to be the most important resources they need to navigate these risks successfully. Overlaps, and important discrepancies can then be identified and highlighted by means of this quantitative data. Qualitative data captured in the initial focus groups interviews can also be revisited at the end stage to elucidate quantitative findings of the various groups.

Results from a RES-360 pilot study conducted in Honduras demonstrated that while actors at all three levels identified the same contextual risks for children and youth, data from students highlighted the ways in which schools themselves often exacerbated these risks. Specifically, young people were often left vulnerable to the predominant dangers facing them on the streets of their communities when schools prevented access to school grounds because children were perhaps late, or not wearing the correct school uniform. Furthermore, while adults (both gatekeepers and advocates) focused on resources that would keep crime and violence out of school contexts (for example, increased school security), younger participants felt that greater access to school property as well as adult protection during their commute to and from school were of greater value (World Bank, 2013b).

As with the approach outlined in the *Pathways* study, the RES-360 approach allows for a comprehensive and holistic understanding of the interaction between resilience resources and related risks or barriers, but ensuring that policy and programme frameworks are included in this understanding. Specifically, this approach fosters a better understanding of the alignment amongst the perspectives of patients, families, various medical staff, as well as administrators and officials related to the medical and health system. In this way, findings can meaningfully inform both frontline service provision and related policy, funding, and administrative structures (For more on the concept of resilience in Children's health and social care policy, see Noyes, this volume).

Strategies for Making Mixed Methods Data Gathering Work

We need to think carefully about the ways in which data is gathered. The complexity of studying resilience is compounded by the fact that many components supporting positive outcomes are integrated into the taken-for-granted of everyday life, leaving them obscured from social actors. As taken-for-granted aspects of life, participants in studies are often unaware of the ways in which these aspects of their daily lives hold relevance to their management of adversity. In this way, they may be unable to identify and discuss the resources they draw on (Liebenberg, 2009; Liebenberg, Ungar, & Theron, 2014). Similarly, should participants be aware of these resources and processes, the language with which to articulate the nature and dynamics of these processes may not exist (Liebenberg, 2009). This absence of awareness or language necessitates the inclusion of more innovative elicitation methods that can facilitate reflection on the taken-for-granted and/or bolster the sharing of narratives. Used strategically, approaches such as video journaling (Barnes, Taylor-Brown, & Wiener, 1997; Rich & Chalfen, 1999), and reflective photography (Liebenberg, 2009), can facilitate a reflection on the taken-for-granted of everyday life that are better thought through before starting an interview. Approaches such as timelines (Liebenberg & Theron, 2015), clay work (Liebenberg & Theron, 2015), and drawing (Bagnoli, 2009) are powerful ways of facilitating such reflecting during interviews.

Administration of quantitative measures holds its own challenges. Working through surveys can present participants already managing numerous stressors and demands with an additional burden. Placing participants in positions where they are left completing measures on their own, often means they may rush through items, without fully considering the meaning of questions. Similarly, without the space to discuss questions, the intended meaning of an item may be lost, resulting in data that is not truly representative of participants' experiences. Children in particular may also feel overwhelmed by a survey approach to data gathering. They are also far more inclined to not fully understand questions as well as the nature and meaning of response options. Older children and youth could experience the process as another "test", or once again, being assessed. Consequently, they may respond with ambivalence to the process of participating in a survey, despite their voluntary consent to do so. Ensuring that survey data is gathered in ways that are more personable, and engaging participants individually in a dialogical process, is an effective means of altering these research dynamics. By meeting with participants one-on-one, or in small groups and working to put participants at ease, often creates a space in which participants tend to think items through more thoroughly, are more inclined to ask clarifying questions where necessary, and discuss how questions are relevant to their context. Put differently, creating a space where participants know that the contribution they are making to the research matters and is taken seriously, encourages participants to engage with research at a deeper level (Sanders, Munford, Liebenberg & Henaghan, 2014; Urry, Sanders, & Munford, 2014). In this way, validity of responses as well as that of the overall data set is increased.

In designing studies of resilience, irrespective of context, researchers need to keep this in mind. As the level of development of resilience knowledge locally is gauged, the value of the overall research approach proposed here—as well as components of that approach—will vary.

Conclusion

This chapter has reviewed some of the key considerations to be kept in mind when conducting research with children and youth that is informed by a social ecological model of resilience and incorporates a mixed methods approach. Beginning with a discussion of the relevance of social ecological model of resilience to the medical context, various approaches to the use of mixed methods are then reviewed through the use of research examples. While none of the examples presented pertain to medical settings, they do demonstrate the ways in which mixed methods can be used to explore, account for and affirm the numerous formal and informal resources required for adaptive resilience processes and the attainment of healthy outcomes. They also provide a guide to incorporating the multiple perspectives necessary to understand the ways in which formal service systems, service providers, gatekeepers, and clients interact in ways that facilitate or hinder these processes.

Collectively, the value of research is enhanced through an iterative mixed methods approach in that the context of the research and its focus are accounted for through an initial exploratory qualitative phase that ensures the content of quantitative measures is of relevance to the context and participants of the research. In this way the reliability and validity of the research are enhanced. By exploring in more depth the emergent findings of the quantitative component, the mechanisms that facilitate successful processes or could possibly hinder positive outcomes can be understood in more detail. This understanding means that findings can be put to greater use within the research context, but will also be of greater relevance across a variety of medical settings and the social contexts in which they are embedded.

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Chapter 17
A Global Perspective on Resilience and Creativity

Bandy X. Lee and Grace Lee

Introduction

The question often comes up as to whether what is important in the progression of disease is the soil or the seed. The soil might be an individual's mind–body makeup, relationships, or the ecology that determines the conditions around a disease. Exposure to the seed of disease is unavoidable, whereas whether a person or a population will fall ill seems to depend on these "soft" conditions of personal characteristics, social and cultural orientations, and the policy structures we collectively choose to implement. In covering global perspectives on medical resilience, we will examine in this chapter: (a) the mind–body continuum that gives relevance to resilience and self-healing in the face of illness; (b) creativity as a characteristic particularly of children that can lead powerfully to a path toward resilience; (c) the opposite of creativity, or violence at both individual and societal levels, and how it can undermine human potential and exacerbate illness; (d) policy implications for creativity-based health promotion and human-centered good governance.

B.X. Lee, M.D., M.Div. (✉)
Law and Psychiatry Division, Yale University, New Haven, CT, USA

Center for the Study of Violence, Ames, IA, USA

World Health Organization, Geneva, Switzerland
e-mail: bandy.lee@yale.edu

G. Lee, Ed.D.
Education Studies Program, Yale University, New Haven, CT, USA

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The Mind–Body Continuum

Evidence for a mind–body continuum has always been present in clinical observations (Lee & Wexler, 1999), but now it is increasingly coming to light through scientific study (Justice, 2000; Pert, Dreher, & Ruff, 1998). Rather than biological reductionism, a model that allows for an integral interaction between mind and brain gives rise to the potential for psychological and physiological resilience and possibility. A picture of how much mental potential one can tap and then apply to the body, for example, has ramifications for the body's expression, wellness, and possibly recovery. Psychoneuroimmunology is a field that has revealed some specific mechanisms that show how various mental processes can directly affect the brain, the nervous system, and endocrine and immune systems. Research in this area suggests that resilience encompasses an individual's physiological ability to adapt to stress and adversity in the form of family or relationship problems, medical problems, or a lack of social and political power (Prilleltensky, Nelson, & Peirson, 2001). Similarly, neuroplasticity of the brain mirrors psychological resilience (Davidson & McEwan, 2012).

While currently only indirect evidence exists for immune measures correlating with disease onset or outcome, research increasingly shows that psychological resilience, as one generates it through flexibility and creativity, influences how the body's defense system functions (Jacobs et al., 2011). Future investigations may reveal the precise mechanisms by which the placebo effect, meditation, prayer, play, and loving support affect healing, but for now evidence for their association keeps mounting. Medical illness, be it an injury, chronic disease, or a malignancy, has many environmental contributors, such as toxins in our environment, the processing of foods, our emotional state, and social relations—in other words, the way we choose to organize and structure our lives—which we can no longer ignore when considering the prevention and treatment of disease.

The physiological consequence of feeling that one's life is no longer meaningful or manageable has the direct effect of the immune system giving up, and the body may then give into disease (Pert, 1997). More directly, of course, individuals who are depressed, or who no longer perceive reasons to live, are more likely to relinquish life through suicide, homicide, or reckless behavior that gives rise to "accidents" (Edwards, 1995).

Resilient individuals, however, are not necessarily free of negative thoughts or emotions but have developed, often by working through difficult experiences, flexibility, and coping strategies that allow them to "bounce back" from crises (Werner & Smith, 1992). Far from irrelevant in cases of medical illness, building psychological resilience through creative experimentation can help release positive emotions that influence physical well-being, a fighting spirit, and even peace with conditions one cannot change. Psychological resilience thus intertwines intimately with the body, possibly increasing its chances for improvement in symptoms, a longer life, or even a cure. Although the extent of this influence is impossible to know, given the complexity of the relationship and the confluence of contributing factors, its benefits are worth pursuing. In some cases, researchers have found that it achieves a greater effect than physical conditioning (Loehr, 1995). If grief, anger, love, and joy alter immune response, that illness or health depend largely turn, can affect the brain and states of emotion, making resilience difficult in those times, but the very act of overcoming disappointment and despair can also help build resilience (Hauser & Allen, 2007). In other words, resilience is a process rather than a trait, arising from adversity as much as play (Masten, 2001), which one can learn to develop throughout one's life span through trial, error, and choice (Rutter, 2008).

Creativity and Resilience

Creativity is the essence of human nature and the height of human impulse for life. When a child is injured, chronically ill, or disabled, entering into a creative space may seem particularly challenging, but it can also be the solution for building new sources of meaning and motivation. It can also engender resilience and greater possibility for recovery. Creativity is an act of being original, but also—essentially and necessarily—generating value (Runco & Jaeger, 2012). Far from being secondary to the treatment process, creativity can mobilize new ways of experimenting with forming connections, making sense, and finding value in the midst of the chaos that illness or disability brings. Even in medically "hopeless" situations, variations in quality of life become realizable, allowing for spiritual recovery where physical recovery is not possible. A common concern with respect to linking creative thinking with recovery is that the emphasis on mind–body interaction might imply heavy responsibility or the possibility of evoking guilt on the part of loved ones or, in serious illnesses, a seeming setup for failure. However, the answer is not to ignore the reality that one has a role in one's own health and healing; the awareness that one is at least partially in charge of one's destiny can ultimately strengthen resources for resilience, wholeness, and acceptance of having tried one's best in the face of adversity, even if it may not have been possible to eliminate the disease. The fact is that there are too many factors to be able to ascribe fault to any person or any one condition, and the ultimate outcome, like a lot of human affairs, will always remain a mystery. However, confronting this uncertainty is a part of the very process of building strength, resilience, and creative approaches in the face of the inevitable. Growth in spite of the disappointment—or rather because of it—is the very hallmark of the human spirit reaching new heights, and often occurs in conjunction with one of the greatest human challenges: facing grave illness or even death.

We can also foster creativity before a challenge happens. Creativity is an important piece in promoting resilience because it teaches new ways of thinking and generates new experiences that allow children and adults to recover, to accept, and to surmount trauma (Corley, 2010). The arts can be an avenue that combines both play and creative expression, but creativity comes in many forms and is not specific to any field. Some forms include: (1) creativity for self-transformation in informal learning; (2) creativity in the context of formal learning; (3) creativity for domain-relevant innovation and invention; and (4) creativity for breakthroughs (Kaufman & Beghetto, 2009). The last is responsible for major scientific and cultural breakthroughs, but one can employ the same principles to enhance any field or life situation. Programs that foster creativity can inform interventions that aim to increase resilience and future resistance (Metzl & Morrell, 2008). This applies to both the levels of the individual as well as of policy and group governance. Calling upon the highest faculties of humanity, generativity, and productivity can allow one to reach new levels of human potential. Recognizing this potential has given rise to several grass roots initiatives, for example, using creativity and innovation to advance the resilience of entire communities (Camponeschi, 2010). Although these barely touch upon the beginnings of possibility, they represent new directions through which communities are groping toward wholeness and healing. The tenet is that, if we thought creatively in the interpersonal, diplomatic, political, social, and cultural domains, we may be able not only to spare much human suffering but also to overcome it. Structural violence in the form of social injustices and inequities cause not only greater suffering but also disease and death (Lee, 2015a). Since stress is one of the mechanisms through which individuals and populations become more susceptible to diseases (Pearlin, 1999), it is possible that collective programs and policies can help prevent illnesses from occurring in the first place—showing the link between individual suffering (including physical illnesses), shared grievances, and global governance.

There is no better time for fostering creativity as in childhood, when children have the opportunity to develop it through imaginative play. The International Day for Disaster Reduction in 2011 placed its focus on children because: “while it is true that they are more vulnerable to risk, they also have amazing qualities that can make them more creative: an open mind, curiosity, and no inhibitions about asking questions” (Haigh, 2011). Creativity arises naturally through play in children out of curiosity and thirst for competence; responding to this abundant impulse also builds relationships and communicates caring. It makes one feel good; it opens the door to laughter, love, joy, and sharing. A safe, loving environment helps the child to become less afraid to take risks and to experiment, leading to new solutions, new goals, and a new sense of agency. Through imaginative play, children create experiences that they have not yet had in their normal life (e.g., “playing house”) and practice representing problems, generating ideas, and evaluating options (Tan, 2012). Medical anthropologist Cindy Clark shows in this volume that practices such as humor, storytelling, and counterfactual play can provide opportunities for children and families to remake meaning and to build resilience. This leads to emotionally charged experiences that build upon their personal and sociocultural resources, establish their identity, and make them more likely to be resilient and resourceful (Feldman, Csikszentmihalyi, & Gardner, 1994; Fredrickson, 1998). We can see an example of this in the treatment of post-traumatic stress disorder (PTSD). PTSD is notoriously unresponsive to medication or any other biological therapy, despite its highly physiologic symptoms, and is very difficult to treat. However, the hypervigilance, exaggerated startle, problems in concentration, and sleep disturbance, as well as all the flashbacks, nightmares, and intrusive thoughts, all disappear when the person is finally able to assign new meaning to the event. This takes creativity and imagination; if one can reintegrate the traumatic event into a worldview that holds meaning once again, or engenders new meaning, then even if one cannot change the tragic event, healing is possible. These characteristics highlight how the human mind works, and can become very useful at times of difficulty or distress, such as when confronting a medical illness. However, while children have the strength of flexibility and openness to learning, they lack the perspective—and the ability to coordinate perspectives—that may help to counterbalance the overwhelming stress of an illness. Therefore, nurturing creativity in children who are ill or facing adversity, in the presence of ample support and reassurance, becomes an especially urgent task. For more on the way creativity and play can help relieve the stress of hospitalization, see Humphreys and LeBlanc, in this volume.

Institutions like schools and hospitals can have a meaningful role in fostering creativity through educational role-play exercises that emphasize cooperation, assertiveness, and perspective taking (Mouchiroud & Bernoussi, 2008). Studies disagree as to how much training is necessary (Gerrard, Poteat, & Ironsmith, 1996; Hennessey & Zbikowsi, 1993), but programs that develop intrinsic motivation can only help. Igniting a path of creativity in childhood, in settings that systematically mold early experience, can help pave the way for a more peaceful, resourceful, and resilient society. The support of the larger culture is therefore critical. A study of a school-based creativity program in New York City public schools noted that the effect is greatly dependent on neighborhood factors, such as the encouragement of creativity on the part of families or neighborhoods (Aber, Jones, Brown, Chaudry, & Samples, 1998). In fact, it is conceivable that hope and encouragement that do not find reinforcement at home or parallels in everyday life can rather engender disappointment and resentment when one encounters a lack of choices or a devaluing of innovative ideas. The results, then, might even be counterproductive in some cases, giving rise to ridicule and social exclusion. Therefore, adults, elders, and influential figures in society have an important role to play. Simultaneous fostering of creativity in the individual and in the culture at large, where its acceptance occurs at a societal level, would be much more effective. Educational programs that include parents or target communities as a whole can aim at this cultural shift and are in greatest need in segments of society that could benefit most from the paradigm.

Countering Violence, or the Opposite of Creativity

While the relationship between violence and creativity remains obscure in popular culture, psychological dynamics point to a violent individual being less resourceful of ideas, projects, and productivity that generate value (Lee, 2015b). Creativity, on the other hand, mitigates the harmful effects of violence (Lee, 2014). Defining resilience as the harnessing of biological, psychosocial, structural, and cultural resources to sustain well-being (Panter-Brick & Leckman, 2013), broader-based interventions that render caregiving environments less violent and more enabling for children are preferable over programs that "save one child" at a time. Creativity can be an integral part of therapy for children, allowing them to interact with life problems to regain skills and resilience for the future (Davis & Pereira, 2014). Some view creative art making as a necessary therapeutic tool finding symbolic ways to distance oneself from the trauma (Chazan & Cohen, 2010). A case study of artists among Hungarian Holocaust survivors now living in Los Angeles describes how creativity not only enhanced their own personal well-being but increased the resilience of the community after trauma (Corley, 2010). Creativity is also useful in refugee communities to promote resilience after suffering emotional trauma (Alayarian, 2007). Interestingly, an online population that encountered adversity and distress had correlated increases in creativity (Forgeard, 2012); although this does not mean creativity requires adversity, it recalls the need to view traumatic life events as mysteries to explore rather than merely problems to identify and solve (Mollica, 2006), given the vast malleability of the human mind.

Violence prevention programs can also use creativity skills to "inoculate" against the disfiguring of one's life in the face of disruption (Gilligan & Lee, 2005), just as they have employed them to prevent other risky behavior like smoking and teenage pregnancy (Goutas, Girandola, & Minaray, 2002). Resilient youths have a variety of useful skills—such as self-efficacy, independence, creativity, and responsibility—and often have protective factors that minimize the impact of risk (Bell & Suggs, 1998; Hurtes, Allen, Stevens, & Lee, 2000). These factors may include caring adults, peer acceptance, peer support, and awareness of neighborhood resources (Garmenzy, Masten, & Tellegen, 1984). Studies of resilient children year after year have surfaced creative problem-solving as a determinant in their ability to cope with their situations and to heal psychological damage (Bogar & Hulse-Killacky, 2006; Coholic, Eys, & Lougheed, 2012). Adults, especially older adults, and the community at large have a significant role to play, as the ecological model of resilience would suggest (Harney, 2007; Ungar, 2011). By recreating ecologies that foster creativity and resilience, we can develop individual capacities and skills; resilience-enhancing ecologies are reproducible at smaller scale in youth programs such as summer camps (Allen, Cox, & Nelson, 2006). The White House Task Force for Disadvantaged Youth has identified day camps, through community centers and local parks and recreation departments, as an effective method to increase resilience, especially when the camp included "outcome-based activities" that went beyond traditional camps to build creativity explicitly (Allen et al., 2006). A similar effect on resilience can arise in organized youth sports (Bell & Suggs, 1998).

Primary prevention, or building resources before an illness occurs, is an important concept in human development. The transition period from childhood to adolescence can be difficult, and teaching interpersonal skills, problem-solving, and self-appraisal is of benefit to increasing resilience and reducing stress in all settings (De Villiers & van den Berg, 2012). For a detailed account of promoting resilience of children with chronic illness during the transition to adolescence, see Lennon et al. in this volume. Creativity also promotes positive, prosocial behavior. Specifically, in a study of 70 young children, social creativity, as developed through tasks such as role-playing, showed a connection to enhanced social competence and improved relationships (Mouchiroud & Bernoussi, 2008). Social relationships are among the most powerful factors capable of increasing resilience (DuMont, Widom, & Czaja, 2007) and the ability to cope with physical illness (Moos & Tsu, 1977). In a training program in New York City public schools, known as the Resolving Conflict Creatively Program, teaching skills such as active listening, assertiveness, perspective taking, and cooperation—all features of creativity—showed a positive effect, but also greatly depended on parental support and positive relationships (Aber et al., 1998; Aber, Brown, & Chaudry, 1996). Accordingly, success of these programs was lower in high-risk neighborhoods, suggesting that addressing individual aggression through creative means shows lesser effect in aggressive and hostile contexts (Mouchiroud & Bernoussi, 2008).

Primary prevention means that creativity promotion ideally happens at the level of entire cultures. Since the creative impulse is fundamental and critical in human beings, as the culmination of a natural life impetus, one should not see its fostering as a mere luxury or as superfluous to other, more essential needs. Depriving individuals of the full resources for thriving, in fact, constitutes structural violence (Galtung, 1969)—and may literally become a matter of life and death. The cultural–historical view dictates that each individual's creative imagination is a product of one's emotional, sociocultural, and historical experiences (Vygotsky, 2004). The levels by which cultures sanction or encourage creativity differ (Briley, Morris, & Simonson, 2000; Feldman et al., 1994). For example, many Chinese view compromises and submission to collective expectation, and hence less original expression, as being more desirable than do most Americans. Furthermore, personal autonomy and self-expression, which receive high estimation in the United States and Western Europe, can be a liability in the Middle East (Alqudah, 2013). The cultural community also defines what is creative in the first place (Amabile, 1983). A solution that one may consider to be creative in one culture, for instance, may not be in another: Asian cultures, for example, may recognize spiritual attainment as creative (Sternberg, 1999). An observation of Afghan women suffering through decades of war reveals that, like individual resilience, community resilience finds its source in awareness, intention, action, reflection, and maintenance, factors that work together to form a synergy that promotes flexibility and adaptation over time (Brodsky et al., 2011), as in the dynamic systems model (Masten & Narayan, 2012). For more on cross-cultural conceptions of resilience, see Yi et al. in this volume. Religion and spiritual programs may be an effective way of fostering resilience in cultures that do not expressly encourage creativity.

Good Governance for Health Promotion

How does one promote resilience through creativity at the cultural level? A society where "all cares for all" would give us the best chance of attaining our highest human potential, but it is a path that requires wisdom. Viewing learning as not just attainment of knowledge but of experiments in creativity might help in building good governance through the education of future leaders. While cognitive intelligence develops through intellectual education, emotional intelligence develops through immersion and experience, a kind of creative approach that the arts can foster (Dewey, 1934). The arts, far from being impractical and irrelevant in the running of daily affairs, can become a foundation for the capacity for social consciousness, a humanistic focus, ethical governance, and ultimately global justice. A program at Oklahoma City University, for example, has incorporated the arts into a variety of courses, including pre-1500 World History and National Security Law (Garrett, 2013). Ninety-seven percent of students responded that they would take another arts-integrated course, noting an increase in student engagement. An arts-integrated program fosters creativity by promoting emotional sensitivity and self-reflection (Autry & Walker, 2011). Serious professional schools are beginning to do the same: a survey of all US medical schools showed that over half of them involve literature, visual arts, performing arts, and/or music as teaching tools to promote: (a) enhancement of student well-being, (b) improvement of clinical skills, (c) promotion of humanism, and (d) active participation of students (Rodenhauser, Strickland, & Gambala, 2004). Humanities curricula with these integral approaches to creativity can foster in-depth considerations of the human condition and finding human solutions for it—in other words, creating social environments that promote resilience, wellness, and human thriving from the source.

Some of the most successful civilizations of human history have used this approach. Ancient China, apart from hereditary power, employed scholar officials to determine the affairs of the state, and chose these very officials for their creativity and humanism, through competitions in poetry, calligraphy, and painting. Many advanced African civilizations had political systems that had no structure other than circles of tribal members, by age group and gender, so that discussions could occur—in whatever creative form necessary—until a problem reached resolution. This maintained order over remarkably widespread areas without centralization or legal enforcement, before Western invasions destabilized the region. Ancient Greece centered around arts-oriented Athens had a much more flexible and therefore enduring culture than the mostly military-minded Sparta. In our day, agendas to promote creativity in children through education can meet with resistance due to the restructuring they require (Vong (Peggy), 2008): the dialectic between new explorations and settling in the status quo is a familiar theme in creativity and recovery itself.

Yet, creativity—originality that generates value—is in critical need at the global level. There are disadvantages to reducing all human affairs into a singular (currently an economic or technological) model as has been happening throughout the world. Rigid profit-driven models are especially destructive, and are currently a large generator of structural violence and injustice, not to mention conditions for violent conflict. These all contribute to adverse physical health and premature deaths, not to mention negative influences on child-rearing and creativity-generation, leading to generations of reduction in social harmony and health (Lynch, Smith, Kaplan, & House, 2000). As entrenched models exacerbate rather than meet the challenges that we face, our current systems require such specialized knowledge to maneuver—all technicalities and little wisdom—that it seems the greater this knowledge, the less room there is for a true understanding of human affairs, not to mention relevant solutions. A result of this is that rampant immorality and injustice are permitted to reign without regard to human and societal casualty—as many leaders in business and government cheat, defraud, and steal—the kind of governance that any scholar official or tribal member in a more flexible system would have long recognized as antithetical to its purpose. Instead, our system allows us to deny almost any problem, some of terrifying proportions: global climate change, destruction of the planet, erosion of democracy, plunder of the poor, and perpetual wars, to name just a few. These forms of structural violence have a direct bearing on short- and long-term health and the production of stress-related illnesses (Cohen, Janicki-Deverts, & Miller, 2007; Pedersen, 2002).

If Plato called for philosophers to become rulers who carry out governance with thoughtfulness, we might call upon practitioners of creativity for ethical bearing. While education empowers populations by alerting them to ways in which oppression can occur, the arts do so by centering the heart such that one will refuse to accept it (Scarry, 1999). In other words, what education achieves cognitively, art does emotionally—and with most problems facing us now originating in humans, we see that we are in great need of collective emotional healing. Given the effects of stress on health, we know that a reduction in social injustice will also mean less physical disease and fewer epidemics of disease. Creativity gives one the armamentarium to resist this injustice, and love of one another in the form of caring fosters a love of life that resists illness. In other words, the emotional bounty that gives rise to creativity and healing also unleashes in the individual an ability to improve the quality of life by not letting illness define it—while becoming one's own person through this love for life. The burden of loving one another should not all be on a deprived community, on struggling parents, or on the self alone but should be a critical part of good governance.

In developing a proper perspective for global love, or caritas, adopting creative practices is a crucial beginning. Cultivating better and clearer thinking, skills of self-management, compassion for others' suffering, and resources for helping comes from having the creative resources to overcome challenges. Sensitivity to the arts, for example, can aid in this cultivation through the experience of sublimity and beauty, which offer visions of a better world while in the midst of adversity. Resilience also results from experiencing the support of parents, peers, and mentors, as well as cultural beliefs and practices that encourage autonomy and agency. These elements are the fruit of good global governance that is the starting point of a serious attempt at restoring humanity, and the fostering of human generativity and creativity on a major scale. They are the foundation for a healthy soil that prevents many ailments from taking root, but allows for the natural gifts of communities, families, and children to spread. Amid changing conditions such as the experience of illness or disability, creativity is especially necessary to uncover new possibilities for organizing our lives in a more human-centered way, for we collectively have the resources, the capacity, the diversity of talents, and the human power to allow for universal flourishing, if we only desired it. Keeping with the purpose of creativity (again value, and not originality for its own sake) emphasizes the recognition of principles over rules, of substance over formulae, and of love over all other ends—which are the gifts of our human capacity. We might then work toward true prosperity rather than a simple absence of violence, true health rather than a mere absence of disease, and an ability to resiliently resist rather than to succumb in struggle. This would be the first step toward creatively restoring our society into a thriving, healthier, and more resilient culture that supports the flourishing of each individual.

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Chapter 18
Recommendations for Promoting Resilience of Children in Medical Contexts

Michel Ferrari

Defining Resilience

Resilience research has moved away from its focus on individual protective factors and is now commonly thought of as a system of interactive processes. Individuals draw on personal skills as well as contextual resources to achieve unexpectedly better outcomes in contexts of adversity (Bottrell, 2009; Felner, 2006; Greene & Livingston, 2001; Lerner, 2006; Masten, 2001; Rutter, 2006; Ungar, 2008; Wright & Masten, 2006). Thus, resilience can be time and domain specific, with children showing evidence of strengths only in particular aspects of their lives (Herrman et al., 2011). On the other hand, developmental cascades are sometimes seen in which resilience cultivated in one domain can generalize to other domains (Sapienza & Masten, 2011). Mattingly (this volume) reminds us that resilience refers, not only to some more or less probable future, but also to the possibilities within each present moment—a "triple present" that incorporates past and future (cf. Ricoeur, 1990). Because life is lived in the present, fostering resilience involves creating the conditions for hope in the present moment, no matter what the future prognosis may be—not through extraordinary actions, but through expressions of competence and resourcefulness in everyday life (Panter-Brick, 2014).

M. Ferrari (✉)
Department of Applied Psychology and Human Development,
University of Toronto, OISE, Toronto, ON, Canada
e-mail: michel.ferrari@utoronto.ca

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Empirical studies of resilience have consistently identified common dynamics that help support children and youth facing adversity. Some of these dynamics require the development of **personal capacities** and resources, but always as contextualized within **sociocultural relationships** and local practices. For example, Leibenberg (this volume) cites cognitive features such as personality (or temperament) that affect one's ability to form attachments and cope with adversity. But these cognitive skills promote resilience only insofar as they allow an individual to establish and draw upon relational resources such as **interpersonal relationships** (family, friends, the broader community), **community services** (health services, libraries, parks), and **institutional access** (hospitals, school systems) (Luthar, 2006; Masten, 1999; Ungar, 2008; Ungar, Liebenberg, Armstrong, Dudding, & Van de Vijver, 2013).

Aim (Best Possible Outcome)

Before we consider specific recommendations for assessment and resource development, it is perhaps best to describe the hoped-for outcome of such interventions—the target that is being aimed at. Here we find a remarkable consensus among the chapters, although sometimes with different emphases. Clearly, a main aim is to improve quality of life for children and their families who are grappling with illness by reducing their levels of distress and suffering. As Mattingly (this volume) says, we hope to foster or support personal aspirations for a good life, or at least the best life possible, under difficult and sometimes tragic circumstances of illness. Our authors are united in their insistence that it is always possible to support families towards resilience—even in situations that appear very grim. To do so, we must be open to an ever-changing picture of what the resilient child and the resilient family look like. For example, in describing the exigencies of palliative care, Goldstein (this volume) argues that resilience should be conceptualized as processes that foster "intactness" rather than "bouncing back," an intactness that allows people to live lives of value no matter what their circumstances.

Implications for Intervention

With this broad consensus understanding of resilience, contributors to this volume propose different ways to establish resilient systems. Considered together, they suggest we must begin by assessing **the strengths and needs** of an individual in their immediate context. We (researchers, clinicians, service providers) can then help to **develop personal capacities/skills** and **strengthen formal and informal relational resources**. But isolated individual or community level interventions are not enough: To build truly resilient systems, we must consider the larger structural forces that enhances or inhibit a family's ability to thrive, and to develop an analysis of resilient systems that is simultaneously wide-angle and the fine-grained reflected in the chapters of this volume, we need to work across academic disciplines and across the researcher/practitioner divide.

In an effort to coordinate the points made by our various contributors, we present some of their main recommendations, beginning with assessment and then proceeding first to the development of individual skills and resources, then to strengthening social relationships, and finally to improving formal and informal community resources—including technological resources. We conclude with a consideration of public policy recommendations as an expression of basic human rights.

Assessment

Assessment must go beyond identifying needs to identify strengths and aspirations. Several authors emphasize the importance of assessing family systems—not just in terms of their needs, but especially in terms of their existing strengths (Noyes, this volume) and their values and aspirations (Mattingly, this volume). Only when we understand what matters most to families can we better understand how to support them in developing additional personal skills and resources, as well as supporting social and community relationships that can provide additional relational resources.

Lennon et al. (this volume) note that clinic screenings identify families that might benefit from interventions to help decrease family conflict and increase family cohesion and expressiveness. Salamon et al. (this volume) add that this typically includes screening at diagnosis and ongoing assessment to identify general psychosocial factors (e.g., coping and adjustment, emotional and financial resources) that can influence the patient and family at time of diagnosis and throughout the course of treatment (Noll et al., 2013). For example, interviews (perhaps by a Child Life Specialist or other hospital staff) or screening questionnaires like the Adolescent Resilience Questionnaire (ARQ; Gartland, Bond, Olsson, Buzwell, & Sawyer, 2011) or the Haase Adolescent Resilience in Illness Scale (HARS; Haase, 2004) can assess both strengths and barriers to resilience (e.g., health beliefs, expectations, skills and knowledge, marginalization). Barakat mentions The Psychosocial Assessment Tool (PAT) (Pai et al., 2008) and The Medical Traumatic Stress Toolkit as useful for screening challenge areas and for preventing medical trauma by assessing sociodemographic, child behavior, and family risks and resources. Ernst and Mellon (this volume) mentions the Acceptance and Fusion Questionnaire for Youth (AFQ-Y; Greco, Lambert, & Baer, 2008).

More generally, Salamon et al. (this volume) mention the Pediatric Psychosocial Preventative Health Model (PPPHM), developed to help assure that all families receive a basic assessment of psychosocial needs, allowing higher and more intensive levels of care for families identified as at greatest risk for psychological and emotional distress or lower functioning. According to Salamon et al. (this volume) about 25 % of families of newly diagnosed children require more intensive psychosocial interventions at diagnosis and/or during treatment (Schwartz, Kazak, & Mougianis, 2009). And Yi (this volume) reminds us, it is critical that such assessment be culturally sensitive, since different cultural values affect patient and family behavior and participation (Guidry, Torrence, & Herbelin, 2005).

Support Personal Skill-Building and Meaning-Making

Enhance Coping Skills

One of the most important avenue for personal resilience identified by several of our contributors is the ability to cope effectively with the complex reality of childhood illness. Experiences acquired though successful coping become integral to personal identity and can be a key part of building the conditions that support resilience (Garland et al., 2010; Velichkovsky, 2009). All agree that families and individuals need to be supported in their ability to cope with illness. Although many ways of grouping personal coping strategies exist (see reviews by Aldridge & Roesch, 2007; Skinner & Zimmer-Gembeck, 2007; also Compas et al., 2014), they can be generally classified as: (1) ***primary control coping*** intended to directly change the source of stress (e.g., problem-solving) or one's emotional reaction to it (e.g., emotional expression); (2) ***secondary control coping*** that involves adapting to an unchangeable stressor (e.g., acceptance, regoaling, imaginal coping), or (3) ***disengagement coping*** that orients away from the source of stress or one's reaction to it (e.g., avoidance, wishful thinking).

Maximizing one's fit to the current situation (i.e., "secondary control") has been most consistently associated with positive outcomes across illness groups (Compas, Jaser, Dunn, & Rodriguez, 2012; Connor-Smith, Compas, Wadsworth, Thomsen, and Saltzman, 2000). For example, secondary control coping was associated with fewer anxiety symptoms in youth with functional abdominal pain (Hocking et al., 2011) and fewer anxiety and depressive symptoms in youth with cancer (Compas et al., 2014).

Secondary control coping requires psychological flexibility; that is, the ability to mindfully change or persist in patterns of thought and action in order to meet the needs of a present moment. Several chapters in this volume argue that psychological flexibility is central to resilience and suggest that therapeutic play can help promote this kind of flexibility. Play promotes ego resiliency and creativity in the way one interprets one's own experiences, as seen in Lee (this volume). Cognitive flexibility allows for regoaling, greater self-esteem and self-compassion, perhaps even post-traumatic growth. As detailed by Humphreys and LeBlanc (this volume) therapeutic play involves specialized play activities that help support emotional well-being through, for example, drawing, journaling, photography, dance, dramatic plays, puppetry, and games. Formal therapeutic uses of play (in play therapy or other clinical interventions) seems closely related to what Clark (this volume) calls "imaginal coping"; that is, everyday spontaneous imaginative reframing of the present moment by children and families. Imaginal coping resembles the therapeutic practices of play therapists, child life specialists, social workers, or others who employ as-if scenarios therapeutically. According to Clark (this volume), whether formal or informally generated, play creates another reality in which themes from the child's everyday life can be safely dramatized. Ironically, this withdrawal from everyday reality can support children's ability to address their fear, anger, vulnerability, and loss. Older children are also very capable of articulating their concerns, perceptions, fears, worries, and needs through therapeutic dialogue, when conducted in child-friendly language. Clark (this volume) notes that therapeutic humor, in particular, provides a momentary escape from one's problems by transporting people to another plane of meaning that exists in "bisociation" with them, reframing the very issue in a way that promotes cathartic release.

Spiritual and cultural practices, especially when supported by the medical team, can also help with coping, perhaps by allowing secondary control. Culturally embedded prayer, meditation, and healing rituals can provide comfort and strength to children experiencing significant health-related stress (Rolland & Walsh, 2006), and adolescents' use of positive spiritual coping techniques can protect against developing depression (Reynolds, Mrug, Hensler, Guion, & Madan-Swain, 2014). Beyond religious and cultural healing practices, but without their deeply spiritual meaning, Cheryl Mattingly (2010, 2014) has called Disney and similar popular culture a "lingua franca" understood by both adults and children in a discourse that spans age, class, and ethnic lines—one useful for parents trying to scaffold their children's ability to cope with illness.

Parental scaffolding of children's resilience. Parents foster resilience when they encourage optimism, flexibility, and problem-solving (Walsh, 2003). Hoehn et al. (this volume) notes that parents can help to create the conditions for resilience by scaffolding children on new tasks in ways that provide minimal structure so that children learn to solve problems independently (Wood, Bruner, & Ross, 1976) what, following Vygotsky, we might call "their zone of proximal resilience." Preparing children in advance for a difficult medical procedure in a developmentally appropriate way can reduce their fears of the unknown, make difficult or painful aspects of the procedure more predictable (Dahlquist, 1999, Hoehn et al. this volume). On the other hand, when parents prompt their children to engage in distracting activities, these children typically protest and cry less during medical procedures and recover more quickly afterwards (Blount et al., 2009; Dahlquist, Pendley, Landthrip, Jones, & Steuber, 2002). However, when parents are very anxious or catastrophize reactions to medical procedure, their children tend to show greater distress (Caes et al., 2014). Parental anxiety also predicts the success or failure of parental efforts to distract children during medical procedures (Dahlquist & Pendley, 2005); by contrast, praising children's efforts at cooperation and coping, and limiting their ability to delay or escape procedures also helps children cooperate with and complete medical procedures (Slifer, 2014).

Engage culturally specific understandings of illness. Coping strategies essential to personal resilience reflect culturally specific understandings of illness and how to respond to it—including through spiritual and cultural practices. As Yi et al. (this volume) notes, the same coping strategy can be either adaptive or maladaptive in different sociocultural contexts. While European American and Latina American mothers of children recently diagnosed with cancer had similar coping strategies in some regards (e.g., gathering information, seeking professional help, problem solving, positive thinking, present-orienting, reframing, avoiding, and religious practice), they also differed in culturally distinct ways: European American mothers compromised with the medical team when negotiating their child's treatment plan, whereas Latina American mothers normalized the situation and kept perspective (Johns et al., 2009). Other studies found that Iranian and Chinese families used information-seeking strategies to restore a sense of control over the situation (Aguilar-Vafaie, 2008; Wills, 1999), while South African families considered additional information about the illness to be an unhelpful additional source of stress (Jithoo, 2010). Nevertheless, these all seem to be culturally specific ways of exerting secondary control since engaging with culturally specific practices allows families to successfully cope with unchanging stressors.

Support should be age-appropriate. Children of different ages need different kinds of support. Studies emphasize that effective healthcare communication must be age-appropriate (Forsner, Jansson, & Sorlie, 2005a, 2005b; Gultekin & Baran, 2007), especially when addressing children's fear of medical procedures and hospitalization (Rokach & Matalon, 2007). Children are naturally information-seeking (rather than information-avoiding) and so it is important that clinicians convey health knowledge to the child directly rather than focusing solely on the parents. Medical professionals should be familiar with mediators (e.g., child characteristics) and moderators (e.g., different forms of stress, coping and adjustment) associated with children's effective coping with painful medical procedures critical to improving resilience outcomes for children (Rudolph, Dennig, & Weisz, 1995).

Young children more naturally cope through imaginative play, while adolescents are capable of more autonomous action and reasoning. Indeed, as Lennon et al. demonstrate in their chapter, developing behavioral and emotional autonomy is a major life task for adolescents that is sometimes challenged by chronic illness. In pediatric type 1 diabetes care, sharing the responsibility for treatment yields better outcome for adherence, glycemic control, and mental state (Helgeson, Reynolds, Siminerio, Escobar, & Becker, 2008). However, according to Lennon et al. (this volume) and Hoehn et al. (this volume), parents need to be careful to not to over scaffold children, allowing adolescents to increasingly take charge of their own medical care. The best outcomes occur when parents increasingly transfer responsibility of care to adolescents once they have developed the skills to manage their illness and to successfully care for themselves.

Support Social Relationships

Beyond improving individual coping of parents or children, it is important to promote healthy family dynamics and social relationships. Masten (2011) is certainly right to say that fostering resilience in children is best accomplished by targeting the systems within which they live, especially in situations that critically challenge those systems, such as pediatric chronic illness (Pai et al., 2007). Ultimately, for Lennon et al. (this volume), the aim is to develop interventions that promote resilience and positive child and family outcomes by developing positive coping skills, enhancing family functioning, and providing better access to resources.

Support successful socialization. Many youth with chronic health conditions feel socially awkward. Their unique experiences and medical needs leave them at an increased risk for both internalizing and externalizing disorders (Lavigne & Faier-Routman, 1992). However, youth with greater social support experience and less peer conflict and can better manage health-related self-care tasks (Helgeson, Lopez, & Kamarck, 2009; La Greca, Bearman, & Moore, 2002). For this reason, including peers in interventions designed to increase medical adherence and adjustment to chronic illness has proven beneficial. Because children and adolescents benefit from interacting with others who shared their health conditions (e.g., HIV; Funck-Brentano et al., 2005; Olsson, Boyce, Toumbourou, & Sawyer, 2005), social media platforms and online support groups can also help foster peer support for those living with chronic health conditions (Letourneau et al., 2012; Quittner et al., 2012).

Improve support for families. Families can impact illness as much as illness can affect the family (Sholevar & Perkel, 1990). One of the most important ways to support families is to help improve communication. Turner Cobb and Cheetham (this volume) provides several recommendations for improving communication between children, their families, and health professionals. Ernst and Mellon (this volume) mentions the example of "mindful parenting" which promotes psychological flexibility in parenting interactions. Maintaining a present moment focus (i.e., listening with full attention), nonjudgmental acceptance of self and child, and parenting in accordance with goals and values (Duncan, Coatsworth, & Greenberg, 2009), has been shown to improve children's behavior management (Coatsworth, Duncan, Greenberg, & Nix, 2010). This and other interventions that enhance family adjustment may help establish the conditions for resilience.

Both Salamon et al. (this volume) and Lennon et al. (this volume) note that it is important to target parent mental health, parenting behaviors, and/or sibling adjustment. For example, the Australian Child Illness and Resilience Program (CHiRP)—a stepped-care mental health promotion intervention designed to support families with a chronically ill child—provides families with practical resilience building strategies and psychoeducational literature along with family-based cognitive-behavioral exercises and parent support groups (Harnall, Heard, Inder, McGill, & Kay-Lambkin, 2014).

Salamon et al. (this volume) mentions that The Surviving Cancer Competently Intervention Program (SCCIP) combines cognitive behavioral and family therapy to reduce ongoing traumatic stress symptoms in cancer survivors and their families. A randomized controlled trial of 150 families found that family members in the SCCIP had fewer traumatic stress symptoms (Kazak et al., 2004). The SCCIP program has now been adapted for newly diagnosed parents (Kazak et al., 2005); however, recruiting and adhering to protocol was difficult at the time of cancer diagnosis (Hocking et al., 2014; Stehl et al., 2009). Programs such as this may be particularly valuable in cultures like Korea, where cancer is a taboo with negative public perception, and children often learn about their cancer diagnosis indirectly or incorrectly. Without finding a culturally appropriate means of communicating with children about their disease, opportunities for modeling resilience and gaining other forms of social support might be missed, leaving children worrying alone or searching online to learn about their illness (Yi, Kim, & Hoidal, 2011; Yi et al. this volume).

Create Mentorship Opportunities. Beyond the family, it is also important to find mentors who can share their experiences and provide examples of successful life outcomes. Pediatric cancer survivors had a deeply felt need to connect with other survivors through mentor-mentee relationships—in particular, with cancer survivors who later had successful careers and other areas of life; such "veteran survivors" can become role models who provide hope for stressed parents and children (Kim & Yi, 2012; Parry & Chesler, 2005).

Improve Effectiveness of Community Resources

Improve coordination among many services dealing with particular cases. The family of a child with a chronic illness will interact with many different kinds of health care providers. The conditions for resilience are realized when medical practitioners collaborate in providing care. Ungar (this volume) notes that because resilience is a multisystemic process, a medical intervention that enhances resilience may not be centered on what a child's medical team does but rather on what multiple formal and informal systems do to help a child. In other words, the locus of resilience may reside in the level of coordination between service providers, families, and community supports. This approach to resilience shares similarities with public health initiatives like battered child syndrome, that recast the problem of children who appeared with signs of physical trauma as both a medical problem and a social issue requiring social services to address (Kempe, Silverman, Steele, Droegemueller, & Silver, 1962).

Based on his own research and clinical practice as a social worker, Ungar (this volume) suggests that we are only as resilient as the systems that surround us, and stresses the need to consider how medical systems interact with families' informal supports and social policies, and the role these systems play in fostering individual development under conditions of adversity. Unfortunately, few studies have examined resilience systemically, but the research that does exist—Ungar's example of Romanian orphans adopted by families in the United Kingdom (Beckett et al., 2006)—shows a cumulative, even cascading effect. Certainly, living within a healthy family and consulting a child psychiatrist, makes other things available, like better education and peers support.

Improve navigation and negotiation within and between systems. Thinking systemically, Ungar points to resilience as being bound up with individuals' capacity to *navigate* to the resources they need to do well, and the capacity of systems to *negotiate* with individuals over how resources will be provided to best meet people's needs. It is this dialectic between navigation and negotiation that best explains how resilience will result from the dynamic interactions between individuals, services, supports, and social policies (Ungar, 2008; Ungar, Ghazinour, & Richter, 2013)—for Mattingly (this volume), such navigation and negotiation are always in the service of achieving the best lives people hope for.

Make hospitals more democratic healing environments that value nonmedical aspects of care. Healing environments like gardens have been used to promote better health for hundreds, if not thousands, of years. (Van de Riet, Jitsacorn, Junlapeeya, Dedkhard, & Thursby, 2014, trace some of this history.) However, unlike gardens, hospitals are sanitized spaces in which biomedical discourse drives diagnostic procedures and medical responses: in the clinical hierarchy, the more biomedical training a person has undergone, the higher their authority—something even critically ill children understand, as shown in Bluebond-Langner's (1978) study of a hospital leukemia treatment center. In this regard, child life specialists lack the power of hospital administrators or physicians (Cole, Diener, & Wright, 2001; Mitre & Gomes, 2007), which limits how broad their support of children can be. As Clark (this volume) notes, framing playtime as distinct from clinical routines and zoning it away from biomedical personnel undermines the chance to relieve children's stress during treatment itself. Indeed, patients in hospitals often feel marginalized rather than central to the power structure of the hospital, with significant implications for their resilience-seeking strategies.

Improve Communication Between Medical Team and Family

Studies suggests that health professionals who have a good working knowledge of the theory underlying a family-centered approach are better able to meet the needs of children and their families (Sholevar & Perkel, 1990). Knowledge of family history, health behavior—including parental communication styles for health messages—and available social support are essential to health professionals' ability to foster resilience (Bacigalupe & Polcha, 2013).

Lennon et al. (this volume) notes that medical practitioners can help parents understand how a child's chronic illness may impact their child's development, and should use their influence to promote coping and resilience through therapeutic collaboration designed to build upon families' existing strengths and abilities (Luther, 1991; Masten et al., 1990; Shapiro, 2002). Unfortunately, many contributors to the volume point out that miscommunication between families and the health care system is not uncommon and it is important to work with both providers and families on communication to encourage optimal outcomes (Seid, Opipari-Arrigan, & Sobo, 2009).

Successful work happens when service providers find ways to support families' strengths (Gilligan, 2004). Families are not "blank slates" or the passive recipients of expert wisdom (Sanders & Munford, 2010); they know what has and has not worked for them within their own unique histories. Service providers who engage families as partners are able to unpack a family's cultural, religious, and spiritual beliefs in order to locate local supports that will help them manage illness. In particular, Munford (this volume) proposes that practitioners develop a deeper understanding of the nature of the care relationship within families. Rather than thinking of care giving as an extraordinary burden on families, supporting family members is frequently constituted as a "labor and love" and of "activity and identity" for primary caregivers. Munford suggests that care giving becomes embedded in everyday activities and ordinary relationships (Collings, 2009).

For Munford (this volume), a strengths perspectives encourages medical practitioners to understand the diversity of family life and invites service providers to see out families' strengths and capacities. This is achieved by enhancing their ability to navigate or negotiate the medical system (Ungar, this volume) in light of their values (Ernst and Mellon, this volume) and hoped for best life (Mattingly, this volume). Families have their own expertise and a deep understanding of the needs of their child, and the challenge for practitioners is to recognize and to harness this in interventions. Effective services respond in timely and appropriate ways to provide resources that enhance family life and well-being—not by making decisions for families, but by working with them as equal team members and tailoring support to what matters most to this particular family. Key to this approach is recognizing that alliances with families should be culturally responsive and respectful of differing meaning systems; no matter how complex issues are, it is families who will be ultimately responsible for deciding and implementing them.

However, Munford (this volume) and Ungar (this volume) report that many families find it a major challenge to form relationships with medical practitioners based on respect and authenticity. Families report that, although service providers have disciplinary expertise, they often lack the resources to coordinate teams and to effectively communicate with families (Munford & Sanders, 2005), echoing Ungar's point about the need for better service coordination. Unfortunately, families often experience added pressures due to changes to service delivery, or from needing to be flexible and adapt to changes in service delivery: Sometimes these changes enhance support networks, but often they simply require families to continually justify access to services as service policy changes.

Develop new educational technologies. Researchers in pediatric resilience are developing new approaches to providing educational content and social support using innovative technologies. For example, Parsons et al. (2013) describe an effective psychoeducational interactive website for parents of children receiving a hematopoietic transplant. Video conferencing with school has also helped inpatients remain connected and maintain normalcy, improving mood and relationships (Ellis et al., 2013) and making a therapeutic music video enhanced the resilience of adolescents and young adults in treatment for cancer (Docherty et al., 2013).

Another intervention targeting anxiety and fear (Shockey et al., 2013) used biofeedback and perceived control to increase solution-focused coping. Virtual reality, which allows youth to engage in a virtual reality scene engaging multiple sensory modalities, has also been used as a distraction technique to reduce pain and overall distress during procedures (Nilsson, Finnstrom, Kokinsky, & Enskar, 2009).

Electronic interfaces also seems to improve engagement in cognitive behavioral pain management (McClellan et al., 2009). Likewise, the Cellie Cancer Coping Kit helped promote adaptive coping through the use of coping interventions, like coping cards for patients and a parent guidebook (Marsac et al., 2012). Hazzard, Celano, Collins, and Markov (2002) reported on a trial of STARBRIGHT World system to help hospitalized children interact with each other; children with SCD who engaged in the STARBRIGHT World system reported an increase in perceived social support compared to a control group who experienced traditional, face-to-face, verbal education.

Improve social participation in community activities. Community factors also contribute to resilience in children: Participating in sports and other organized activities supports the emotional, social, and physical well-being of children with chronic health conditions in a variety of ways (Murphy & Carbone, 2008). Further, Munford (this volume) notes that access to specialty medical care also has clear implications for resilience in pediatric populations (Newacheck, Hung, & Wright, 2002).

Improve policy. In her chapter, Noyes (this volume) notes that many of the policy imperatives that aim to promote resilience in children and families overlap substantially with existing policies to promote good parenting practices and strong families and communities. She draws on Newman and Blackburn (2002) who described three groups of children who can show resilience and from whom lessons could be learned in developing policy: (1) children who succeeded, or did not succumb to adversities, in spite of their high risk status (e.g., low birth weight babies); (2) children who exhibited maturity and coping strategies in situations of chronic stress (e.g., children of alcoholic parents); and (3) children who suffered extreme trauma (e.g., through natural disasters or abuse) and who had recovered and prospered. Her detailed description of public policy initiatives undertaken by the Scottish government shows that resilience can be articulated within a policy context and that shaping the climate of intervention and service coordination at the policy level is an important aspect of creating conditions that support resilience.

Assess effectiveness of policy implementation. Despite the positive steps taken in this direction Noyes (this volume) notes that it is difficult to definitely demonstrate public health policies actually achieve their anticipated outcomes. The few policies that exist with the stated aim of promoting resilience do not all have the same tools or funds to fully implement the concept of building resilient systems into health and social care services and practice. For example, empirical measures of resilience are rarely used outside of research contexts, so Governments typically rely on sources such as UNICEF reports of child well-being to gauge the success of policies designed to build resilience in children and families coping with adversity. Of course, these results are always conflated with prevailing economic conditions and other factors likely to affect children's resilience over time, making it extremely difficult to determine what policy context works to improve and sustain resilience in children and their families. There is a clear need here to develop measurement tools that can be used to gauge the effectiveness of public policies that promote resilience.

Beyond Health Care to Civil Rights

In the end this is not just a matter of good health care, but of fundamental civil rights, especially for those living with disabilities or chronic conditions that impact their ability to fully participate in civil society. As Munford (this volume) notes, providing effective support to families and children enhances resilience and contributes to their full participation in all aspects of community life—this is thus a community concern that ultimately becomes an issue of **rights and citizenship**. In fact, she notes that current perspectives on the experiences of disabled people have shifted from seeing their condition as an inevitable consequence of their impairment to a consequence of living with that impairment in a disabling society.

Conclusion

The aim of this concluding chapter was to distil some clear recommendations from the chapters in this volume considered as a whole. While many more subtleties exist in the chapters than can be summarized here, a few recommendations stand out:

1. *Assessment must go beyond identifying needs to identify strengths and aspirations*. It is critical to gauge the level and type of support needed and to be culturally sensitive.
2. *Support personal skill-building and meaning making*. In particular, resilience requires families and individuals be able to cope with illness through secondary control of their reaction to the medical situation. Spiritual and cultural practices, especially when supported by the medical team, can often enhance resilience, perhaps by allowing secondary control. Play is an important therapeutic tool that promotes psychological flexibility and, thus, a patient's ability to adapt and creatively re-frame adverse circumstances. Coping strategies should be age-appropriate and engage culturally specific understandings of illness in order to best support resilience.
3. *Support social relationships*. In particular, to improve communication within families. Beyond the family, it is also important to support successful socialization and to find mentors who share childhood illness experiences and may be able to provide examples of successful life outcomes.
4. *Improve effectiveness of community resources*. Hospitals should be made more democratic healing environments that value nonmedical aspects of care. In particular, to improve coordination among many services dealing with particular cases and to improve navigation and negotiation with system, this requires improved communication between medical team and family. Ungar (this volume) provides a nice summary of the features of medical programs that have helped young people cope better and become more resilient. He suggests that these programs share at least five practice principles:

   (a) Make services multisystemic and complex, paying attention to as many different needs of patients as possible.
   (b) Make services coordinated, both within services as well as across medical and social service agencies.
   (c) Ensure services are continuous, with as little disruption to a patient's connection to a service provider, team of providers, or social supports.
   (d) Negotiate with patients to design interventions that meet their needs in ways that are meaningful.
   (e) Make services culturally responsive by helping medical practitioners develop cultural competence.

5. It is also important to *continue developing educational resources* that will help patients and families understand their illness and how to access and navigate the health care options available to them. This may increasingly take the form of innovative technology that harnesses the power of social media to bring children together in virtual communities.
6. Finally, it is important to *improve social participation of children and families in community activities*. This may require improve policy to allow greater support to them and, assure access to that support. It is equally important to assess effectiveness of policy implementation. Ultimately, these issues point beyond health care to fundamental civil rights.

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