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THE PALGRAVE HANDBOOK OF ETHICS IN CRITICAL RESEARCH

Edited by
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Phindezwa Mnyaka, Gareth J. Treharne

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Not My Science

Watch me as I decolonise
Undress
Seek redress
I am going to regress
Be irrational
Be subjective

Look at me
You will see
That I cannot be known
Through method
I am not based in evidence
I am not quantifiable
Theory does not drive me
I am not a man
I am dark
Not white

I will not be replicated.
You will not clone me.
I am not parsimonious
I am not generalisable therefore…
I am not valid
I am a foreigner in my own territory

Yet, I have value,
My unique vantage point.
I will not let White, Male, Science
Cloud my lens
Block my view
So difficult to do
When most white men
Are taller than you

Thirusha Naidu

This poem was composed on 20 September 2017 at the First Pan African Psychology Union Congress during a roundtable discussion on the Science of Psychology in Africa and the Global South.

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Georgina Cundill is a Senior Program Officer at the International Development Research Centre in Canada, and a Research Associate at Rhodes University in South Africa. She has 14 years of experience working with transdisciplinary research processes in the context of environmental governance. She has worked in Chile, Peru, and South Africa, and oversees large-scale transdisciplinary research networks working on climate change adaptation across the African continent and South-East Asia. She has published more than 45 academic publications on related topics.

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Jean Hay-Smith trained and practised as a physiotherapist; she transitioned from clinical practice to full-time academia after PhD completion. She uses systematic review methods to summarise evidence and is interested in the applications and challenges of this methodology in quantitative and qualitative research synthesis. She also undertakes qualitative research and supervises clinicians from a range of registered health professions engaged in research with patient-participants. Jean is, at heart, a pragmatist, and the original typology development featured in her chapter was undertaken to address a practical need—as a supervisor—to prepare and support postgraduate clinician-researchers well.

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Ethics in Critical Research: Stories from the Field

Catriona Ida Macleod, Jacqueline Marx,
Phindezwa Mnyaka, and Gareth J. Treharne

This handbook is about researchers' encounters with ethical dilemmas in the conduct of social and health research in which a critical approach is being applied. Each chapter in the handbook is a story from the field in which authors, writing from different countries, in a range of disciplines, and using varying methodologies, narrate the ethical dilemmas that confronted them as well as the ways in which they navigated these dilemmas. Authors highlight a range of issues, including: struggles that require critical researchers, at times, to traverse traditional ethical imperatives; ethics conventions that unravel in the face of power relations encountered in the field; the blurring of boundaries between researchers and participants, and between the different roles researchers inhabit; how critical research that is declared ethical on paper can be judged by standards of social justice as unethical; how cross-national standards of research ethics may fall apart in local interpretations and adaptations; and the ways in which institutional power relations can hinder ethical practice.

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There are four sections to the handbook, each focussing on particular ethical quandaries encountered by critical researchers. In the first section, entitled *Encountering Systems*, chapter authors explore the challenges posed by the systems with which social and health researchers engage during the course of conducting research. The ethics committees[1] set up to preview ethics protocols have become one of the most foundational systems that critical researchers have to navigate. Given the biomedical history of ethics review processes, critical researchers may face many challenges in seeking approval from ethics committees. In addition, authors in this section reflect on the institutions and wider social systems within which social and health research is often conducted, and which regulate and shape what is possible in critical research. The second section of the handbook is entitled *Blurring Boundaries*. Authors of chapters in this section tackle the question of when and how it becomes ethical to blur the boundaries imposed by conventional models of ethical research, in particular the relationships between researchers and participants. Some critical methodologies encourage this blurring, and this can result in challenges for the researcher while carrying out research and when 'exiting' the field. Chapters in the third section, *The Politics of Voice, Anonymity and Confidentiality*, speak to situations in which the requirements of anonymity and confidentiality may not be appropriate ethically or possible for individual participants or institutions, especially when participants want to be recognised for their contribution to the research. Authors outline a range of circumstances and considerations demonstrating how different responses are needed in order to work through alternatives to anonymity and confidentiality. The final section is entitled *Researching 'Down', 'Up', and 'Alongside'* to capture the various structural positions participants can have in relation to the researcher(s). The authors address ethical complexities when conducting critical research that questions the framing of participants as being subject to research. Critical research continues to develop ethical ways of researching with the marginalised or with the elite, and deeply engaging with co-researchers who can research alongside academics.

The dilemmas raised in each section of the handbook are summarised in the introductory chapters to the section. In the rest of this overarching introductory chapter we outline what we mean by critical research and why the consideration of ethics in conducting critical research needs to be nuanced and complex. We discuss the potential of speaking simultaneously to overarching ethics principles whilst grounding ethics in local realities. Finally, we highlight why drawing on stories from the field in a range of geographical, social, and discursive spaces is useful in bringing key ethical issues to the surface. We argue that the challenges posed by authors featured in this handbook provide fertile ground for thinking through cross-national ethics principles in critical research, including the need for relational and situated ethics approaches.

Critical Approaches to Research

What it means to be a ‘critical’ researcher continues to be debated. Don Foster (2008), a South African psychologist, characterised critical psychology as ‘a rather loose, undisciplined and rag-tag headboard for quite a number of diverse streams of theorising and practices’ (p. 92), and the same may be said about ‘critical’ research in the range of disciplines, departments, and other categorisations of fields of research evident in this handbook. While a researcher’s field (anthropology, psychology, sociology, etc.), career position in the hierarchies of academia, and subject positioning within ‘real-world’ systems may play a role in taking up critical research, the researcher’s epistemological and methodological positions are key. Indeed, critical researchers from very different fields may have more in common with each other intellectually than with their respective colleagues in the same field. This is because a number of theories that enable critical research (e.g., Marxism, feminism, postcolonialism, poststructuralism, critical realism) have been taken up in a range of disciplines.

But what exactly are we talking about when we say ‘critical research’? Perhaps the first clue is that critical researchers are rehearsed in defending their knowledge claims against ‘mainstream’ hegemony, which is often cast in the shadow of biomedical and/or positivist research, as indicated throughout the stories in this handbook. As argued by Painter, Kiguwa, and Böhmke (2013), however, creating neat categories of ‘critical’ or ‘mainstream’ research along the lines of ‘us’ and ‘them’ may be neither possible nor useful. That said, one of the hallmarks of critical research *is* to be critical of the mainstream and to find better ways of doing ethical, meaningful research which contributes to social justice. In this handbook we address the long-standing marginalisation of critical research in many fields by giving prominence to rich examples of a diversity of critical approaches and their relation to research ethics.

Critical research also draws attention to mainstream assumptions about specific fields that become naturalised and shored up as the default. For example, in relation to health psychology, Murray (2014) noted that ‘there is a tendency to ignore the very historicity of the field’ (p. 7), which has been grounded in natural science and biomedicine. If mainstream approaches to particular fields are founded on taken-for-granted epistemologies, then how do these foundations shape what is considered ethical in research? And how does critical research develop a critical awareness of research methods with origins in fields antithetical to the critical endeavour? The central way in which this handbook addresses the latter question is through stories from the numerous fields of critical research.

Critical approaches to research are also characterised by reflexivity and self-criticality in relation to the purpose, methods, and ethics of the research. Reflexivity has been conceptualised as the ongoing application of critical reflection in research praxis (Finlay, 2002). It 'involves taking an explicit look at the broader consequences of practices within a discipline' (Lyons & Chamberlain, 2006, p. 26). More precisely, the consequences and enmeshment of power relations between researchers and participants, researchers, and ethics committees, as well as the range of social and historical systems, are acknowledged and unpacked.

This kind of deep reflexivity is neatly demonstrated in the poem featured at the beginning of this handbook by Thirusha Naidu, also the author of one of our chapters. These verses were penned during a round-table discussion on the Science of Psychology in Africa and the global South hosted at the first Pan-African Psychology Union congress that took place in Durban, South Africa, in September 2017. In the poem, Naidu voices her frustration with assumptions about what counts as science; how research inscriptions capture, define, and reduce the 'other'; and the blindness of certain methodologies, based in White masculinist science, to particular experiences and ways of being. Using metaphors of irrationality, foreignness, regression, the subjective, and undress, she highlights the colonialist, raced, and gendered nature of much research. She demands a space to do research differently, refusing to let particular understandings of research 'cloud my lens'. Simultaneously, she demands that researchers see her, as a potential research participant, on her own terms. Poignantly, she concludes that neither of these is easy: 'When most White men Are taller than you'.

The signifier 'critical', demonstrated so clearly in this poem, contains the exact processes that underpin the approach that we take in this handbook, namely that what appears most obvious should and can be questioned; debates and contestations of issues are important; and difficult questions should be asked and thought about deeply. Murray (2014) argued that '[t]here are different meanings of the term critical. One the one hand, critical is the concern with meanings; while on the other, it is the concern with issues of power and exploitation' (p. 9). Broadly speaking, we view 'critical' research as seeking to unpack power relations, promote social justice, and highlight inequities.

Although 'critical' research is often associated with qualitative methods, this is not necessarily the case. Indeed, some of the studies featured in this handbook used both quantitative and qualitative methods (e.g., Edelman, Section 1; Paphitis & Kelland, Section 2; Mirfin-Veitch, Conder, Treharne, Hale, & Richardson, Section 4). A number of studies featured in this handbook commit to criticality by using methodologies that are designed to promote social justice and healing, including participatory methods that imply patient and public involvement (Edelman, Section 1; Paphitis & Kelland, Section 2; Lovell & Akhurst, Section 4), transdisciplinary research (Cockburn & Georgina Cundill, Section 1), and arts-based methods such as poetry, storytelling, and theatre (Naidu, Section 3; Paphitis & Kelland, Section 2; Rice, LaMarre & Mykitiuk, Section 3). In others, interventions are combined with research, such as critical health interventions (Akhurst, van der Riet, & Sofika, Section 2; Paphitis & Kelland, Section 2), poetry therapy (Naidu, Section 3), and home-based care (Naidu, Section 3).

Critical Approaches to Ethics

The literature on ethics in the context of research is extensive. It reveals a wide variety of approaches informed by different epistemological traditions and political commitments. Despite this pluralism, most formal processes of ethics review are dominated by a principlist approach to research ethics, based on the principles of respect for autonomy, beneficence, non-maleficence, and justice (see Beauchamp & Childress, 2009). The dominance of a principlist approach to research ethics has been linked to the involvement of the state in the development of ethics governance (Evans, 2000). In the past two decades, an increasing number of countries around the world have developed national policies governing the ethical conduct of academic research. This has been done in an attempt to establish similar ethical standards for research conducted both in and between countries. In the context of the development of ethics governance, the presumed 'calculability and simplicity in ethical decision-making' (Israel & Hay, 2006, p. 18) that a principlist approach suggests has an obvious appeal to those tasked with drafting national guidelines (Evans, 2000). The mandate of ethics committee members is, after all, to provide guidance that can 'be understood with relative ease by members of various disciplines' (Beauchamp, 2010, p. 36).

There is, however, considerable criticism of principlism, partly as a result of the prominence of this approach in the regulatory ethics context. It is argued, for example, that the assumed universality of the principles has imperialist undertones (Dawson & Garrard, 2006) and limited applicability, particularly when individuals are not autonomous (Baines, 2008). Competing ethical imperatives can sometimes occasion deadlock in ethical decision-making (Baum, 1994), and critics argue that if principlism cannot provide sufficient guidance in the moments in which it is most needed, then it is inadequate to the task (Clouser & Gert, 1990). Although far from settled, one outcome of these sorts of debates is that few still view principlism as a 'straightforward framework for problem solving' (Israel & Hay, 2006, p. 19). It is now generally agreed that ethics principles provide guidelines for ethical decision-making that have to be '*interpreted and made specific*' (Beauchamp, 1995, p. 184, italics in the original).

The chapters making up this handbook are a response to this challenge. In fact, the idea for the book came to us at the 2015 International Society of Critical Health Psychology conference, where a significant number of presenters spoke about their experiences of the limitations of principlism for guiding ethical conduct in research. They spoke about how critical researchers are compelled to engage with principlism because it dominates the ethics governance assemblage in international conventions, national guidelines, professional codes of conduct, institutional policies, funding eligibility, gatekeeping, and so on; it is now almost impossible to proceed with the conduct of research without first successfully navigating 'procedural' ethics that arise from principlism. Speakers at the conference, many of whom feature in this handbook, also highlighted the contextual challenges of conducting ethical research, challenges that are not always foreseen or accommodated in bureaucratic ethics assemblages.

So, grounded in stories from the field, in different geographic locations, in different social and political contexts, and in the complexities of real-world research informed by different disciplinary and epistemological approaches, the chapters in this book offer critical engagement with the establishment of certain conventions in the interpretation of ethics principles. For example, authors interrogate common assumptions about what constitutes 'vulnerability' (Feltham-King, Bomela & Macleod, Section 1), 'risk' and 'harm' (Edelman, Section 1), and the way in which these are deployed by powerful stakeholders (Marzano, Section 4). Mindful of histories of colonialism, apartheid, and other systems of oppression, authors highlight the significance of the imperative for democratic 'collaboration' (Lovell & Akhurst, Section 4; Paphitis & Kelland, Section 2) and the rights of participants to claims of 'ownership' of data (Mayeza, Section 4). Others trouble some of the assumptions underpinning the requirement to obtain 'informed consent' (van den Hoonaard, Section 1; Cockburn & Cundill, Section 1; Rice et al., Section 3;

Mirfin-Veith et al., Section 4), and demonstrate how identity masking can undermine 'respect' for persons (Naidu, Section 3) and the 'justice' imperative (Ashdown et al., Section 3; Marx & Macleod, Section 3). The chapters illustrate why it is important to challenge 'conventional' wisdom and to avoid complacency which is unlikely to lead to ethically responsible research. In this regard, the chapters in our book constitute an arsenal of carefully considered and well-argued responses to many of the standard interpretations of ethics principles.

As each chapter is a story from the field, this handbook grapples not only with the frustrations of procedural ethics but also with the ethically important moments that arise in the actual conduct of research. Authors discuss, for example, the ethical complexities of inhabiting multiples roles (Barker & Macleod, Section 2), of positioning oneself and being positioned by others (Harvey, Section 3; Akhurst et al., Section 2; Mayeza, Section 4), of the blurring of boundaries between researcher and researched in participatory (Lovell & Akhurst, Section 4) and arts-based research (Rice et al., Section 3). Underpinning these and a range of other issues are deep concerns about the significant power differentials that exist among and between various stakeholders in research, including our own investments in what can be referred to as the bourgeois simulation of research excellence (Stewart, Section 4).

Ill-prepared by deliberations characterising procedural ethics, and frustrated by the limitations of principlism, authors were motivated to seek guidance in alternate approaches to ethics. These included relational (Barker & Macleod, Section 2) and situated (Marx & Macleod, Section 3) approaches to ethics, as well as insights informed by psychoanalytic (Harvey, Section 3; Stewart, Section 4), feminist (Feltham-King et al., Section 1), and postcolonial theory (Stewart, Section 4), and critical disability studies (Rice et al., Section 3; Mirfin-Veitch et al., Section 4). In each instance, authors grounded their discussions of the usefulness of alternative approaches in the specific situational and relational dimensions of their research, effectively eliminating distinctions between applied ethics and ethics in theory, which is so often what undermines the usefulness of an ethical perspective. Indeed, the usefulness of this handbook lies in the careful balance recommended by authors of: the universal versus the specific; principle-based versus reflexive actions; abstract versus grounded reasoning; and rigid versus flexible practices.

The chapters featured in this handbook point to the necessity of constructing and practising research ethics in a 'both/and' rather than an 'either/or' fashion: *both* cross-national principles *and* contextual responsiveness. This is in contrast to some authors who advocate what they call situated or situational ethics in opposition to principlist approaches (Piper & Simons, 2005; Usher, 2000). For example, in their edited book on ethics in educational research, Simons and Usher (2000, p. 2), argue, 'Researchers cannot avoid weighing up often conflicting considerations and dilemmas which are located in the specificities of the research situation and where there is a need to make ethical decisions but where those decisions cannot be reached by appeal to unambiguous or univalent principles or codes'. While being sensitive to sociopolitical contexts, as well as taking account of the ethical implications of different research methods and practices, is clearly important in critical research, this in no way implies, we believe, the wholesale abandonment of ethics principles that have cross-contextual and cross-national significance.

Stories from the Field: Complicating Ethical Imperatives

A number of national and international conventions have tackled the question of how to conduct ethical research. Most notable among these are the Nuremberg Code (1947), the Declaration of Helsinki (World Medical Association, 1964), and the Belmont Report (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1978). These guidelines were developed in the context of concerns about atrocities carried out in the name of research, the lack of regulation of research, and the potential to do harm. In particular, research conducted by Nazi scientists on concentration camp inmates and the Tuskegee experiments in which African American subjects were kept ignorant of being infected with syphilis and left untreated underlined the need to regulate medical research that is conducted within wider social, political, and economic inequalities (Fairchild & Bayer, 1999). Importantly, the necessary corrective to these grossly unethical practices came from stories from the field. Students of research ethics are often inducted into the necessity of research ethics principles through the telling of these historical narratives.

In thinking deeply and in a nuanced fashion about ethics in research, especially critical research, it is important that lessons are learnt from researchers' stories. Drawing on the experience of researchers in the field helps to surface important ethical quandaries that require consideration in critical research. The power relations that play themselves out in, firstly, creating these quandaries and, secondly, in working towards some form of resolution are highlighted.

The point of departure for each story narrated in the book is the extent to which experiences of conducting research generate unforeseen crises. Stories from the field outline significantly the ways ethical guidelines or principles are translated in practice in both predictable and unpredictable ways. Arguably, it is through their application that the textures and fissures of ethics guidelines are apparent. In turn, in their being based on concrete examples, the chapters indicate how practice can have bearing on the theorisation of ethical research practice.

It is worth considering the extent to which a notion of criticality lies dormant in the notion of ethics, and how this is activated through translation into praxis in the field. As an unpredictable space, interactions in the field can highlight the limits of the 'prevention of harm' model that underpins ethical guidelines. Each story in the book draws attention to contingency in the field and highlights the constraints of both a forecasting and an instrumentalist approach to ethical practice.

In the first section of the handbook, authors tell stories that unpack the constraints of systems, both institutional and otherwise, on research practices. Their narratives ask whether there may be divergences between critical research methods and the commitment to beneficence. As the stories in the chapters suggest, political values as abstractions do not readily translate to the prevention of harm when encountering participants and the more dynamic space of the field. Researchers may encounter individuals and organisations that mediate access both physically and discursively, as narrated in Section 1. What happens, therefore, if researchers find themselves having to take on an authoritative position that reinscribes a particular power dynamic in order to undertake empirical work while, simultaneously, committing to critical practice?

Implicit in the construction and application of ethical guidelines are prescribed research roles, as highlighted by authors in Section 2. After all, it is the researcher who is tasked with finding strategies to minimise harm, to ensure confidentiality and anonymity, and so on. Contingency in the field means that such roles may be disrupted. Participants may have expectations unforeseen by the researcher prior to undertaking research; the role as primarily a researcher, written into the contract between researchers and participants, may be dislodged temporarily. Sensitivity to context, as the stories suggest, means a continual interpretation of one's ethical guidelines while remaining committed to their core principles. In a number of chapters throughout the handbook, authors provide insights into different strategies employed to negotiate the unexpected.

Changing contexts also means rethinking prior assumptions about harms when considering confidentiality and anonymity from the perspective of participants, as highlighted in Section 3. While standard practice may take for granted anonymity as a preventative measure, participants may feel differently. Chapters in Section 3 draw on a range of stories from the field to highlight the complexities of navigating a way through contested anonymity and confidentiality practices.

In different inflections, stories from the field draw attention to the circuits of power in the process of undertaking research. If the writing of ethical principles grants the researcher responsibility, what is one to make of the relationship between responsibility and power? Ethical guidelines may be inscribing both actual and imagined participants as powerless in a preventative framework. A number of authors of chapters in Section 4 reflect on their experiences of consciously negotiating power. For the reader, this lays bare dynamics that may be concealed when the 'doing' of ethics remains in preliminary bureaucratic processes. In short, while researchers are tasked with foregrounding ethics prior to entering the field, this abstracted process remained indebted to ongoing, and *particular*, stories that provide feedback in the act of translation.

Going Forward

As a result of the complexity of conducting critical research, researchers are called upon in innumerable ways to re-evaluate what it means to be doing ethical research. Critical social science researchers, students, and teachers of research ethics increasingly find themselves navigating the dilemma of choosing between doing good (being ethically responsive to the people being researched) and doing good research (maintaining pre-approved protocols). In understanding research ethics as a process that is responsive to the complexities of the field, researchers may find themselves in a quandary in relation to the administrative necessities of ethical clearance.

The increasing regulation of research ethics has led to some scholars noting that 'the regulatory concerns are more technical than ethically substantive. … the format of review can readily induce a 'tick-box' mentality: a preoccupation with filling in the forms correctly' (Posel & Ross, 2014, p. 3). The bureaucratic process, which engages a priori with imagined ethical dilemmas, is often viewed as a hoop through which researchers must leap before getting on with the real business of gathering data. But, as pointed out by Posel and Ross (2014), ethics and research is 'often unruly and abidingly ambiguous, their complexities resistant to simple and neat formal assurances' (p. 3). As researchers approach gatekeepers, enter research sites, interact with participants, and engage with groupings of people and institutions, so the messiness of life, the quandaries of unforeseen actions and circumstances, and the complexities of power relations make themselves felt.

The completion of ethical clearance applications is useful in inducting new researchers into research ethics and in focussing a research team's initial conceptualisation of ethics on a particular project. If, on the other hand, ethics considerations are limited to administrative processes, then it is likely that researchers will not be prepared properly for the ethical dilemmas that inevitably arise in the field, especially when conducting critical research. The stories from the field told by the authors of the chapters in this handbook may resonate with challenges faced by many researchers. A number of pertinent questions are posed in these narratives: what are the implications of power relations within the various systems relating to the conduct of research (Section 1)? How do we draw lines between research and other relationships (Section 2)? Who has the responsibility of defining 'harms'? How do anonymity and confidentiality assist or potentially impede social justice research (Section 3)? How are power relations between researchers and participants navigated (Section 4)? How do researchers ensure that ethics and methods are responsive to the situations within which the research is conducted? As such, these stories provide spaces for nuanced and reflective thinking about the complexities of conducting critical research.

The research featured in these chapters all received ethical clearance from the relevant ethics committees and/or other institutional gatekeepers. While critical of established interpretations and applications of a principlist approach, authors do not shun procedural ethics entirely. Instead, their stories demonstrate the contextualised and multifaceted ways in which the principles implied in ethics review may be stitched together with situated and grounded ethical praxis in the field, a praxis that is necessarily circular in its reflection and action cycle. We continue our cycle of discussion of the chapters and overarching themes of ethical critical research in the introductions to each section and also in the final reflection chapter of the handbook.

Notes

1. The bodies tasked with reviewing research ethics prior to researchers' engagement in the field have different names, depending on context. In this handbook, authors have been free to use the names pertinent to their context (e.g., Internal Review Board in the United States). We use a generic term, ethics committees, in our introductions and conclusions.

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Section 1

Encounters with Systems

2

Introduction: Encounters with Systems Within Which Critical Research Is Conducted

Gareth J. Treharne and Jacqueline Marx

How can critical researchers simultaneously work within and resist systems and institutions that often do not comprehend critical methodologies? The aim of this introduction is to set the scene for the stories from the field featured in this section. These stories focus on how critical research is shaped by researchers' encounters with systems. Each chapter in this section tells a story of encounters with an ethics committee or committees. But many other systems are also encountered by critical researchers, and the chapters in this section raise questions about how critical researchers navigate hierarchal power relations inherent in the variety of systems and institutions within which critical research is conducted. These systems and institutions include hospitals and larger healthcare organisations, non-governmental organisations (NGOs), schools, and universities. Many of these systems and institutions have formal policies on research with a range of specificity and complexity all the way up to an ethics committee.

Ethics committees have many different names and specifiers in international settings. For example, in Canada they are known nationally as 'research ethics boards' (REBs), and within US academic institutions they are commonly known as 'institutional review boards' (IRBs) (van den Hoonaard, 2011). In Aotearoa/New Zealand, there are the Health and Disabilities Ethics

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Committees (Ministry of Health, 2017). Like some other nations, these health-only ethics committees work in parallel with ethics committees of tertiary institutions, with evolving boundaries around which kinds of research are reviewed by which committee (Ministry of Health, 2017). In England specifically, the term 'research ethics committee' has been formally adopted by Research Councils (e.g., Economic & Social Research Council, n.d.) and the National Health Service Health Research Authority (n.d.). The label of 'research ethics committee' is also applied in South Africa within the national guidelines on ethical health research (Department of Health, 2015). These names and constitutions have solidified over recent decades but will continue to shift under changing climates of research, and so we use the shorthand label of ethics committee.

Ethics committees are the lynchpin of ethics approval assemblages (Reubi, 2010). These assemblages of bureaucratic processes are known also as 'the ethics regime' in some critical scholarship (see van den Hoonaard, 2011). The approval processes of ethics committees are not necessarily equivalent across countries, institutions, or disciplines. But health and social researchers are now almost universally required to go through a process of seeking approval for research, and a certain neoliberal bureaucracy has become normalised in academic research involving human participants (van den Hoonaard, 2011). This bureaucracy, as Denzin and Giardina (2007, p. 27) highlight, may reflect a troubling shift in which 'there seems to be a move away from protecting human subjects and toward increased monitoring and censuring of projects that are critical of right-wing ideologies'.

In this introduction we draw on four thematic distinctions that underlie the stories shared in this section. These distinctions help to demonstrate some of the very real implications for critical researchers when inevitably working within systems and institutions. The first of these distinctions is a comparison between the realms of research that are broadly labelled as health research and social research. Within both of these realms we also highlight a second distinction: the contrast between research and practice. To practice can refer to the provision of healthcare and other caregiving professions. But to practice can also refer to critical praxis: the politically conscious work done to challenge the status quo through radical ethical methods (Denzin & Giardia, 2007). The third distinction we make is between risk avoidance models of ethics bureaucracy and relational models of ethical researching that support situational adaptation in the field. In the fourth and final distinction we return to the abrasion between critical research and biomedical models of research. We also summarise recommendations that arise across the chapters in this section by outlining how the authors speak to working within, and resisting, constraining research ethics systems that critical researchers encounter.

Regardless of the global location or name of a particular ethics committee, health and social researchers commonly become all too familiar with the process of proposing research, receiving feedback, and amending or defending the proposed protocol. For critical researchers, the ethics review process is often marred by a disconnection between critical research methods and the research ethics assemblage, a concern that features across the stories in this section and subsequent sections. These stories are reflexively critical of the authors' own research practices whilst also revealing ways in which critical research can come to be constrained through the ethics review processes. As Denzin and Giardia (2007) note, ethics committees have a reputation for being 'routinely ignorant of or unsympathetic to new developments in interpretive approaches' (p. 13). This misunderstanding of critical research often spills over into the encounters critical researchers' experience when accessing or working within systems other than the ethics committee (e.g., the hospital that is required to follow research 'governance' or the NGO with diverse formal or informal responses to research).

Another diverse but central aspect of the ethical approval assemblage is the ethics codes and principles that serve as the benchmarks used by ethics committees when reviewing proposed research. These codes include national projects such as the 'ethical standards' determined by the National Ethics Advisory Committee in Aotearoa/New Zealand (Ministry of Health, 2017), Canada's Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans (Canadian Institutes of Health Research, Natural Sciences and Engineering Council of Canada, & Social Sciences and Humanities Research Council of Canada, 2014), and the principles outlined in the Belmont Report (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1978) and enacted by the 'Common Rule' procedures that are applied by IRBs in the US (see also van den Hoonaard, 2011). Denzin and Giardia (2007) critique the Belmont Report's three principles for drawing on conflicting moral philosophies and for being decontextualised from local settings and international declarations such as the United Nations (2006) Convention on the Rights of Persons with Disabilities. The three principles are respect (commonly achieved by informed consent processes), beneficence (commonly achieved by attempting to predict a balance of useful outcomes outweighing risk of harm), and justice (attempting fairness in participation and distribution of benefits). These closely reflect the four principles of biomedical research ethics proposed by Beauchamp and Childress (2001): autonomy, beneficence, non-maleficence, and justice. Likewise, there are international principles that speak to the ethics of healthcare and health research such as the Hippocratic Oath and the Declaration of

Helsinki (World Medical Association, 1964). But what ethical challenges occur when these principles are applied to critical research on health or social issues?

Critical Research on Health or Social Issues

The chapters in this section of the handbook feature stories on a range of critical research projects on health and social issues. There is no simple distinction between health research and social research because health research is socially located and social research so often addresses well-being. But what is evident in these stories is how biomedical research governance has ‘crept’ (Haggerty, 2004) into critical research. Pam Carter, Sarah Chew, and Elizabeth Sutton (2018, this section) discuss their experiences of the ‘pseudo-ethics’ of the English research governance of clinical trials that has crept into a requirement that critical researchers engage in tangentially relevant training. Natalie Edelman (2018, this section) critically analyses her experience of multiple ethics approvals from a university, the UK health system, and an NGO all of whom had to review and approve and thus shape her research with a ‘vulnerable’ group of participants who were users of illicit drugs. This exemplifies the important questions about which health and social issues are considered ‘problematic’ and by whom. Likewise, Tracey Feltham-King, Yolisa Bomela, and Catriona Macleod (2018, this section) provide a Foucauldian perspective on their experiences of recruiting ‘problematised’ subjects (i.e., subjects in the discursive sense, not just people subjected to biomedical research). Their work on teenage pregnancy in South Africa again involved multiple research ethics systems in gaining approval from a university ethics committee and a state healthcare organisation; this necessitated navigating contradictory social constructions of teenage pregnancy and ongoing challenges in recruiting women through gatekeepers within the healthcare organisation.

The later chapters in this section move outside the regulatory realms of clinical research governance but continue to detail encounters with systems underpinned by the ‘ethics creep’ (Haggerty, 2004) of objectivist biomedical research into the diverse fields of critical research. Jessica Cockburn and Georgina Cundill (2018, this section) outline transdisciplinary approaches to research in sharing their research on environmental stewardship in South Africa. Transdisciplinary research requires a participatory form of research that is inherently social, often action oriented, and again requires encounters with multiple research ethics systems in working with community organisations whilst being governed by academic research ethics committees. Their work speaks to the wider project of critical research in asking who benefits from research and what improvements communities desire.

Catherine Smith, Emma Tumilty, Peter Walker, and Gareth Treharne (2018, this section) question the differentiation between the ethical attention paid to human participants and non-human animal participants with a focus on domestic and service dogs. Research on the interactions of humans with other animals is by no means new but it frequently foxes disconnected research ethics systems that are attuned to protecting either human participants or non-human animals subjected to experimental methods. In asking what research ethics might look at within a system that could support an integrated ethical approach to human–animal interaction research, Smith et al.'s work highlights some of the intricacies of research ethics systems and assumptions about sentience and ethics. Will van den Hoonaard (2018, this section) closes the section with a focus on the state of sociological research and argues that such research inherently is, or should be, critical. Drawing on his research alongside Canadian REBs and an analysis of the ethics code laid out in the Canadian Tri-Council Policy Statement (Canadian Institutes of Health Research et al., 2014), van den Hoonaard provides a tour of the facets of critical research that raise ethical challenges in a range of examples from health and social research.

Research as Praxis but Distinct from Practice

Engaging in research is distinct from engaging in practice when fulfilling roles such as a health professional or NGO worker. In addition, critical research is a form of praxis in the Marxist tradition and more recent interpretations (see, e.g., Barnard, 1990; Lazar, 2005). Critical research moves beyond the model of research as merely serving to inform evidence-based practice, although healthcare practice can itself be a fruitful focus of critical research. Health professional practice and health research praxis have ethics systems that are often organised around a split between 'clinical governance' and 'research governance' (Carter et al., 2018, this section). But health professional practice and research praxis might be described as sharing a goal to change the well-being of an individual or a community. The methodologies applied by the authors in this section of the handbook include a range of qualitative and ethnographic approaches leading to a multiplicity of perspectives on research embedded in healthcare practice and other social settings.

Carter et al. (2018, this section) analysed how good clinical practice training is a form of 'ceremonial conformity' (Dingwall, 2008). This semi-regulated and very brief form of training is commonly required of health researchers who are not employed by the UK National Health Service but is not about inducting researchers into the world of healthcare practice. Instead, it is a way of attempting to ensure that all researchers know the ethics and bureaucracy of a ‘good’ clinical trial regardless of their own intended methodology. Edelman (2018, this section) reflects on the pragmatic aims of her research in which she explored the reasons women with ‘problematic drug use’ do not attend sexual health services. Edelman’s aim was not directly to provide the women with a clinical service, although through critical research it is possible to reorient services to better meet the lives of marginalised groups. Feltham-King et al. (2018, this section) reflect on their research praxis in experiencing gatekeeping of pregnant teenagers receiving care in a clinical setting that medicalises and problematises young women. The aim of the research was not to provide a second layer of care for the young women but this was a presumption that needed to be corrected and which shaped the accessibility of participants. Likewise, van den Hoonaard (2018, this section) outlines critical sociological praxis and reiterates many of the broad concerns critical researchers have about how their research is viewed by ethics committees as a colonising bureaucracy.

Cockburn and Cundill (2018, this section) share their experiences of transdisciplinary praxis including the pre-proposal phase during which academics and community members discuss the problems both parties want to address. Building relationships and opening the conversation about what participatory research might achieve is a form of praxis as are the ongoing phases of transdisciplinary research and many engaged forms of participatory research. Smith et al. (2018, this section) explore the place of interactions between dogs and humans. This raises questions about how researchers might reconceptualise sentience and attend to signs of assent or its absence during research with those who cannot verbalise or necessarily understand conventional notions of consent to participate in research.

Reactive Bureaucracy Versus Proactive Ethics

Another tension across the chapters in this section is the way that ethics committees as we know them arose in reaction to ‘unethical’ research with the aim of avoiding the same injustices being repeated (see Denzin & Giardia, 2007; Neill, 2016; Smith, 2012; van den Hoonaard, 2011). Rather than instilling ethics in a way that is appropriate for all forms of research, the ethics systems that have emerged enforce a constrained set of recommended research procedures to avoid unethical research. Moreover, authors in this section argue that these procedural ethics have become a barrier to proactive ethics during the journey of critical research. Although not an absolute beginning to unethical research, it is possible to trace the current state of concerns about research ethics to the atrocities of research carried out on prisoners in Nazi death camps in the name of science and in ways that apply many of the principles and narratives of experimental research as being for the benefit of the people (Smith, 2012). Medicine, psychology, sociology, and other disciplines all have their own subsequent fables of unethical research that are cited as warnings and woven into the fabric of ethics systems. Two of the fabled examples of unethical research in psychology are somewhat ironic as Zimbardo and Milgram were attempting to understand how 'regular' people could be responsible for wartime atrocities using a mock prison or attempting to convince people they were punishing someone with deadly electric shocks (see Neill, 2016, for details of these fabled studies). The fable of unethical research has a corollary that researchers need to consider the balance of harm enacted against knowledge gained. The argument goes that if the research enhances our understanding of issues such as compliance and torture then the gain in knowledge might be said to be worth it. But who does the resulting knowledge serve? When we ask who benefits from research and from the knowledge that is generated and disseminated, then we can often be left with the concerning realisation that commonly only academia and academics benefit from research findings whilst individual participants or communities bear the brunt of harm from unethical research practices.

The chapters in this section all speak to some of the ways that research ethics are upheld by critical researchers resisting the rigid ethical procedures that originate from biomedical research by engaging in proactive ethics, also known as micro-ethics, everyday ethics, ethical mindfulness, or applying an ethical sense (see in particular Carter et al., 2018, this section; Cockburn & Cundill, 2018, this section). In the same way that critical researchers often cannot know the scope of their findings before the research is undertaken, it is not always possible for critical researchers to know what ethical challenges they might face. These challenges cannot be categorised in the same way as can 'adverse events' in pharmaceutical research, and yet that very model is all too often applied to critical research, as emphasised by Carter et al. (2018, this section).

In many of the chapters in this section, the authors also discuss research with people who might be labelled 'vulnerable' and thus problematised. This includes people with moderate literacy (Carter et al., 2018, this section), women who use illicit drugs and are likely to be inebriated during participation (Edelman, 2018, this section), pregnant teenagers (Feltham-King et al., 2018, this section), non-human animals who cannot speak for themselves (Smith et al., 2018, this section), and researchers who stick to ethical principles in the face of legal action (van den Hoonaard, 2018, this section). Research with vulnerable people rightly deserves ethical mindfulness in order to avoid exploitative procedures. But critical researchers must also resist insinuations that: (1) all vulnerable participants are better off not taking part in research and (2) absolutely all participants are vulnerable merely because they are not privy to the training afforded to researchers. Can researchers ever bridge the divides between communities with a different perspective on research, sometimes a deep and understandable distrust of research following historical injustices under colonialism (Smith, 2012)? Working with communities and from within communities to bridge these gaps in familiarity with what research involves and can achieve is particularly pertinent in research using participatory or emancipatory critical methods. This bridging is another theme across many of the chapters in this section and lends itself to making recommendations that may transfer from the experiences of the individual authors of chapters.

Recommendations for Ethical Critical Research as Distinct from Objectivist Research

The chapters in this section have a wealth of recommendations ranging from small procedural insights to bigger picture insights into the aims and value of critical research. One feature of critical research that stands out in the stories shared in this section is a sense of being an outsider to research ethics systems that are not set up to recognise such approaches to research. Carter et al. (2018, this section) note that as critical researchers, we often have to self-regulate our ethics and our own well-being in the face of ethical challenges. This might sound like a lonely existence but Edelman (2018, this section) notes that one critical researcher's ethical realisations can have ripple effects locally, and these ripples are widened by the stories shared in this handbook.

Another way of facilitating the ripple effect of ethical realisations is to form an epistemic community of practice, as highlighted by Cockburn and Cundill (2018, this section). How might decentralised communities of research practice be organised? Perhaps they might best be formed for an individual project (see Treharne & Riggs, 2015), or perhaps they might be coordinated around a discipline or particular method. Perhaps communities of research practice might be local to a particular place or perhaps they might include national or international colleagues. And who might these communities of practice include? In addition to academic colleagues, communities of research practice are a way of applying participatory approaches to critical research included in many of the studies featured in the chapter in this section.

When formal community engagement is part of an approach, it comes with many challenges. Firstly, how can critical researchers get started with community engagement? Cockburn and Cundill (2018, this section) discuss how ethics systems do not typically account for a consultation phase before the 'main' research phase. Who to consult is another challenge of community engagement addressed by Edelman (2018, this section) in describing how she worked with two experts-by-experience. Edelman also noted the difficulties of maintaining engagement over time which might be heightened in her work with women who use illicit drugs. The issue of engagement over time also applies in all forms of community engagement when the often slow pace of research becomes evident, coupled with the reliance on finite and insecure sources of funding that require a researcher to plan for the ethical conclusion to a line of research when a community may pin its hopes on long-term research or solutions that are not forthcoming.

Having established that the homogenising objectivist biomedical models of research upon which research ethics system are built are not always fitting for critical research, what guidance do the chapters in this section offer to critical researchers who are about to submit an application to an ethics committee or to those who have received approval but face challenges in the field? Carter et al. (2018, this section) discuss how they critiqued homogenising terminology in their answers to a 'study outcome monitoring form'. Acts of protest on an ethics application form might delay an individual application but an organised form of petition might be a better way of supporting critical researchers who encounter that same system.

Many of the chapters in this section raise hopes for ethics systems that can account for community consultation and critical methods. Likewise, Smith et al. (2018, this section) discuss how new forms of ethics review might be necessary for research on human–animal interactions, and if that can be achieved in a way that simplifies existing bureaucratic confusion then it will be a valuable model for enacting progressive principles. Edelman (2018, this section) raises questions about the ethical requirement of conducting studies that are methodologically sound. This notion of soundness or quality is often the concern raised by research ethics systems formed of people with limited knowledge of critical research. There are ways of considering the quality of qualitative research (see Treharne & Riggs, 2015) but there are many complexities in taking a critical perspective on the issue of methodological soundness without forming a new homogenising of critical research that stifles methodological creativity and ethical responsiveness.

Conclusions to This Introduction

Critical researchers encounter a nexus of systems that shape research. At the centre of this nexus are ethics committees that draw on systematised ethics codes and mandate how the principles within those codes should be met. But a wider assemblage comes together to form an ethics system that claims oversight of research often with many unique features in response to historical atrocities, national rulings, and local idiosyncrasies. There is no one universal ethics code but the chapters in this section demonstrate some common concerns and unique learning in relation to four organising themes that help to characterise critical research and achieve ethical critical research. There is a subtle distinction between critical health research and critical social research. Both aim to challenge the status quo, but health and social research may call for distinct locations that bring distinct forms of research governance to be navigated. Within both health and social research there is a need to contrast research and practice, but the two processes intertwine when critical research is conceptualised as praxis or engages with systems of 'routine' practice such as healthcare, teaching, and NGO work. Many ethics committees and other systems apply a risk avoidance model of ethics bureaucracy; in contrast, the authors in this section raise a need for situational adaptation in the field when conducting critical research and call for relational models of ethical researching. The inevitable relationality of critical research praxis is perhaps harder to codify than 'good' biomedical research. The stories shared in this section of the handbook serve as good examples to stimulate critical engagement with ethical issues by critical researchers working to adapt ethically to the systems they encounter.

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3

Ethics in Theory and Pseudo-Ethics in Practice

Pam Carter, Sarah Chew, and Elizabeth Sutton

In this chapter we present two 'cautionary tales' based on our experiences of conducting qualitative health research. In a spirit of 'ethical mindfulness' (Pollock, 2012) we share our reflections and begin with introductions. We are researchers based in a Department of Health Sciences in an established UK university. We are not medically trained coming from a variety of disciplinary backgrounds, namely social psychology, sociology, and cultural studies. We use qualitative methods to address applied health research questions. Our work is often ethnographic, using a range of data collection techniques including interviewing, observing, collecting documents, and spending a significant time in settings which can be particularly sensitive from the point of view of ethics and governance review. In this chapter we apply a distinction between *research ethics* as the principles of good practice (avoiding harm, ensuring transparency, upholding integrity, etc.) that apply throughout the research process and *research governance* as the regulatory processes designed to ensure these principles are upheld. In our own research practice, we are expected to comply with certain standard operating procedures. This chapter is about the demand imposed on qualitative researchers that arises from current forms of governance and how, paradoxically, these can constrain good practice in the field. We open the chapter with an overview of governance as it applies to qualitative research in health care by drawing on the writing of other scholars who have engaged with the problems in the current system and related implications. We then present two case studies before providing a discussion

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that situates our experiences in the literature and offer some advice for qualitative health researchers seeking to work in the field.

In the UK, the Health Research Authority (HRA) was established in 2011 and is responsible for governance of all types of research including the clinical trials and social care studies that take place within the UK National Health Service (NHS) (Health Research Authority, 2016). Beside governance and assessment of legal compliance, the HRA also has responsibility for the UK Departments of Health's Research Ethics Committees. Not all UK health research requires ethical review and there are some differences in the systems for England and other countries of the UK. The new and evolving HRA system can appear complex but at our university we are able to draw on the resources of a research governance office and can access training. This support is enabling, but it can also serve to make what should be a valuable, ethical, and reflexive process feel like an instrumental exercise in navigating the research governance minefield (Shaw, Petchey, Chapman, & Abbott, 2009).

Qualitative researchers have critiqued existing NHS ethical and governance review processes (Armstrong, Dixon-Woods, Thomas, Rusk, & Tarrant, 2012) and some, including Dingwall (2008), argue against regulation. Dingwall comments that certain bureaucratic requirements cause harm and cites an instance where researchers were prevented from adequately studying harmful non-compliance with a medical practice so opportunities to learn and to improve practice were lost. Others take a more nuanced perspective and caution against unthinkingly adopting the moral high ground and assuming that researchers can be trusted to act professionally and ethically 'to position oneself on the right side' (Guta, Nixon, & Wilson, 2013, p. 308). Ethical debate aside, there is consensus that the processes involved in gaining ethical and governance approval in the NHS are cumbersome and protracted. There is some evidence that the burden of regulation affects research activity; for example, Bentley and Enderby (2005) noted that applications for NHS ethical approval in 2003–2004 had dropped by 40 per cent. A later survey of academics' opinions of the UK Research Governance Framework (Richardson & McMullan, 2007) found that 45 per cent of respondents had modified their designs to avoid researching within the UK National Health Service altogether, and some respondents had resorted to 'gaming' to avoid the scrutiny of NHS ethics committees by classifying studies as 'audit' rather than research.

Reclassification of activities (i.e., specifying research as 'audit') (Health Research Authority, 2016) or conducting less than rigorous research are understandable responses to perceived over-regulation but arguably contradict the spirit of ethics codes. Such practices constitute ‘ceremonial conformity’ (Dingwall, 2006b) which is often a way of circumventing ‘ethics creep’. The notion of ethics creep describes the spread of inappropriate governance constraints over increasingly broad areas of academic inquiry (Haggerty, 2004). Ethics creep has been linked to the ‘pauperization of fieldwork’ (van den Hoonaard & Connolly, 2006, p. 66). For example, when studying the impact of the research ethics review on Canadian master’s theses, van den Hoonaard and Connolly (2006) found an increase in studies described as ‘ethnographic’ that relied solely on interviews as a form of data collection.

Dilemmas and Debates for Qualitative Health Researchers

Besides critiques generated by frustrated academics, UK policymakers have recognised that regulation of health research needs to adapt in order to become more effective and efficient. In the context of an international knowledge economy, health research has been acknowledged as a potential source of innovation and wealth creation, and consequently, academic institutions and government departments seek to produce useful knowledge to a high ethical standard to pursue competitive advantage (HM Treasury and Department for Business Innovation and Skills, 2011). Ethical regulation of health research has been criticised for impeding innovation and research through disproportionate procedures for assessment of the risks associated with different types of research. Following a review by the HRA, research governance and ethics procedures have been revised (Health Research Authority, 2012). The review acknowledged differential and proportionate risk and consulted experts in qualitative research, indicating that regulators appear to value qualitative contributions to health research. This review was a positive step and had the potential to enable a revision of existing procedures so that qualitative and quantitative research could be treated equivalently in UK health research, but our experience shows that significant change has yet to be realised and the reasons for this might be located at the institutional and organisational level.

Achieving policy change across a range of research organisations and NHS institutions takes time, and, as our case studies illustrate, implementation of policy change in practice may not be straightforward. Although the HRA as regulator has attempted to streamline research governance and is producing a new UK policy framework for health and social care research, individual academic institutions are still legally responsible for their researchers' practice and NHS institutions still retain legal duties of care for their staff and patients. There may be inherent risk aversion at this institutional level where organisational reputations are protected (Hedgecoe, 2016). We have found that the protocols and templates that qualitative researchers are required to complete tend to be designed primarily for research that takes the form of biomedical hypothetico-deductive study designs. Our case studies describe the practicalities of engaging with that bureaucracy.

Current NHS ethics procedure necessitates researchers completing a 'Statement of Activities' spreadsheet, much of which deals with medical tests and interventions that are irrelevant to qualitative research (e.g., 'imaging tests and investigations', 'laboratory tests and investigations', 'individual patient drug accountability time'). Despite the HRA's attempts at streamlining the process, our experience is that completing an ethics and governance application for UK-based health research takes many days of work and the acquisition or production of numerous documents, including a Research Passport, letters of access, and the completion of lengthy application forms. A Research Passport authorises researchers who do not have a contract of employment with the NHS to carry out research, but can require researchers to have an occupational health check and a Disclosure and Barring Service disclosure, which depends upon whether they will be working with 'vulnerable groups'. Furthermore, a full study protocol has to be prepared along with information sheets and interview schedules. But there are significant issues relating to ethnographic fieldwork that can be problematic for researchers to justify in protocols and which ethics committees may not understand, such as not gaining consent from *all* staff and patients during periods of observation, as well as issues around how to act if poor clinical practice or harm is observed.

It is well known among qualitative researchers that ethnographic methods in particular cannot be completely specified and predicted (Librett & Perrone, 2010). Our experience has been that research administrators at NHS sites are more familiar with the notion of recruiting patients to clinical trials than they are with ethnographers who work inductively and therefore cannot predict precisely where they will be and what they will do when they are in the field. Thus, we still find ourselves trying to fit square qualitative pegs into round quantitative holes. Below are two case studies that illustrate the impact that (1) inappropriate regulation and (2) inappropriate monitoring has had on our practice.

Case Study 1: Inappropriate Regulation and Training

As well as negotiating bureaucratic requirements, the system demands that we undergo 'training'. Holding Good Clinical Practice (GCP) certification is an essential criteria for getting into our 'field'—usually NHS sites in the UK. According to the UK National Institute for Health Research (n.d.), GCP is defined as

> the international ethical, scientific and practical standard to which all clinical research is GCP training conducted. Compliance with GCP provides public assurance that the rights, safety and wellbeing of research participants are protected and that research data are reliable.

The UK HRA states that 'training should be appropriate and proportionate to the type of research undertaken' (Health Research Authority, 2012, p. 1) and notes that GCP training may not be appropriate. Local practice, however, often lags behind and our experience has been that we have been expected to complete GCP to gain access to NHS sites. GCP embodies implicit assumptions about research. We will go on to reflect on these and consider what, if anything, completing GCP training means for researchers or participants.

The GCP guideline was developed by the International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use (ICH) (1996) drawing upon the good clinical practices of many nations and the World Health Organization (WHO). According to the ICH, the guideline is consistent with principles that have their origin in the Declaration of Helsinki which was a response to the obscenities committed as 'research' during the Second World War (World Medical Association, 1964). The Declaration is a means by which the medical community regulates its research activities with human participants, and is effectively a code of ethical conduct. That GCP is grounded in such a principled tradition is not questioned, but the problem for us as social science researchers is the unfulfilled expectation that GCP should apply to the research we conduct as non-clinical health service researchers. The question is what is the process behind becoming the subject of the 'assurance' spoken of by the National Institute for Health Research?

GCP training has become something of an industry, and an online search will reveal many sites advertising training. This suggests the existence of a process whereby this aspect of ethical assurance has become commodified and that trade in this particular commodity is profitable. As a rule, online training takes around six hours. The training costs, plus the time costs, are usually absorbed by the researcher's institution. All courses have a similar content based on the ICH guidelines and candidates usually complete a multiple choice exam; when the pass mark is achieved a certificate can be generated which notionally acts as an assurance that the candidate is fit to conduct research. All authors have experience of GCP, but Liz recently had to update her GCP training which expired after two years and she reflects here on the experience of completing an online package.

The Experience of Good Clinical Practice Training (in Liz's Voice)

The first step in the somewhat laborious process involved setting up an account and logging into a dedicated training site that is approved by my institution. I then viewed slides that covered different issues, such as the different regulatory bodies responsible for overseeing clinical trials, ethics, and the correct procedures for managing research, and completed a set of questions to assess my learning. GCP was framed as something which offered protection to me and my participants and as a quasi-legal document that, without which, a study participant could sue or my indemnity might be invalidated. Risks of litigation may appear to be being mitigated by GCP training but it is unclear who would be protected if there were a complaint against a qualitative, non-clinical researcher.

The material set out in the training was strongly predicated on a model of research consistent with the experimental paradigm that stands in stark contrast to ethnography. For example, I was asked an assessment question about what to do if a participant experienced a suspected unexpected serious adverse reaction (SUSAR), to what authority should the SUSAR be reported, and the maximum length of time that reporting should take. I was asked what I would do in the event that there was a loss of power to the fridge in which I was storing the medicines that I was trialling. As with most of my colleagues, I made a spirited attempt to pass it 'properly'; in common with many colleagues, I failed. At the second attempt, I noticed a discreet button on the screen that, if clicked after answering incorrectly, would reveal the correct answer. Aided by a pen and paper, I passed the third time. Had I noticed the button earlier, I could have expedited the process and gained my certificate in two attempts.

It left me with the uncomfortable feeling that by complying I was somehow colluding in a deception because I knew it did not apply to my research and offered no ‘safeguard’ either to me or my participants. This in itself is unethical and dishonest—in effect it is a form of practice that we term ‘pseudo-ethics’. At the end of the ‘test’ was a feedback form that comprised a series of multiple choice questions. These questions offered a series of words to choose from to indicate how well this training enabled me to do my job. The answers were already formatted to answer ‘strongly agree’, and so I had to proactively seek out alternatives. I responded honestly, and chose two words which were ‘pointless’ and ‘irrelevant’. I was not able to feed back anything about the fact that I felt I was acting unethically because the ‘assurance’ I had acquired by completing the process was worthless.

My access to my field was thus conditional on compromising my own ethical principles and those outlined in the Concordat to Support Research Integrity (Universities UK, 2012), which stresses that integrity and honesty are core principles of conducting research. I also felt that I had been complicit in an avoidable waste of resources. In the *Lancet* series of papers on ‘Waste in Research’, Salman et al. (2014) point to the bureaucratic burden of obtaining permissions that entails submitting reams of paperwork and we feel that this should be seen as an indefensible waste of money.

There are numerous moral and ethical challenges that arise when conducting qualitative research. Because GCP training focuses on avoiding medical harms, it fails to equip researchers to be prepared for the realities of confronting other forms of harm that can arise when conducting qualitative fieldwork. To illustrate, my current research explores how staffing is organised and care delivered to emergency medical patients in different hospitals at weekends compared to weekdays. It involves non-participant observations, interviews with different clinicians and with patients and their relatives. The observations involve shadowing on-call doctors and other members of staff. As such, this study offers many potential opportunities for difficult and challenging ethical encounters that go beyond the notion of a SUSAR.

Case Study 2: Inappropriate Monitoring

Our next case study describes some of Pam’s experiences of ethics ‘in the field’ and some forms of ‘harm’ that can occur both to participants and researchers. This case derives from Pam’s doctoral ethnographic research in which she studied early-years childcare conducted in the UK in 2006–2009 (Carter, 2011). The study ‘sponsor’ was Keele University and a favourable ethical review was received from North Staffordshire Local Research Ethics Committee (reference number 06/Q2604/95) on 18 August 2006.

Reporting Harm (in Pam's Voice)

Although the majority of the participants in this study were not NHS patients, there was a possibility that my ethnographic work would include NHS sites and so I applied for ethical approval via the NHS system. I promised all interviewees a transcript of their interview, believing that this might mediate otherwise unequal power relationships between the interviewees and myself. The Local Research Ethics Committee had approved an informed consent process whereby participants signed to document that they agreed to be interviewed and for the interview to be digitally recorded before I switched the audio recorder on. Once I had completed the interview and switched off the audio recorder, I introduced the second part of the form which sought consent for verbatim quotations to be used. Technically I was complying with the research governance requirements, but I realised after several interviews that people would be able to give a more informed consent to the use of their verbatim words *after* they had had chance to read their transcript and that therefore this might be more ethical. When this was presented to them as an option, several participants did read their transcript and chose not to give me permission to quote them verbatim. I understood this to mean that I could include their interview transcripts as data in my analysis but that I missed the opportunity to select and represent some 'juicy quotes' (Schostak, 2005, p. 122). Some, for example Buchanan, Boddy, and McCalman (1988), regard this form of censorship as innocuous and they give the example of cleaning up data to suit a sponsoring organisation by removing a colloquial phrase. Buchanan et al. claim in that instance the meaning was not altered, but I would argue that colloquial metaphors can be very meaningful and my qualitative analysis relied heavily on metaphor and other linguistic tropes. For example, I transcribed non-verbal communication (umms and errs) so that I could analyse hesitancies, gaps, and silences for what they communicated (Aldred, 2008). However, this methodological decision gave rise to a further ethical dilemma centred on consent. Dingwall (2006), distinguishes between the 'fetishization of consent' governed bureaucratically through contractual arrangements and 'the construction of a customized relationship between researcher and researched' (Dingwall, 2006, p. 56). Rather than viewing the consent process as contractual, I attempted to manage the ethical dilemma of informed consent as a respectful relationship. This sits at odds to what critics have termed the 'dominant approach' to confidentiality, which 'dissuades researchers from having ongoing discussions with respondents about the use of their data' (Kaiser, 2009, p. 1636). Two interviewees told me that they would prefer to see their quotations in context before giving me their permission but this meant that I was writing up the research and including quotes from their transcripts without knowing whether permission would be granted.

Having drafted the findings, I faced the choice of how much context to give these participants to inform their decision of whether to grant consent or not, for the use of verbatim quotes. It seemed ethical to try to put myself into people's shoes to try to understand, from their perspectives, why they might be unwilling for me to use their words. One interviewee had been critical of elected politicians with whom she worked closely and so I guessed that she may have felt awkward or embarrassed and perhaps wary of how secure my promise of confidentiality and anonymity could be. I sent her a section of my analysis that incorporated her critical comments and included similar quotes from other people, as well as reference to theory to support my argument about complex forms of management and governance that were being enacted. I reasoned that perhaps she would feel reassured in not being a lone voice and hoped that the theory and my analysis might make some sense to her. The other interviewee's transcript contained comments I wanted to use about her employing organisation being a feminist organisation which was not reflected in the organisation's 'mission statement'. Again I had to decide how much surrounding text to extract from the research findings to inform her decision about granting me permission to quote her. Both granted me permission to use their quotes, and I presume they were satisfied that I had made reasonable use of their words and not abused the trust they had placed in me. This dialogic process happened outside the formal research ethics governance process and yet felt more meaningful and ethical as it was dependent upon trust and dialogue rather than a standardised research governance format (Murphy & Dingwall, 2007).

In another instance, I confess I caused distress and this confession entails an embodied, situational approach to research and to ethics (Miller, Birch, Mauthner, & Jessop, 2012). I interviewed two people (who happened to be local elected councillors) together and I posted the transcript to them. I received a reply saying that they wished to withdraw their permission, they felt abused, and would never take part in research of this nature again. Following the complaint I destroyed the transcript and only reproduce a minor detail here. The interviewees spoke in a local dialect that I shared, and sought to reproduce. Grammatical errors were not corrected as I believed that it would be more honest to send a transcription including colloquial speech in the same format that I might subsequently want to reproduce verbatim quotations from. I had included their hesitations as 'umms' and 'errs' and represented dialect, such as 'going to *me* meeting', rather than the grammatically correct 'going to *my* meeting'. The informal complaint made by these interviewees made it clear that in reproducing their grammatical errors and colloquial speech, they felt I had abused their trust and misrepresented them. The participants possibly had expectations arising from their experience of local bureaucratic committee work and may have anticipated an 'official' type of document or report rather than the verbatim transcript. I replied to their complaint, apologising and offering a meeting but heard no more. Whilst their reaction could be rationalised as a lay misunderstanding of the transcription process and of the purpose of qualitative research, I personally felt ashamed of my conduct. At some level I had been aware that I wanted readers of the research to infer from these quotations aspects of the interviewees' identity such as their working class location. I became immediately aware of the distress I had caused in deliberately representing these interviewees as undereducated. I felt I had disempowered the participants and abused their trust.

I still feel ashamed that I caused distress and remain concerned that the harm I have spoken of has no legitimate place in the current regulatory system; it cannot be reported, documented, or learned from. The reporting structure made it difficult for me to account to the ethics committee for changes made in the field or to report this form of distress. In an annual progress report required by the research governance arrangements, the 'amendments' section asked, 'Have any substantial amendments been made to the trial [sic] during the year?' I stated in italicised block capitals, '*THIS IS NOT A TRIAL*', and wrote: 'My research has had to respond to the exigencies of fieldwork', without describing what this process was. An astute reader of my report responsible for monitoring my research replied, asking for clarification. I responded honestly and more openly this time, explaining that as predicted, opportunities had arisen for further data collection and I had maintained ethical standards in pursuing these. I described some of my fieldwork contingencies such as my opportunistic sampling of meetings and observations of a local network. I explained that I had obtained informed consent from the group at an early meeting but pointed out, 'I cannot be 100% certain that subsequent new members joining the group are all fully informed about my research'. I offered the following justification: 'As I am maintaining strict confidentiality and anonymity I do not believe that any harm could arise to these participants whom I have observed'. Frustrated at non-recognition of my ethnographic method (and the assumption that my research was a clinical trial), I argued that my study had not diverged from the approved protocol.

My attempt at a dialogue about ethical research practice was ignored but I was informed in writing that my response was satisfactory. The harm that the interviewees felt I had caused them remained outside the purview of the biomedically dominated framework and so the supposed regulation was ineffectual and the broader system did not learn. This was partly because the ethics review process could not monitor every aspect of the ethnographic study but also because of the biomedical bias that did not recognise ethnography's emergent research design and conceptualised 'adverse events' as those resulting from medical intervention or medical negligence. Satisfying the ethics committee thus becomes the primary concern, and there are no means to respond in a way that ensures ethical conduct or to engage in dialogue about this.

Reflections on Our Experiences of Situated Ethics

Our two case studies demonstrate the tension between compliance with research governance requirements and maintaining an ethical sensibility. Most biomedical research rests on a positivist approach: assuming a stable truth, discoverable and verifiable through the application of experimental methods (Shapiro, 2009). Within the positivist paradigm, the investigator and investigated are independent entities, so the investigator can study a phenomenon without influencing it or being influenced by it; 'inquiry takes place as through a one way mirror' (Guba & Lincoln, 1994, p. 110). By contrast, qualitative methodologies, increasingly being used in health services research, such as ethnography, grounded theory, phenomenology, and case study methods are intended to be '[a]n enquiry process of understanding social and human problems based on building a holistic picture' (Cresswell, 2003, p. 1). Underlying these is the epistemological assumption that 'reality' is socially constructed (Berger & Luckmann, 1990) and is not reducible to measurable variables.

Our experience has been that the structure of ethics and governance processes in the UK and internationally is shaped by positivist approaches to knowledge epitomised by the randomised controlled trial; this claim is evidenced by the fact that more guidance is available for the assessment of the validity and reliability of quantitative research than for qualitative research (Dixon-Woods, Fitzpatrick, & Roberts, 2001; Oakley, 2002). Our aim in presenting these case studies was to foreground some ethical paradoxes and problems that qualitative researchers face as the direct consequences of the embedded assumptions within governance processes. The HRA is clearly interested in learning from practice and sought evidence on 'non-compliance with approved research protocols and the principles of Good Clinical Practice' (Health Research Authority, 2014, p. 1) to identify general principles of research governance to include in the revised Research Governance Framework. No requests were issued for evidence of 'breaches' or ethical dilemmas arising from qualitative studies.

A more extensive and nuanced understanding of what constitutes harm can be gained from the sociological literature (Dingwall, 2006; Hoeyer et al., 2005; Miller et al., 2012). Pam felt she had offended her participants because they indicated they felt distressed and abused, but this form of harm is not recognised by the GCP or by the clinical notion of a SUSAR. When we first drafted this chapter, a senior colleague challenged us, asking whether it was ethical at all to discuss a case when the participant had exercised their right and withdrawn from the study. Our considered response was that the risk of further harm was minimal and was outweighed by the benefit of facilitating learning from our fieldwork experience with the ultimate aim of enhancing ethical research practice.

Theories around empowerment and the representation of marginalised populations advocate allowing research participants' voices to be heard (Schostak, 2005; Sutton, 2009) but voice is essentially different from the written word in that non-verbal communication, tone, dialect, and inflection convey more meaning than 'mere' words (Alldred & Gillies, 2012; Forbat & Henderson, 2005; Hoeyer, Dahlager, & Lynöe, 2005). A study exploring the use of verbatim quotes produced mixed results (Corden & Sainsbury, 2006). Some participants valued the process of being represented through direct quotes, while others objected to the ways in which their quotes were contextualised and categorised according to researchers' judgements; for example, a person suffering mental illness preferred to be categorised simply by their gender. Hoeyer et al. (2005, p. 1746) argue, 'The psychological reaction to seeing oneself and one's ideas described, objectified and relativised, is difficult to predict and, thus, difficult to prepare for'. Forbat and Henderson (2005, p. 1116) note that 'analyzed quotations regularly appear in academic articles without any parallel reflection on how the participants might interpret that particular use of their words'.

Thus ethical dilemmas remain around the responsibilities of authorship, transcription, and representation. GCP ignores these issues and biomedical research has a tendency to treat participants as subjects, whereas participatory research methods allow for greater dialogue with participants. For example, in a study located in the discipline of social policy, Liz used direct quotations from disadvantaged children and represented them, following their direction, as 'estate children' and as 'private school children' (Sutton, 2009). Colloquial speech gave the research more analytical power and provided insights into the children's identities. It is important, however, to be mindful of how to represent research participants and to consider whether, and if so how, to gain their approval beforehand. We hope we have shown that the process of sharing transcripts is not straightforward but should encourage ethical reflexivity. Epistemological issues cannot be avoided and social constructionism challenges the positivist idea that there is a single authoritative meaning to be derived from a transcript. We have no simple recommendation to offer other than to urge qualitative researchers and members of ethics committees to familiarise themselves with the relevant ethical debates. There is currently no mandatory requirement for training that might address these ethical and qualitative issues of representing participants.

Embodied Ethics

A key question is *who* regulates research (Aldred, 2008), but a further question we ask is how *effective* is the regulation? Our experience has been that health researchers in the field are largely responsible for regulating their own ethical practice and that ethical practice is not something that can be signed off beforehand. Ethnographic researchers in the field inevitably face a range of occasions that demand emotional labour (Bergman Blix & Wettergren, 2015), for example, when hearing difficult information (Hubbard, Backett-Milburn, & Kemmer, 2001). We have learned from our experience that emotional labour in research is unacknowledged by GCP, consequently qualitative researchers can be left vulnerable and yet responsible for managing their own well-being. We have found that the emotional labour exacted by situational ethics is silenced in formal reports and in clinically oriented academic publications that may publish qualitative studies without fully appreciating the nuances of intersubjective fieldwork relationships. Expected to complete GCP and comply in ceremonial fashion with bureaucratic processes, we as qualitative researchers must, paradoxically, continue to act—at times—unethically in order to comply with regulation. Ironically, we become our own pseudo-ethical regulators.

Conclusion

Gaining ethical approval from committees and informed consent from participants may appear to legitimise research practice, but there are significant differences between a set of prescribed ethical codes and individual researchers' ethical practice. Qualitative researchers working in applied health research need to be aware of ethical codes but also require an understanding of how these may or may not be operationalised when responding to contingent ethical dilemmas. Thus, we practice in the interstices of the dominant biomedical regulatory gaze and we continue to labour in a space characterised by tensions that arise from fundamental differences between research paradigms and the shadow cast by one over another. Early career researchers deserve access to appropriate training and ethics committees need to understand the contingent nature of fieldwork so that applications to conduct qualitative health research can be judged appropriately and consistently. The current system requires that lengthy processes of securing research governance and ethical approval (even though ill-fitted to qualitative health research) must be factored into work planning, as funders of health research and participants alike have legitimate expectations of a timetable for completed research. The alternative (as we have heard from an experienced qualitative health researcher at a recent conference) is to abandon empirical health research and publish only theory. This solution is not an option as we are genuinely committed to undertaking fieldwork research that addresses the extant problems in the health field.

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4

Researching Sexual Healthcare for Women with Problematic Drug Use: Returning to Ethical Principles in Study Processes

Natalie L. Edelman

In this chapter I reflect on ethical issues encountered when I led the development and implementation of a mixed-methods survey-and-interview study on sexual health needs among British women with problematic drug use. As with all research studies, this involved planning a detailed set of research processes by which the study aims would be operationalised. Conventions can arise in research processes such as gaining consent or collecting data. For example, it is common in Britain to allow people who are eligible to take part in a study at least 24 hours to consider and ask questions about participation. This is usually put into practice by distributing participant information sheets to eligible recruits well in advance of consent and data collection. These conventions may emerge in the context of onerous research governance processes as a strategy to avoid anticipated delays and rejections.

Research processes (and therefore conventions which arise in relation to them) are a means of operationalising not only the research objectives but also the four fundamental principles—those of autonomy, beneficence, non-maleficence, and justice (Beauchamp & Childress, 2001). In certain instances, however, conventions can inadvertently undermine these ethical principles. Specifically, this chapter describes how adherence to research conventions would have led to the principles of non-maleficence and autonomy sidelining the principle of justice by denying some individuals the right to participate in a study of sexual healthcare needs among women with problematic drug use.

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The same study is used to provide examples of how conventions around consent can therefore be rejected in such instances, and alternative means of enacting research processes developed which still articulate fundamental ethical research principles. Central to this, the chapter illustrates the benefits of stakeholder consultation—with relevant services and especially with patients (as experts-by-experience)—in both identifying ethically sound alternatives and justifying those alternatives to systems.

Despite extensive stakeholder consultation and research ethics and governance approvals, ethical issues arose during implementation of the sexual health study. These included: risk of harm to researchers during recruitment, risk of harm to participants following qualitative interviews, and the ethical challenges of balancing justice (participants' right to speak) with non-maleficence during the qualitative research interviews. This latter issue is situated within a broader concern with how society and research systems constructed the researchers and participants as 'different kinds' of women.

Researching the Sexual Healthcare Needs of Women with Problematic Drug Use

The impetus for this study came when, as a sexual health researcher, I was invited to meet with a psychiatrist who specialises in substance misuse and who was concerned about the sexual health of women attending the service at which he worked. An 'outreach' sexual health clinic running one day a week from within the service was failing to attract patients, and so I examined the evidence surrounding sexual health services for women with problematic drug use (both those accessing and not accessing drug treatment services).

What emerged was a very small evidence base which mostly reported on women accessing drug treatment services in the United States and which rarely investigated patients' preferences for sexual healthcare. In addition, most studies did not look at levels of sexual health service use in the context of individual patient need, instead blanket assumptions were made that low service use represented *unaddressed* need rather than *lack of* need for individual participants. In response, I formed and led a small research team to apply for research funding to conduct our own study. This team comprised myself, a psychiatrist, and a consultant doctor in genito-urinary medicine—and after funding was obtained—a research fellow and research assistant. The key aim of this study was to develop a model of sexual health service provision for women with problematic drug use for use in Britain.

The term 'problematic drug use' is used with varying definitions all of which have a public health focus on the behaviour rather than the individual (to avoid stigmatising) and which encompass the notion of long-standing drug use, or of drug use which has significant negative impact on personal circumstances (Terence Higgins Trust, 2015). In the research described in this chapter, my colleagues and I invited women to participate who self-identified as having a 'substance misuse problem' as this is the most commonly used British term (Edelman, Patel, Glasper, & Bogen-Johnston, 2013). This was in keeping with our study's focus on the individual's experiences and needs, rather than a biomedical focus on objective definition or diagnosis.

The study was comprised of three key research activities:

1. A cross-sectional survey of women with problematic drug use to identify levels and types of sexual risk, engagement with services, and service preferences.
2. An in-depth qualitative interview study with a convenience sample of women who had completed the survey in order to gain a deeper understanding of the key barriers and facilitators to the uptake of sexual health interventions.
3. Development of a model of sexual healthcare provision. In order to maximise the chances of the research findings having an impact, the model was designed to be used by British Local Authority areas and was written as a commissioning framework which could be used 'off-the-shelf' by commissioners to tender local providers and to monitor implementation.

Applied sexual health research such as this often covers sensitive topics which people might find embarrassing, distressing, or compromising to discuss (Fenton, Johnson, McManus, & Erens, 2001). Therefore, very careful attention must be paid to research ethics. Beauchamp's four principles of biomedical ethics (beneficence, non-maleficence, autonomy, and justice; Beauchamp & Childress, 2001) is the most recognisable framework for research ethics in Britain. Therefore, my colleagues and I adopted it both as a way of addressing study ethics and as a means of articulating research plans to the systems in which the work was embedded.

In addition to the ethics of researching a sensitive topic, this study focused on a population whose susceptibility to harm or coercion may be greater than that for some other groups. Women with problematic drug use are often framed as a 'vulnerable' population. However, the notion of 'vulnerability' has also been criticised as stigmatising and decontextualising (Nathanson, 2013).

I chose, therefore, the notion of 'susceptibility to harm' as a construct which recognises how the research environment can attenuate that susceptibility through ethically sound processes (Levine et al., 2004). The tendency for populations deemed 'vulnerable' to be under-researched is well recognised; the term 'therapeutic orphans' was coined originally to describe the lack of paediatric health research (Shirkey, 1999). Women with problematic drug use are arguably another type of 'therapeutic orphan' so that the very act of researching this under-researched population can be viewed as an ethical act aligned to the principle of justice.

Identifying Salient Ethical Issues for This Study

Early conversations with relevant stakeholders (such as drug treatment services, homeless organisations, and police outreach) enabled my colleagues and I to better understand the ways in which our target population might be susceptible to harm, by identifying certain characteristics common among many women with problematic drug use that would need to be carefully addressed in the study design. In particular, there was a need to account for the likelihood that participants would variously be dealing with difficult emotional issues, insecurely housed, struggling to attend pre-arranged appointments, reluctant to engage with authority figures, and under the influence of alcohol and drugs.

These population characteristics had the potential to develop tensions in the study between the right to participate (justice) and other principles. Firstly, there was a need to grapple with the right to participate in the context of inebriation (which might affect capacity to consent and therefore would also affect autonomy). Staff at the local drug treatment service indicated that if the study required women to have taken no drugs or alcohol at the time of recruitment, we would have extremely few eligible women. Secondly, there was a need to address the right to participate in the context of women's ad-hoc and sometimes chaotic engagement with health services, which might also affect autonomy and non-maleficence by limiting opportunities to digest participant information sheets at leisure before consenting to the survey. Thirdly, there was a need to consider the right to participate in the context of emotional distress: in particular, non-maleficence was very important as evidence suggests women with problematic drug use experience high rates of sexual assault and abuse (Lincoln, Liebschutz, Chernoff, Nguyen, & Amaro, 2006).

Research Processes, Conventions, and Underlying Ethical Principles

The challenges of researching a particular population, ethical principles, and any tensions between those principles must be addressed and resolved through study processes. These research processes operationalise the research ethical principles outlined in the Declaration of Helsinki (World Medical Association, 2013) which broadly correspond to those set out by Beauchamp and Childress (2001). For example, informed consent to participate in a study pertains to autonomy, while the use of proxies when capacity to consent is problematic pertains to non-maleficence. These processes can give rise to more specific conventions. Examples from previous National Health Services (NHS) research include: *written* informed consent, the use of formal 'capacity to consent' assessments, and adherence to specific format and content in participant information sheets.

Over-reliance on specific conventions may, ironically, limit the scope and integrity of the very ethical principles which they are designed to operationalise. In particular, conventions are often exclusionary and best suited to non-opportunistic recruitment of patient groups who are predominantly highly literate, socially enfranchised, and receiving ongoing care for the condition being studied. For example, the requirement to read a participant information sheet at least 24 hours before recruitment may not be achievable for episodic disease or for populations which make contact with health services in an ad-hoc or chaotic fashion. Where a specific convention inadvertently acts against the ethical principles which it is designed to support, it is important to identify the principles underlying that convention in order to find an alternative means of enacting those principles.

While examining which principles underlie which conventions, it emerges that ethical principles can conflict at times. In particular, NHS research conventions could be argued to privilege the tenets of non-maleficence, beneficence, and autonomy in a way that conflicts with the principle of justice (the 'right to participate' in research) in a generalised way. This was manifest in our sexual healthcare study as described in the previous section. Arguably, many NHS research conventions do not attend to the ways in which the principle of justice may be made vulnerable by written informed consent, or by repeat visits to ensure participant information sheets have been read. Interestingly, the privileging of non-maleficence has not been found to guide ethical decision-making when dilemmas arise during implementation (Page, 2012).

Importantly, by ignoring justice as a legitimate principle, research may contribute towards population health inequalities. Specifically, when we repeatedly study—and therefore base healthcare on—society's most enfranchised, we unwittingly privilege their health over those in greater need. In order to respond to the ethical concerns and tensions of our particular study, my colleagues and I rejected some of the conventions of NHS research processes and instead sought adaptations which were nonetheless underpinned by core ethical principles (Beauchamp & Childress, 2001). This was a daunting task and needed expert advice from those who knew our target population. Therefore, we consulted a number of stakeholders on the design of our study before we sought ethics approval, not only from relevant services, but most importantly women with problematic drug use themselves.

Patient and Public Involvement

In Britain and other countries across the Western world, it has become common practice to consult patients and/or the public about proposed health research and sometimes to invite their ongoing collaboration as 'experts-by-experience' within the study team (INVOLVE, 2017). There are competing rationales for this patient and public involvement (PPI) that can be defined broadly as consequentialist (to improve the quality of the research) or deontological (because it is morally right to involve those who potentially would be invited to participate and/or who stand to benefit from the study's findings) (Edelman & Barron, 2015). Interestingly, both these justifications are congruent with the idea of maximising recruitment because protecting the right to participate is both a justice issue and, by increasing the number and diversity of potential participants, a methodological issue also. In the context of this study, PPI allowed us to find appropriate alternatives to research conventions which sought to maximise recruitment in exactly these ways, as well as helping to operationalise non-maleficence and beneficence.

My colleagues and I were fortunate to have obtained funding to be able to meaningfully engage experts-by-experience in the study design process before applying for research ethics and governance approvals. Funding for PPI is usually only available as part of large grants. Ironically, by the time the application process is complete, a great deal of the study design has been finalised. The processes and structures by which research funding is obtained can be thought of as the first system which is encountered in the research process and which will affect research aims, methods, and consequently research ethics processes too. Specifically, narrowly defined health outcomes, quantitative methods, and recruitment conventions may be favoured by research funders.

The research team followed key guidance on how best to conduct PPI (INVOLVE, 2012). Firstly, we drew up a role description (rather like a job description) which was handed to women attending the drug treatment service, when staff felt that individuals met the criteria. We were mindful that PPI is not subject to the same ethical scrutiny as is conducting the research itself, yet we were approaching the same population and the topic would still be sexual health. My colleagues and I were also mindful that we had only limited resources for this activity. Therefore, after lengthy discussion, we included in the role description criteria that women should be at a stable time in their drug use, literate, and not likely to be unduly distressed by the topic.

Six women subsequently rang the team, of whom three elected to join the study as experts-by-experience. One immediately ceased contact and another ceased contact after the first six months (thus, she was involved throughout the design stage). We used a mixture of one-to-one meetings in person and by phone, postal review of documents, and attendance at group study meetings to gain input from our experts-by-experience. Nonetheless, PPI was challenging to implement at times because none of the women had internet access or were familiar with email use at the beginning of the study. We also had to ensure they did not incur financial costs related to their study involvement, and that we could reimburse them and reward them for their time without making vulnerable their statutory benefits. This involved strategies such as sending out stamped addressed envelopes with documents for review and recompensing with gift vouchers.

PPI proved to be a powerful tool in crafting the study design to our specific population of interest, in identifying alternatives to research conventions, and in providing sound justification for doing so when we sought NHS and university research ethics approvals for the study. These are the concrete ways in which the design of the survey and interview studies were informed by the PPI during the design stage of the study, before ethical approval was sought:

1. Consideration of novel recruitment sites for the survey (certain public toilets, a soup kitchen, 'crack-houses' where drug use and dealing was known to take place). These were ultimately rejected as environments where we could not protect the well-being of the individual during participation. However, these discussions enabled the research team to improve our understanding of the lives of the women we wanted to recruit and the adversities they faced.

2. Distinguishing between study advertisement and study recruitment, and subsequently co-designing advertisements which invited women to attend the drug treatment service or homeless centre in order to participate in the survey.
3. Identifying relevant advertising sites for the survey—including specific public toilets, supported housing projects, and local counselling services, which were all known to be used by women with problematic drug use regardless of their engagement in drug treatment.
4. Rejecting the recommended format for participant information sheets for both the survey and interviews (on the basis that no one would read them) in favour of colourful and abbreviated designs in which each section of the recommended format was depicted as a speech bubble with a first-person question (e.g., 'Do I have to take part?').
5. Displaying the participant information sheet for the survey as a poster (and as takeaway leaflets) in all the recruitment sites' communal and waiting areas for three weeks before the recruitment period and until the study ceased.
6. Developing a capacity to consent three-item checklist which recruiting staff could use before taking consent for both the survey and interviews and which did not require complete sobriety. This was adapted from one commonly used in mental health settings—with help from service staff—as a tool which could be used to assess unobtrusively whether an eligible woman was too inebriated to be able to give informed consent.
7. Ensuring that non-offensive and clear language was used in the survey questionnaire (colloquial terms for different sexual acts were rejected as offensive, the survey instructions instead relying on clear descriptions such as 'vaginal sex means a man's penis inside a woman's vagina').
8. Establishing the type and value of recompense for participation in both surveys and interviews: to avoid coercion, to meet hidden costs that might prevent participation such as childcare or travel, and to recompense without affecting statutory benefits or otherwise causing harm (gift vouchers were therefore offered for shops where alcohol could not be purchased).

Overall, these amendments point towards the value of PPI in every element of the design process for health and social care research studies. This value is both methodological and ethical with regard to maximising recruitment potential and the right to participate, and also acts as an important ethical strategy towards identifying and minimising potential harms which might otherwise be invisible to the researcher.

Working Within Systems that Govern Research

Over-reliance on research conventions (certainly in British settings) may be a response to an onerous system of research approval, often with the added pressure of a deadline from the research funder. Recruitment and data collection procedures often mimic other studies which have previously achieved approval in the hope of minimising rejection and delay. Approval systems vary between countries, but in every setting, they will form the infrastructure in which ethical issues intrinsic to each study must be addressed, resolved, and explained.

As British research involving NHS patients, our sexual healthcare study was subject to review and approval by Britain's National Research Ethics Service (NRES). The study was approved by the Brighton West NHS Research Ethics Committee in 2009 (reference number 08/H1111/104). Alongside this, individual universities in Britain also require researchers to use their own ethics and research governance approval systems and to obtain their sponsorship. Individual NHS providers also require research governance checks to be completed. Finally, other systems and organisational structures must be traversed in order for applied health research to be conducted 'in the field'. For example, in this study, my colleagues and I recruited in a drug treatment service and a day centre. Each site had its own processes for working with external agencies and, of course, its own working structures and timetables to which we had to conform.

While seeking university ethics approval, I had to address two issues raised informally by an ethics committee member. Firstly, I had to provide reassurance that the survey's drug-use questions had a strong precedence of use in research and that drug-taking itself is not illegal in Britain (so that it was not ethically problematic for researchers to keep such information confidential). There was also concern around our plans to offer shop vouchers as recompense for participation, in case women stole from those shops while buying products with their vouchers. These concerns arose from poor understanding of drug use and populist representations of drug users, demonstrating how systems can unwittingly re-enact discriminatory treatment of certain groups in society. In the application I was careful to point out that it would be ethically unsound to amend the study design in order to attend to unfounded prejudices. I also reported in detail on the consultation which had led us to design the study in that way (discussed earlier in this chapter). Consequently, not only was approval granted, but I was able to challenge entrenched prejudices.

Ethics Beyond Approval

The strategies put in place at ethics review seemed comprehensive, particularly as they were informed by extensive PPI and other stakeholder consultation. Indeed, it is likely that the burdensome nature of British NHS ethics and governance processes can lead to false reassurance about the ethical integrity of a study. However, ethics approval cannot 'bulletproof' the ethical integrity of research, and it was important to continue to notice and address ethical concerns beyond those specified in the protocol. A number of ethical concerns emerged *after* ethical approval had been granted which had been unforeseen by any of the parties involved and which related to non-maleficence.

The first of these concerns involved the research fellow and I experiencing hostility from some male attendees while we were sitting in the main café area of the day centre waiting to recruit. This was a particular issue as approximately 90% of attendees were male, and nearly all women who attended the day centre did so with a male partner. The issue was discussed in-depth with centre staff and our experts-by-experience. The solution was that we volunteered at the counter of the service's café. We became familiar faces with a visible role as café staff and researchers. In this way we became acquainted with regular attendees and answered their questions about the study, and we developed a rapport with women who might be eligible for the study. It also gave us a 'safe space' behind the counter should we experience verbal or physical hostility. It was an extremely rewarding experience which broke down barriers and allowed us the opportunity to relate to people we did not ordinarily encounter.

The second concern with non-maleficence concerned the timing of research interviews. In preparation for conducting semi-structured interviews, I and the other researcher had undergone specialist training in which we focused on how to ensure a safe space for the interviewee by keeping a focus on the research questions, maintaining clear boundaries, addressing distress sensitively, and so on. Despite these precautions, I became concerned about the well-being of a woman who took part in a research interview with me one Friday lunchtime. During the interview she disclosed a sexual assault experience which had happened while sleeping on the streets, and became distressed as she was also anticipating sleeping on the streets that night. I followed due protocol by asking if there was a trusted key worker on site whom I could invite into the conversation, and she elected to talk separately to her. Her key worker assured me that it was beneficial that she now knew this woman's experience, but communicated that she was unable to secure immediate housing or other support for her at such short notice. As a result, I decided, in my role as Chief Investigator, to suspend research interviews on Fridays to avoid a re-occurrence of this experience for other participants.

Thirdly, both this particular interview and others raised tensions between each woman's right to speak freely during research interviews versus a responsibility to ensure her emotional well-being. This tension manifested, and was situated, within a broader concern with the ways in which 'the interviewer' and 'the participant' might consider each other to be 'different kinds' of women, reflecting the societal and research systems which generate these roles. This is discussed further in the next section of this chapter.

The Right to Speak

The focus of the research interviews was women's experiences and attitudes towards sexual and reproductive health interventions and services. Therefore, participants were asked about experiences of use and reasons for non-use of these services. We adopted a suitably broad definition of service and intervention use, including contraceptive advice, cervical screening, sexually transmitted infection (STI) testing, and pregnancy care. Discussing experiences in relation to these topics led some women to either directly report or hint at painful experiences, including sexual assault, domestic violence, and the removal of children from their care. Implicit disclosure often involved strong hints of traumatic experiences, such as reporting that 'upsetting things' had been done that they did not want to talk about, or talking in general and hypothetical terms, for example, about the difficulties of attending appointments if 'someone' has a controlling partner.

The different ways in which these experiences were communicated required extra attention to non-verbal cues. I and the research fellow consciously tried to balance participants' agency (their right to speak and autonomy) with non-maleficence (by not probing for women to disclose or reflect when they weren't comfortable to do so). In other instances, the research fellow and I were mindful that participants were discussing 'off-topic' but very sensitive issues they had not previously consented to. We were keen to ensure that such discussion did not leave them feeling unsafe, while also not wishing to be paternalistic in determining what was best for that participant by 'shutting down' that topic of conversation. Our specialist training was invaluable in these situations, enabling us to guide the respondent back to agreed topics in a sensitive manner.

These reflections and dilemmas speak to differences between colloquial and academic understandings of what constitutes an interview. In particular, I reflected that women had consented to be interviewed about certain topics, but not necessarily to be questioned in-depth about inconsistencies between beliefs and behaviours (such as recognising the need for a cervical screen but not attending) or to be pressed into discussing topics at which they only wished to hint. Reassuringly, several participants volunteered that they had found their interview useful as an opportunity to reflect on their experiences and reasons for non-engagement with services. This feedback—that women welcomed an opportunity to think through their sexual health needs and how to meet them—formed a key part of the recommendations that arose from our study.

We also became conscious that we were conducting interviews in the context of a perceived power imbalance in which we, as researchers, were viewed by some participants as powerful authority figures. This became apparent when we noticed that interviewees would quickly disclose their drug-use history in detail, regardless of the opening question. From discussions with service providers and experts-by-experience, we realised participants were habituated to offering this information in the context of interviews with perceived authority figures. To redress this we arrived at specific actions. Firstly, extra efforts were made to adopt a non-judgemental stance both verbally and non-verbally. Secondly, participants were given physical control of the audio-recorder and advised to record or cease recording according to their wishes. Thirdly, after struggling to avoid drug history disclosures at the start of interviews, a drug history was consciously built into the topic guide. This acted as a way of beginning a rapport between the interviewee and researcher and became a useful starting point in building a 'framework' for each woman's life events upon which we could better explore her experiences of sexual health interventions and services.

This perceived power imbalance between participant and researcher manifested how each of us positioned—and was positioned by—the other, which reflects how society more broadly positions us as 'different types' of women. This notion also emerged when some interviewees appeared ashamed of their experiences. At such moments I felt a desire to self-disclose my own experiences of intimate partner violence and considerable recreational drug use as a younger woman in the hope that the interviewee might see me as less different from herself and particularly not as 'better'. This notion of challenging the boundaries between the researcher and the researched has been taken up particularly in feminist research (Oakley, 1993). In feminist research, self-disclosure is an established ethical and methodological approach aimed at creating equity of power in the research interview (Reinharz & Davidman, 1992). If this approach had been adopted the data generated might have been less 'polluted' by power and difference. However, I decided not to pursue it as the approach is contentious (Baker & Benton, 1994), and not one in which I or the research fellow had experience. Also the research fellow did not share my personal experiences. Nonetheless, with greater forethought, training, and planning, the use of self-disclosure in qualitative interviews may offer a means of more ethical research practice where power inequity between researcher and interviewee impact negatively on the latter and on data quality.

Conclusions

Competing priorities and tensions will always underlie research ethics. Outside the study impetus itself there are a number of research and non-research organisations and systems to consider and work within, regardless of in which country the study is situated. In the British context these are: NHS research ethics, university ethics and sponsorship, NHS research governance, research funders' stipulations, and the structures and processes of the NHS and other care organisations where research may be enacted. Alongside the agendas and priorities of structures and organisations, tensions between ethical principles are easily induced and exacerbated by research conventions. In particular, there can be a tension between the right to participate (justice) and the right to be unharmed by that participation (non-maleficence). Where research conventions act to contravene rather than support an ethical approach to research, it is vital to revisit the ethical principles which purport to underlie them in order to identify ethically-sound alternatives. This offers a meaningful way to work within the restrictions which systems place upon research, particularly among populations that are 'therapeutic orphans'.

Consultation with experts-by-experience (and other stakeholders) provides a firm foundation for identifying pragmatic and ethically sound alternatives to research conventions. PPI can be a powerful force in both identifying alternative procedures which meet ethical principles and presenting a convincing argument for those alternatives to existing systems and structures. This can be particularly valuable in the context of research ethics committees which may have a propensity to approach review of study processes through an acritical and/or positivist lens. Equally important is that researchers maintain a critical gaze on research ethics beyond the approval stage in order to respond to concerns and take up opportunities to improve ethically our research practice.

Research systems and study processes themselves can echo and perpetuate not only societal rules, but also the disenfranchisement of certain populations in society. This mirroring of societal issues into research and service contexts was extant in this study. Firstly, I understood the perceived inequity of power, which we tried to counter in the research interviews, as a reflection of how the participants experienced authority figures and drug treatment services in everyday life. Secondly, it was striking how many qualitative interview participants reported never being asked about their sexual health needs or service use. This may reflect both a lack of confidence among staff to do so, but also perhaps the way in which society tends to sexually objectify and yet simultaneously 'de-womanise' those women who experience problematic drug use (Ettorre, 2007).

The contribution of experts-by-experience in improving the ethical integrity of studies is valuable and unique. At the same time, the recognition of a shared humanity between researcher and participant can also act to guide ethical practice with regard to honouring participants' right to speak and minimising the impact of broader societal inequities in the research environment. The enactment of ethical health research can also lie in the subtle ways by which we treat participants with dignity and respect and so practice non-maleficence and beneficence.

Future research would benefit from critical reflection on whether the research processes are directed by convention or by ethical principles with a view to engaging experts-by-experience in giving primacy to the latter. Attention to ethical integrity is a vital component of study implementation, responding to power inequities and balancing non-maleficence with justice in order not to sideline the latter. Happily, my colleagues and I have found that research conventions in our local area have shifted to incorporate more opportunistic recruitment strategies since this study was conducted in 2010, and we have become aware that some of the ideas in this study have been used subsequently. Perhaps this is indicative of how the setting of precedents can allow new and more inclusive conventions to take hold. Nonetheless, the best possible new convention would be a return to ethical principles for each new study that is developed in order to ensure that those principles are placed before convention and can be enacted in the systems which underpin research practice.

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5

Contesting the Nature of Young Pregnant and Mothering Women: Critical Healthcare Nexus Research, Ethics Committees, and Healthcare Institutions

Tracey Feltham-King, Yolisa Bomela, and Catriona Ida Macleod

When researchers enter institutions to collect qualitative ethnographic data, they inevitably encounter complexities within these systems (Ball, 1990). These complexities not only call for nuanced means of data collection and analysis, but also have implications in terms of the ethical engagement of researchers. In this chapter we describe how systemic contradictions may complicate ethical site entry and data collection, particularly for researchers adopting a critical lens. Using our Foucauldian-based ethnographic research within South African antenatal and postnatal clinics as an example, we explore how the process of negotiating ethical clearance and interviewing participants (in this case, teenaged pregnant and mothering women) may lead to major contradictions. In our case, these contradictions consisted of diverging views of minors in different state-produced policies and legislation; discrepancies in our research aims and the assumptions made about the research by members of the University Ethical Standards Committee (UESC), managers, healthcare providers, and parents; the

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dilemmas we experienced in health service providers' negotiating access to teenaged pregnant women[1] for us; and the contradictions that our socially assigned demographic characteristics brought to the fore in the actual interviews.

We conducted ethnographic research in two public healthcare clinics located in an urban area of the Eastern Cape, South Africa. We were interested in examining the reproductive healthcare nexus surrounding teenaged pregnant and mothering women who access antenatal and postnatal healthcare provision. We defined this nexus as the intersection of the power relations which construct various individuals, groups, institutions, associations, private companies, and government departments as they collectively deliver antenatal and postnatal care. Utilising a feminist Foucauldian approach, we asked questions and approached the topic in a critical manner that sought to overturn the usual negative framing of teenage pregnancy and to highlight its embeddedness in multiple power relations. In this chapter we outline how it was exactly this kind of critical framing that brought us face to face with a range of ethical dilemmas, mostly generated from the taken-for-granted notion of the pregnant and mothering teenager as a marginalised and problematic subject who needs remediation.

In the following section we provide some background to our research problem regarding the construction of pregnant and mothering teenagers and of the health service providers within the healthcare nexus. We briefly outline how we conducted the research before turning to the major ethical dilemmas that we faced. We explain how the power relations that were implicit in the divergent views of teenaged pregnant and mothering women were negotiated within specific institutions such as the UESC and the clinics in which the research was conducted. We discuss relational spaces within which we were working, which allowed for multiple locations, representations, and positions.

Background to Reproductive Healthcare in South Africa

It has been acknowledged by researchers in South Africa that, despite a stated policy commitment to a rights-based approach to sexual and reproductive healthcare for all women, the translation of these rights into practice is often not achieved at local and community level (Rhoda et al., 2014). The attainment of sexual and reproductive rights is considered especially important within the historical context of South Africa, since many 'black'[2] women were excluded from claiming these rights under Apartheid. The legacy of Apartheid continues to hamper the development of health services. Despite excellent legislation and policy, health service providers are often hard-pressed to deliver services in clinics which are over-subscribed and under-resourced, resulting in a lack of access to healthcare provision for many people, particularly those living in rural areas or former townships (areas designated for 'black' people under Apartheid) (Müller, Röhrs, Hoffman-Wanderer, & Moult, 2016).

The South African Demographic and Health Survey 2003 (Department of Health, 2007) shows that compared with pregnant women who are 20–34 years old, pregnant women under the age of 20 are more likely not to receive any antenatal care. They are less likely to be informed of the signs of pregnancy complications; to have their weight, height, and blood pressure measured to have urine and blood samples taken; or to receive iron supplements.

The lack of access to quality antenatal and postnatal healthcare experienced by pregnant teenaged women is tied to their perceived illegitimacy as healthcare users. The World Health Organization (2011) reports that globally adolescents are overlooked as legitimate recipients of reproductive healthcare owing to the problematisation of teenaged pregnancy and sexuality. In mainstream research, the pregnancy of a teenaged woman is identified as evidence of her immaturity and neglect, and of a failure of the system to prevent and reduce teenaged pregnancy, thereby creating unneeded pressure on antenatal and postnatal healthcare service provision (Cherrington & Breheny, 2005).

Our Research

From the outset, our interest was not focused on individuals or institutions per se, but rather on how the healthcare provision nexus formally and informally constructs teenaged pregnant and mothering women (their sexual and reproductive conduct, their gendered and familial relationships, their individual habits, their feelings, their knowledge, and their mothering potential). We explored the discursive positionings made available to teenaged pregnant and mothering women and health service providers through the practices of reproductive health service provision, as well as how these young women and the health service providers comply with or resist these discursive positionings and healthcare injunctions.

Our data collection made use of a wide range of sources to capture the traces of diverse yet recurring discourses (such as adolescence, pregnancy, womanhood, motherhood, and heterosexuality, to name but a few) to ascertain how these discourses made particular kinds of antenatal and postnatal interactions possible. So, for example, we conducted observations of the formal and informal practices within the clinic. In the waiting rooms we observed and recorded the delivery of informal health education and collected the accompanying booklets which were distributed by salespeople to waiting women. We conducted formal observations of consultations between young women and the health service providers as well as interviewed both health service providers and young women individually about their experiences. We also collected a range of documents utilised in the clinic.

Researchers working from a critical perspective argue that we should be vigilant about the power relations that the very notion of 'teenage pregnancy' (and subsequent motherhood) allows. This involves an analytics of the gendered/raced/classed power relations that cohere around young women and reproduction and a refusal of abstractions that pre-define the pregnant teenager (Macleod, 2013). In the specific context in which we conducted the research, the operation of the power relations was complicated by an already problematised subject entering a problematic healthcare context. We were aware that a particular politics of representation and location were at work in our negotiations for access, in our interactions with the participants, and the complex ethical issues with which we were faced. By representation, we are referring to how we, as well as the young women and the health service providers, were positioned and represented in particular ways. By location, we are referring to our epistemic position as researchers, our own and the participants' racial and gendered identities, as well as the geographical space of the former township (Macleod & Bhatia, 2007).

Institutional Power Relations: The University Ethical Standards Committee

In South Africa, debates about social science ethics have only taken place fairly recently as a result of researchers being obliged to engage with ethics review (Wassenaar & Slack, 2016). The South African Department of Health issued national guidelines for the conduct of ethical health research in 2004 which have subsequently been updated (Department of Health, 2015).

These guidelines outline standards for research conducted with minors in South Africa. Pregnant teenaged or mothering women are potentially classified not only as technical minors (if they are younger than 18 years) but also, by virtue of their (current or recent) pregnant status, as additionally vulnerable research participants. This had implications for our application for ethical clearance.

We lodged our application with the UESC in 2011.[3] The UESC is registered with the National Health Research Ethics Council (registration number REC-241114-045) and reviews research proposals and ethical standards protocols in accordance with national policy and guidelines. The University's ethics policy stipulates that the committee should operate independently and be composed of nominated members from each Faculty as well as ex-officio members. We thus anticipated that our application would be considered by a diverse group of individuals who would have varied views with regard to the vulnerability of research participants.

Our first application was not approved and was accompanied by an unusual set of responses such as 'Would you like your pregnant teenaged daughter to be interviewed by a Foucauldian?' and 'If I was the pregnant teenager (and I had the power to do so) I would tell the researcher to Foxtrot Oscar [fuck off]'. We know that our experience was not unique, since many researchers such as Singh et al. (2006) had previously outlined the disjuncture experienced by South African researchers who acknowledge the critical need to research sexuality and young adolescent women but face numerous constraints in getting permission to do so. We interpreted the combative tone of the UESC's responses to our proposals as signifying that they were alarmed and concerned about our engaging research participants, who had an ambiguous status in the eyes of the law and whom they chose to position as vulnerable, immature, and incapable of independent decision-making.

South Africa's regulatory framework around adolescent sexual reproductive health is complex and, at times, contradictory (Müller et al., 2016). The South African Constitution (1996) protects a minor's right to make decisions regarding reproduction and to access healthcare services. While several laws action these constitutional rights and make them accessible to children, they are often contradictory. For example, the Choice on Termination of Pregnancy Act (CTOPA; Act 92 of 1996) allows girls of *any* age to request an abortion up to 12 weeks, and the National Health Act (NHA; Act 61 of 2003) mandates that all information concerning a patient is confidential. In slight contradiction to this, the Children's Act (CA; Act 38 of 2005) states that minors from the *age of 12* may not be refused condoms and contraceptives, and that such provision must be kept confidential. This contradiction with regard to age is compounded by the Sexual Offences Act (SOA; Act 32 of 2007), which says that children may only freely consent to sex at 16 years of age (prior to this, sex is statutory rape). This framework is complicated further by mandatory reporting requirements imposed by two of these Acts: the SOA mandates that any person with knowledge of a sexual offence against a child (including consensual sex below the age of 16) must report this act to the police, while the CA requires certain professionals to report reasonable belief of sexual abuse to a range of reporting agencies, including social workers. Therefore, attempts to regulate aspects of teenagers' access to sexual reproductive healthcare, to demarcate acceptable and unacceptable sexual conduct, and to specify the obligations and responsibilities of sexual and reproductive healthcare workers are ambiguous.

These points were made clear in our initial application with our proposing a way through the conundrums. However, the UESC took very different views from ours about two matters that the above contradictions highlighted: (1) whether the teenaged pregnant or mothering woman could autonomously consent to participate in the research and (2) the responsibilities of the researchers who, being party to knowledge of underage sexual activity, would be required by law to report it (in accordance with the framework). These two issues had to be attended to before we received ethical clearance to proceed.

The UESC clearly viewed the teenaged pregnant or mothering woman as a vulnerable minor who is at risk of harm and could only participate if she had the permission and support of her parents or guardians. Phrases such as 'a particularly vulnerable population targeted because of its vulnerability' were used throughout the feedback. By contrast, we argued that how vulnerable or 'at-risk' young mothers are in relation to older mothers in similar sociodemographic circumstances is a matter of debate, with some arguing that the age, per se, of young women does not mean that they are at increased risk. We referred them to a summary of the debate in Macleod (2011). We did, nevertheless, acknowledge that some of the young mothers may be vulnerable and argued that the ethical provisions that we put in place spoke to this possibility.

Aside from the question of specific vulnerabilities, we viewed our participants as autonomous or mature minors (Department of Health, 2015) who, despite the contradictions noted above, were recognised legally as being able to decide on contraceptive usage and to terminate a pregnancy. Indeed, in a ruling on a high court challenge to the stipulation of the CTOPA that minors do not need parental consent to access abortion, the judge found that age should not be used as a criterion on which to judge the competence of a woman to make a decision regarding a termination of pregnancy (Christian Lawyers Association v Minister of Health and Others, 2004). In line with this, we argued that these young women, whether supported or not by their parents, could consent autonomously to an interview about their experiences of antenatal or postnatal care. In either case (whether the young woman had informed her parents or not), we believed that she would nevertheless derive some benefit (but certainly no irreversible harm as initially implied by the UESC) from participating in research interviews. We believed that those who were in the early stages of pregnancy and could potentially still terminate their pregnancies but who had not told their parents should not be forced to tell their parents in order to participate in the research.

We drew on the Council for International Medical Science Guidelines (2006), which state that in some cases, the ethical review committee may waive parental permission, especially if parental knowledge of the subject matter (such as a pregnancy) might place the young women at risk of further questioning or even intimidation. Furthermore, in the South African context, the *Ethics in Health Research* guidelines (Department of Health, 2015) specify clearly that there are exceptional circumstances in which minors may autonomously consent to participate in research projects if four conditions are met. These conditions are as follows: (1) that the adolescent participant is placed at no more than a minimal risk; (2) that the nature of the research is such that, in the opinion of the research ethics committee, the parents, legal guardians, or community at large are unlikely to object to the adolescent herself consenting to participation in the research; (3) that the research protocol provides sufficient evidence to justify clearly why adolescents should be included as participants and why they should consent unassisted; and (4) that the purpose of the activity must be to meet the health needs of the mother and that the risk to the foetus should be minimal.

We allayed the concerns of the UESC by arguing that participation in a research project of this nature did not *further* compromise the health needs of the teenaged pregnant woman or the foetus. In addition, we argued that a precedent had been set in the CTOPA in which it is recommended that in the absence of parental consent, young women would be counselled to talk to a 'trusted' adult before deciding to undergo the procedure. We suggested following the same protocol in that should young women (younger than 18) not want to ask their parents for permission to participate in the research, we would counsel them to talk to a trusted adult about their participation. In practice, the need to refer a participant to speak to a trusted adult never arose, since the few participants who were younger than 18 were more than willing to get parental consent before participating in the research.

With regard to the second issue (namely the responsibility of the researcher to deal with the legal requirements of the SOA (Act 32 of 2007) by reporting knowledge of underage sexual activity), it was agreed that we would enquire from the clinic manager how this issue is dealt with, at the clinic, prior to engaging in data collection. As researchers, we undertook to ensure that the legal stipulations were covered in such a way that made it unnecessary for us to complete an affidavit to report knowledge of illegal activities. We believed that health service providers probably would have engaged with this piece of legislation, whether they agree with it or not, and therefore conversations around how they negotiate the law so as to facilitate the well-being of the teenagers would be of interest to the researchers. McQuoid-Mason (2011) argues that the reporting requirements under the SOA contradict the intention of the CA (Act 38 of 2005). The latter Act prioritises the need to protect adolescents' health. While these tensions may be resolved in practice at the discretion of the healthcare workers, in theory, the current legal framework does not provide such discretion, and also does not differentiate between consensual and non-consensual sex amongst children under the age of 16. In practice, we found that clinic managers were unaware of the Act so we provided copies of the legislation, thereby facilitating access in order to make them aware of the stipulations.

The frustrations that we experienced in negotiating permission to conduct our research highlighted important linkages for us. We noted how the politics of location and the politics of representation are linked in the process of data collection. In terms of the politics of representation, we were taking up a position in relation to our research participants, and were informed by a critical approach which was not familiar to the UESC. Our representations of what the envisaged focus of our research would be (namely the power relations within the healthcare nexus) could not be recognised. The ethics committee's locational power as gatekeepers (who enjoy epistemic privileges to dictate the way in which the research problem could be framed) enabled their obstruction of our progress. We had to adjust our ethical protocol to accommodate their view of the doubly vulnerable, non-autonomous, pregnant or mothering young women.

Even once we had gained permission to proceed, we understood that we would have to be very clear and explicit about locating ourselves theoretically and specifying the purpose of our research activities to those we encountered in the field. In the section that follows we describe the ethical dilemmas that arose despite our attempts to be explicit.

Institutional Power Relations: Antenatal and Postnatal Clinics

Once we received ethical clearance from the UESC, we had to go through the time-consuming and bureaucratic procedure of obtaining ethical clearance to conduct the research from the Department of Health at the provincial and local level.[4] Whilst this process was frustrating owing to inexplicable delays, eventually permission was granted eight months later without requiring any revision to our applications. However, despite this official permission and ethical clearance, there were still a few health service providers who viewed us with suspicion as non-trustworthy outsiders when we presented ourselves at the clinics. We tried repeatedly to articulate the purpose of our research projects as *understanding the provision* of antenatal and postnatal care to teenaged women within the nexus. This was translated by many health service providers as equivalent to an evaluation of their actions within antenatal and postnatal healthcare provision. We interpreted this suspicion as justifiable in the context of systems of surveillance that operate as tools of management within clinics as well as the deluge of negative media publicity of service provision in public healthcare facilities. The unintended consequences of these accountability systems (which very often point the finger of blame at the individual health service providers) are that while the health service providers continue to struggle to work in under-resourced and over-subscribed environments, they also develop a sense of mistrust and resentment of any form of external interference.

Once in the field we found ourselves negotiating continuously with clinic managers, health service providers, and parents about what they assumed our focus should and would be, namely the individual teenaged pregnant or mothering woman for the purposes of remediation. The health service providers whom we interviewed (in a series of 18 interviews) ranged from medical specialists and consultants to doctors, professional nurses (including midwives), staff nurses, nursing assistants, interns, and student nurses. Two-thirds of the interviewees were women. The men who were interviewed were either doctors or student nurses. While these participants had different levels of interaction with pregnant and mothering young women, they shared a fairly homogenous traditional medicalised view of teenaged pregnancy and motherhood as problematic in terms of both health and socially. We were reassured by health service providers that teenaged pregnancy and motherhood was a growing problem, that health interactions were more complicated with young women, and that if we were looking for pregnant teenagers, ‘we had come to the right place’. We were welcomed and hailed as allies who could ‘do something about these girls’. Even parents who heard about us would approach us in the waiting room with requests to ‘talk some sense’ into their daughters.

The sheer volume of these representations, the regularity with which we encountered them, and the conviction with which they were delivered made them difficult to counter. We recognised these representations as a kind of focusing illusion. By foregrounding the age of the pregnant woman, the clinic managers, health service providers, and parents reduced teenage pregnancy to an individual problem. We were forced to accept that we could not easily have our different focus recognised as valid, and that we would have to allow the illusion to continue because it was too complicated to undo in brief conversations. Instead, we resolved to uncover the multiplicity of power relations in our analysis of this research project by shifting the narrow focus from the problematised individual subject to making visible other intersectional complexities.

Medical Hierarchical Power Relations

At both sites we felt initially that it would be useful to befriend the nurses first, as they would be able to facilitate introductions to teenaged pregnant and mothering women. Very soon, however, we realised that there were power relations embedded in the way in which health service providers interacted with patients. These relations demonstrated a very different understanding from ours regarding the subjectivity of young pregnant or mothering women. It became clear that it was not easy for health service providers to disrupt these taken-for-granted hierarchical ways of interacting with 'patients' which were at odds with what was considered acceptable and ethical practice for researchers when dealing with research participants.

For example, we had explicitly stated in our discussions with health service providers that we would appreciate their help in recruiting teenaged women. We anticipated that the health service providers (with access to the maternity case file) would refer women (who were younger than 20 years) to us in private by simply giving them our information cards and taking down their contact details. We envisaged that we would telephone these women when they were no longer at the clinic to discuss whether they would be willing to be interviewed. On one occasion, however, and without our prior knowledge, a well-meaning health service provider used her institutional authority by publicly calling for women (younger than 20) in the waiting room to identify themselves and proceeded to instruct them to participate in our research. Such actions could be interpreted as an example of 'street-level bureaucracy' (Müller et al., 2016, p. 71), which is a process by which health service providers develop their own day-to-day processes to manage and simplify their workloads despite knowledge of policy and legislation around informed consent of patients.

This recruitment strategy was untenable for us. We experienced a self-silencing because we knew that speaking out immediately was risky, since it could be read as contradicting the authority of the health service provider in the presence of the patients. We relied on health service providers' cooperation and permission to remain as observers in the waiting room. But by choosing to remain silent, we also had to acknowledge that this could be read as collusion with the institutional power relations by the teenaged pregnant and mothering women who were our potential research participants. In an attempt to undo the damage, we did not follow-up with any of the participants who identified themselves on that day. We cannot know how these potential participants responded to our lack of follow-up, but in the context of the possibility of coercion, we felt that this was the best route to follow.

As a result of this experience, however, we changed our recruitment strategy. We worked on setting up alternative recruitment avenues which excluded the direct involvement of health service providers. Identifying women (younger than 20 years) based on their appearance proved to be a very inaccurate method. Older women in the waiting room were also often curious about what we were doing there. Therefore, to clarify our presence as well as shift some of the power into the hands of the participants, we started giving all women in the waiting room (regardless of their age) information cards. On these cards, we explained our research (in English and isiXhosa) and asked them to return the cards with their names and contact numbers if they were younger than 20 and willing to be interviewed. Interestingly, many women in the waiting rooms who were older than 20 years were unhappy about their exclusion and felt that their experiences were problematic and in need of research. Even though we were not able to interview older women, it highlighted for us our point that women of similar socio-demographic characteristics share similar challenges, regardless of their age.

This new recruitment method gave potential participants time and space to volunteer confidentially and unobtrusively. In addition, when we received contact details, we waited until they had time to carefully consider participation (and possible withdrawal) and telephoned them when they were away from the clinic to arrange a time for an interview. Sometimes, young women declined participation at this point. Often, the interviews did not take place within the perimeter of the clinic, but in other informal spaces such as coffee shops, and even in our cars parked in the parking lots outside the clinics. In this way, we hoped that we could minimise the institutional power relations which we felt could have had an effect on our research interview interactions.

Our Own Gendered and Raced Positions

Our own gendered and raced positions featured as factors in the process of the complex contestations of discursively positioning young pregnant and mothering women, and assumptions about what our research should be or was about. Data were collected by the first two authors, one of whom is a middle-class, middle-aged, 'white', English-speaking woman, the other a middle-class, middle-aged, 'black', isiXhosa-speaking woman. Both these authors were conducting their PhD research in Psychology at the time under the supervision of the third author, a middle-class, middle-aged, 'white', English-speaking woman. All three authors have children, and are thus familiar with the process of antenatal care, albeit in more privileged situations than in the clinics we researched.

For the first author, her racial designation as a 'white' person led to contradictory positioning. At the security checkpoints, at the entrance to each site, it was often assumed that she was a doctor and was automatically greeted as such. This highlighted the historical legacy of Apartheid when 'white' people would enter the hospital intended for 'black' people for the purposes of delivering services and not for healthcare, since their healthcare was more likely to be serviced by private healthcare practitioners. Ironically, she was also misrecognised by other health service providers within the clinic who assumed that she was a patient. A 'white' intern expressed surprise when she introduced herself as a researcher, admitting that he had been trying to avoid her since, according to him, 'white patients have such a sense of entitlement'. For the second author, while her racial designation as a 'black' person and isiXhosa speaker positioned her as similar to the vast majority of healthcare users, as an older professional woman, it was also assumed that she was employed at the hospital and was often approached for requests for help from patients. Thus, age, race, and class designations, all contributed to contradictory positionings of the researchers.

The relationships that all of us experienced with teenaged pregnant and mothering women were never equal and hardly reciprocal by virtue of the classed, raced, age, and professional power relations at work in our encounters. These real-world ethical dilemmas, which were encountered during this research, kept in check any romantic notions we might have harboured about our role as researchers. Many teenaged women expressed surprise and confusion about our requests to interview them. This confusion sprang from a lack of familiarity with research processes, conflation of the role of psychologists as possible healthcare providers,[5] and researchers working in the discipline of psychology, as well as interview anxiety. Despite our best efforts, it was necessary to provide continued and additional clarification as the research process unfolded in order to overcome some of the common misconceptions about our respective roles as researchers in the process of data collection.

One participant, for example, responded to a request for an interview in the mistaken belief that we were interviewing her for the purposes of offering employment. One of the questions we routinely posed about antenatal and postnatal care in the course of our interviews was: 'Beside the antenatal or postnatal services you receive at this clinic, are there any other services available to you?' Routinely, participants would reply that they had no access to any services other than the most basic healthcare offered by the clinic. One participant articulated this as, 'I only have the clinic and you'. In this way, she was articulating that she saw us as a resource and as facilitators to access other services or better attention in the services she was utilising. Indeed, there were instances where young women approached us in the clinic, knowing that our intervention could easily resolve issues. We were not only older women who knew the health service providers by name (by virtue of spending an extended period of time in the clinic), but as outsiders, we had the power to advocate on behalf of patients. Thus, when a young woman (who had been seated in the queue for hours and was clearly experiencing labour pains) was repeatedly ignored by the nurses, we were approached to intervene, and this led to an immediate resolution of the delay. Our positions as older, middle-class women allowed the young women participants to view us in a particular light.

We began to understand that many of the young women were searching for psychological support for a variety of issues, many of which were not directly related to their pregnancies or mothering identities. Unsolicited and personal disclosures about experiences of sexual violence, rape, abandonment, homelessness, and exclusion from school were articulated in the course of our research interviews. Our association with a psychology department possibly encouraged the young women to make these disclosures. We referred those participants (whom we deemed in need and who were willing) to appropriate psychological support services at the local university (at no cost to them).

Discerning the extent to which we could ethically deviate from a professional research relationship into a personal relationship was by no means clearcut. Besides the personal toll of being a witness to instances of social injustice, we also needed to discern which requests for help were reasonable and which extended beyond what it was possible for us to fulfil. For example, when we were contacted by a participant with a request to advocate for continued financial support for her studies from her mother, we were left in a quandary. After discussion, we felt that such a request was beyond what our knowledge of the situation allowed. We also felt that it was not our place to pry into the private affairs of the family by *initiating* contact with the mother. By way of compromise we made our number available to the participant so that her mother could telephone us for a discussion but that offer was never taken up.

Finally, our positions as 'experts' led the participants to understand the interviews in particular ways. Two participants admitted that before our interview, they had gone for extra consultations, wishing to be fully prepared for the interview. Ultimately, most of the participants expressed surprise or gratitude upon completion of the interview because it had not been the daunting evaluative experience they had anticipated and possibly because sharing their experiences had had a cathartic effect. This indicated that despite our attempts at reassuring participants, it was difficult to ensure that they felt completely comfortable from the start of the interview. Perhaps this was simply because of the nature of interviews, when feeling unsure or vulnerable in the face of questioning is to be expected. Or it may relate to the extent to which power relations dictate that young women are not familiar with the process of being listened to with regard to their experiences of pregnancy and motherhood. Their experiences in the clinic, up until that point, had possibly been more interrogatory and, as a result, they were expecting to be held to account for their pregnancies or potentially to be shamed about being young mothers during conversational interactions.

Conclusion

Our research illustrates the ethical conundrums and potentialities that conducting systemic research using a critical lens foregrounds. Glaring divergences in our assumptions and those of the UESC and the health service providers became evident with regard to (1) understandings of the pregnant and mothering teenaged subject (as generally autonomous agents, with the possibility of particular vulnerabilities, versus vulnerable, immature, and incapable of independent decision-making) and (2) what the focus of our research was or should be (power relations operative within the healthcare nexus versus locating the source of the problem of 'teenage pregnancy'). These discrepancies resulted in our being silenced in ways which could have been read as collusion with the hierarchical power relations of university ethical standards committees and of healthcare institutions. We could not forego ethical clearance by contesting the ways in which teenaged pregnant women are represented in legislation; neither could we insist that health service providers change how they view the pregnant or mothering women in their care. On the positive side, we were able to devise alternative strategies to subvert some of the dominant power relations, realising that contradictions are a feature of the various intersecting discourses at work in the research and healthcare nexus.

Aside from the politics of representation that these varying assumptions display, we used our critical lens of the politics of location to understand how our own socially assigned demographic characteristics added another layer of contradiction. Through our experiences, we realised that effecting epistemic violence (violence in the course of producing knowledge (Macleod & Bhatia, 2007)) does not require specific intention. Our socially designated positions in terms of age, race, and class meant that our research was, in many instances, experienced as surveillance of a problematised subject (young pregnant and mothering women) and of a problematic healthcare system.

We experienced the demands of ethical engagement as a continuously reflexive, active, and ongoing process of questioning the dilemmas which saturated not only the research process but also us as living research instruments. The use of our critical lens foregrounded the contradictory fluidity, multiplicity, and historical contingency of our own and other identity positions within any power nexus (for more detailed discussions on self-recognition and reflexivity, see Feltham-King, 2016[6]).

We argue that epistemic harms and violence are wrought when there is a failure to acknowledge the power relations at work in research (both outside of and between researcher and participants). Failure to do so results in single taken-for-granted accounts and traditional explanations of complex phenomena which are perpetuated as 'the ways things really are' if not challenged by researchers. This form of social injustice can be mitigated by researchers questioning entrenched ways of thinking about research or research participants, and by negotiating the contradictory positionings of self and others.

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Notes

1. We acknowledge that our use of the signifier 'women' excludes transgender men who may give birth. We retain the term women, however, as our research was intended to focus on the constructions of young women specifically, and all of the pregnant or mothering participants in our research were cisgender women.

2. Racial signifiers have had particular pertinence in South Africa. We use inverted commas in recognition of these categories which are socially constructed and have continued real effects in power relations and the allocation of resources.
3. Ethical Clearance (2011Q4-2 and 2011Q4-3) was granted by the Rhodes University Ethical Standards Committee on the 1 April 2012.
4. Permission to conduct the research was granted by the Eastern Cape Provincial Department of Health in a letter (without a clearance number) dated 14 December 2012.
5. Given the under resourcing of public mental health services, it is unlikely that these participants would have consulted a psychologist; at best, they may have been referred to a social worker. Nevertheless, as indicated, many mistook the researchers for healthcare providers.
6. As a part-time student, Yolisa's thesis is still being written up.

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6

Ethics in Transdisciplinary Research: Reflections on the Implications of 'Science with Society'

Jessica Cockburn and Georgina Cundill

There is growing recognition of the need for science to improve its contributions to solving urgent societal problems and for academia to critically question its contributions to improving human well-being (Perry, 2006; Seidl et al., 2013). One strategy which has been proposed in social-ecological systems and sustainability research is for researchers to take a transdisciplinary research (TDR) approach and to conduct 'science with society' (Seidl et al., 2013). TDR approaches have arisen as a critique of the narrow focus of positivist or realist approaches dominant in natural and (some) social sciences (Klein, 2014; Popa et al., 2015), and we consider a critical realist underpinning an important foundation for TDR (Bhaskar, 2016). By adopting a critical realist stance in a field of science mostly characterised by positivist or realist paradigms, we recognise the importance of critical research that foregrounds the subjective role of the researcher, emphasises reflexivity on assumptions and values (Popa et al., 2015), and goes beyond the conventional epistemological boundaries between research fields to address societal problems (Bhaskar, 2016). Thus, we consider a transdisciplinary approach in sustainability science to be well aligned with the shifts to critical research that are evident in the social sciences.

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We begin this chapter by describing TDR as defined in the sustainability sciences. We then consider the potential ethical implications of taking a TDR approach. This is followed by a reflective case study on the preliminary consultation processes of a PhD research project in which we are explicitly taking a transdisciplinary approach. Through this case study, we share our experiences of the ethical challenges involved in research not accounted for in current procedural ethics systems, since these primarily focus on minimising negative impacts on human participants during formal data collection activities. We explain the ethical clearance procedures which we encountered at the university and also how we went about adopting a transdisciplinary approach in this context. We reflect on lessons learnt while reading for this PhD on the ethical challenges of TDR and conclude with some recommendations, both for individual researchers and for institutions of higher learning, for addressing these challenges and building ethical practice in TDR.

The Process of Transdisciplinary Research

Transdisciplinarity is a reflexive research approach that addresses societal problems by means of interdisciplinary collaboration, and, by transcending the boundary between science and society through collaboration between researchers and societal actors, enables mutual learning and knowledge co-production (Jahn et al., 2012; Lang et al., 2012). TDR thus involves the engagement of non-academic societal actors throughout the research process, from question formulation through to the re-integration of results at the science–society interface (Fig. 6.1). This engagement requires effective, trust-based working relationships between academic and non-academic actors, which brings with it particular implications for ethical research practice, as will be illuminated below. Although primarily we draw on interpretations and practices of TDR in the sustainability sciences, there are alternative lineages of transdisciplinarity and various understandings of the approach and its implications for researchers (Hirsch Hadorn et al., 2006; Klein, 2014; Russell et al., 2008). Reflexivity in TDR comprises four aspects: (1) deliberation on the overall normative and epistemic orientation of the research; (2) deliberation on the socially relevant framing of research problems; (3) generation of reflexivity on values and understandings in concrete problem-solving and social experimentation processes; and (4) generation of reflexivity on normative commitments and ideological orientations in social transformation processes (Popa et al., 2015).

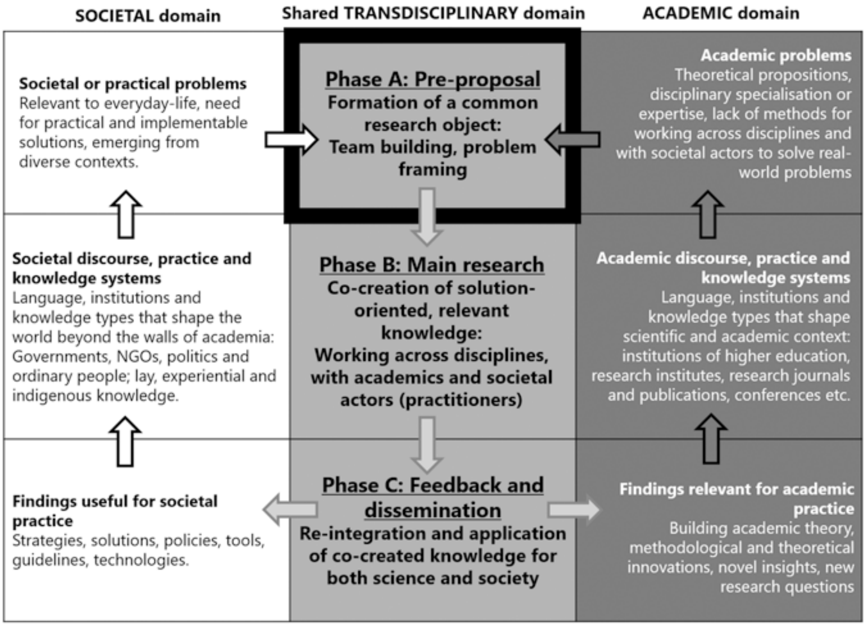

Fig. 6.1 Conceptual model of a TDR process which bridges the gap between societal and academic domains and seeks to co-generate socially relevant, solution-oriented knowledge (modified from Lang et al. 2012; Jahn et al., 2012)

As shown in Fig. 6.1, the TDR process considers research problems and questions (top); discourses, practices, and knowledge systems (middle); and the context in which results of findings will find meaning (bottom) in both the societal (left) and academic (right) domains. These are brought together in the shared transdisciplinary domain (middle). The research process in the transdisciplinary domain can be divided into three phases, though these are not as distinct nor are they as linear as portrayed here. In Phase A, the team is formed and research questions are identified. Some applications of this model of TDR have suggested adding a 'Phase 0' before Phase A, in recognition of the time and resource-intensive nature of building meaningful research relationships, even before research questions can be jointly formulated (Cockburn et al., 2016). In Phase B, the research is conducted collaboratively by working across disciplines and including both societal and academic actors and knowledge systems to co-produce knowledge. In Phase C, research is re-integrated into both societal and academic domains, taking cognisance of the kinds of knowledge products most suited to each domain. This chapter is focused on the ethical challenges which we faced during Phase A of the TDR process: the pre-proposal phase.

Ethical Considerations of Transdisciplinary Research

As more researchers take up the challenge of TDR, current research ethics clearance procedures (i.e. procedural ethics) in institutions of higher learning pose a challenge. Procedural ethics are often based on conventional, positivist research in which societal actors only become involved during the data collection phase as subjects of research rather than as participants. Therefore, these procedures do not account for ongoing engagement from the early stages of research (Fig. 6.1, Phase A). Current timelines, structures, and institutional arrangements which govern research ethics committees (RECs) do not allow for the kind of flexible, preliminary, and open-ended arrangements required for the pre-proposal research engagements which were necessary for a TDR process in our study. We reflect further on these limitations below.

Ideally, for PhD students to stay true to TDR principles, they would work collaboratively as part of a team which includes participants from diverse disciplines within academia and participants who are ‘societal actors’ (i.e. who are themselves not academics). In other applications of sustainability science, researchers may work in unidisciplinary teams and would not engage with societal actors at all; thus, TDR explicitly bridges the divides between disciplines, and between academic and non-academic actors (Lang et al., 2012). Not all PhD students, however, are embedded in such teams with existing working relationships, and it has been recommended that individual PhD students seeking to conduct TDR could consider building a ‘transdisciplinary epistemic community’ around themselves (van Breda et al., 2016). This means developing a team of people from different disciplines and from non-academic communities of practice in support of the PhD project (Cundill et al., 2015). The case study presented in this chapter is an individual transdisciplinary PhD project in which the student had to build new relationships and develop a ‘transdisciplinary epistemic community’ from the start of the project. The ethical concerns of working with and collecting information from human research participants or research partners during this early stage of research, before ethical clearance was received, are the focus of reflections in this chapter.

Limited literature exists on the ethics of TDR. However, with its focus on engaging with societal actors beyond academia, working collaboratively and encouraging participation, emphasising reflexivity, and taking a problem- and change-oriented approach, TDR has similarities with action research, participatory and collaborative action research, participatory community-based research, and other allied research approaches and methodologies. Researchers working with these approaches, which are more well-established than is TDR, have begun to grapple with the ethical implications of engaged, dynamic research and the challenges that are faced with institutional ethical clearance procedures (Box 6.1).

Similar concerns have been raised by researchers working in the social sciences using qualitative research methods such as ethnography and narrative (Israel, 2015; Parsell et al., 2014), longitudinal research studies exploring individuals, groups, and phenomena over time (Miller, 2013), and creative and transformative research methodologies (Kara, 2015). Many of these concerns are linked to the historical origins of ethical review procedures in the biomedical and clinical disciplines and their underlying positivist research paradigm (Parsell et al., 2014). Critical researchers share similar concerns, as is evident in the contributions to this handbook. Our case study thus contributes to a growing body of research on the ethical challenges of engaging societal actors as partners in the research process, whether this be in an explicitly transdisciplinary approach or in the allied approaches with similar foundations that are mentioned above.

Box 6.1 Procedural ethics challenges faced by researchers who adopt engaged, dynamic research approaches allied to transdisciplinary research

- Lack of experience of research ethics committees in dealing with and reviewing unconventional research projects (Locke et al., 2013; Parsell et al., 2014).
- The nuanced and complex relationship between the researcher and the 'researched' is not often appreciated (Locke et al., 2013; Smith, 2008).
- The key role of good relationships and trust between researchers and research participants as a means of mediating ethical practice is not recognised (International Institute for Environment and Development, 2014; Locke et al., 2013; Smith, 2008).
- Overemphasis on individual autonomy whereby informed consent is seen as an individual, one-off activity, rather than a collective, negotiated, ongoing process (Locke et al., 2013; Smith, 2008; Williamson & Prosser, 2002).
- 'Informed consent', 'beneficence', and other principles of procedural ethics cannot be clarified at the start (Locke et al., 2013; Parsell et al., 2014; Smith, 2008) because the focus and nature of the research often only emerge over time through interaction between researcher and research participants.
- There are unclear boundaries around the 'ownership' of research data and findings (Locke et al., 2013; Smith, 2008), and difficulties are faced in guaranteeing confidentiality of data in collaborative research processes (Parsell et al., 2014).

Case Study of a PhD Doing 'Science with Society'

Overview of the PhD Research Project

The project which is the focus of this case study is currently under way. The authors of this chapter are the PhD student (Jessica) and her supervisor (Georgina). The aim of the research is to explore enablers and barriers of collaboration for environmental stewardship in agricultural landscapes, through the lenses of social-ecological systems and sustainability science. A transdisciplinary framing was chosen for the research as it is based on collaborative relationships with practitioners, such as local non-governmental organisations (NGOs), who are working with local farming communities to facilitate improved environmental stewardship. Furthermore, the research is interdisciplinary, working across the social and ecological disciplines. Through this engagement with environmental stewardship practitioners, we aim to facilitate mutual learning between researchers and practitioners to co-produce new knowledge on the theory and practice of environmental stewardship.

Engagement with Societal Actors in the 'Pre-proposal' Phase

This PhD research project differs from conventional research processes in which research questions are defined by researchers prior to engaging with research participants, particularly in the pre-proposal phase (Phase A, Fig. 6.1). During this phase, we sought to co-develop the research questions for the PhD in partnership with environmental stewardship practitioners. The intention was to draw research questions not only from the academic literature, but also to include the research needs, interests, and questions from practitioners actively working with local farming communities to facilitate stewardship. This included six months of informal discussions and meetings with practitioners whilst Jessica was still working as a stewardship practitioner before beginning full-time PhD studies, as well as continued engagement once the PhD had officially started in January 2015.

The aim of this engagement was to capture insights and questions emerging from the practice of stewardship in South Africa to frame the research. This was done through participation at a practitioners' conference, through key informant interviews, and, where possible, a site visit, to gain an understanding of the local contexts of potential case studies. An integral consideration in the process of case study selection was a recognition of the social, economic, and political contexts in which this TDR was unfolding. In a South African context, Swilling (2014) has warned of the 'dramaturgy' of co-production in a context wherein research participants have unequal capacity and opportunity to contribute. Since this study focused on the rural South African contexts where race, class, and power find expression in land ownership and tenure security, it was decided early on that case study selection would specifically include both private and communal land. This decision was made in order to pursue inclusive conversations about stewardship that would not privilege the voices of wealthy and predominately white private land owners. Indeed, it was noted early on that most NGOs were pursuing stewardship on privately owned land, and therefore additional effort was expended by Jessica to identify and engage NGOs that were explicitly breaking this mould and working with black communal farmers.

During this time, it was also crucial to emphasise the preliminary and scoping nature of the discussions and visits so as not to raise expectations. It was also important to clarify what the implications would be of joining in the TDR process. Jessica also had to make assessments of the suitability of practitioners as research partners based on their willingness to participate, their availability, and their openness to mutual learning. For example, one practitioner who seemed exceptionally supportive of the research was eventually deemed an unsuitable research partner, as he was never available for meetings to discuss the next steps. Similarly, in another potential case study, the overall approach and design of the case study seemed like a good fit for the project. The case study leader, however, felt that there had been too much research conducted in the area already and that there might be resistance to participation in yet another research process. Thus, Jessica carefully had to navigate the various possible case studies, in order not to jeopardise relationships while making the best decisions for the research project and ensuring the inclusion of marginalised voices which might otherwise not find their way into stewardship research. In the six-month period from January to June 2015, this information gathering was complemented with a literature review on stewardship, and in this way, the research questions and framing was a combination of societal and academic discourses and knowledge systems (Fig. 6.1).

Ethical Approval Process at the University

The ethical approval process at our university is governed by an ethical standards committee and a university policy on ethics. This policy dictates that all university research involving human participants must have prior approval of the committee or one of its authorised sub-committees. This PhD research project does involve human participants as it includes social science research methods, primarily qualitative interviews, and participant observation. In the case of this project, a departmental sub-committee (Department of Environmental Science) is the authorised committee for ethical clearance procedures. According to this sub-committee, doctoral students are to prepare a research proposal in which they outline the potential ethical concerns of their proposed research, along with suitable strategies to address such concerns. The research proposal, including a specific section outlining research ethics which is in effect the ethical clearance application, is submitted to the sub-committee for consideration (as a written proposal supported by an oral presentation). The sub-committee can then give ethical approval for the research project, or if there are ethical concerns which cannot be dealt with at the departmental sub-committee level, the proposal and the ethical clearance application are then forwarded to the ethical standards committee of the university for further consideration. It is recommended that the development of a research proposal (including the ethical clearance application) at PhD level should take approximately six months in the case of full-time studies. During these six months, the student is expected to spend time reviewing the literature and developing research questions, methods, and a detailed research plan. Once the proposal and ethical clearance application have been accepted, the student may then begin data collection.

In our case, however, we did not follow this procedure, as Jessica spent the first 12 months of her PhD gathering information, generating knowledge, and building relationships with societal actors (environmental stewardship practitioners in South Africa) to co-develop the research questions and frame the research project collaboratively. This was done outside the bounds of the university's policy on ethics. The question now arises: how did we ensure that we followed appropriate ethical principles during this pre-proposal stage of the research? What lessons have we learnt from this unintended experiment of researching beyond the conventional rules of procedural ethics and working closely with societal actors in a research project which took place beyond the boundaries of formal, institutionalised rules, and guidelines for ethical conduct?

Reflections and Lessons: 'Science with Society' Requires Everyday Ethics, Reflexivity, and a Relational Approach

By taking personal responsibility for the day-to-day decisions on the ethics of engaging with societal actors in this research, we recognised an important lesson: making a clear distinction between 'procedural ethics' (i.e. the ethics which are codified in institutional ethical clearance procedures (Guillemin &

Gillam, 2004)) and 'everyday ethics' (Rossman & Rallis, 2010), also called ethics in practice (Guillemin & Gillam, 2004). This means that as researchers we recognise the role that procedural ethics play in formalising ethical practice and in keeping both researchers and institutions accountable and responsible (Israel, 2015), but we appreciate that ethical research practice actually takes place outside the bounds of the procedural ethics system and that researchers must bear the ultimate responsibility for ethical research decisions so that they need to 'think ethically on their feet' (Guillemin & Gillam, 2004; Rossman & Rallis, 2010) and actively develop an 'ethical sense' (Farrimond, 2013). This means being conscious, aware of, and reflecting on the key ethical principles as outlined in procedural ethics and applying them in practice. The following guiding principles of ethical research practice which we considered as informing our practice of everyday ethics were drawn from the university's policy on ethics:

- Respect and dignity of research participants
- Transparency and honesty in all aspects of research
- Accountability and responsibility of the researcher
- Integrity and academic professionalism of the researcher

The principles of respect and dignity were applied, for example, when we co-developed the research questions in partnership with stewardship practitioners and presented some of these initial themes and findings at a conference. We kept the identity of the practitioners confidential, even though no formal commitment had been made to them in a formal informed consent process. When Jessica started developing a 'transdisciplinary epistemic community' (van Breda et al., 2016) in the early stages of her PhD, the importance of the principles of transparency and honesty became apparent: she made it very clear that although she was scoping for case studies for later in the research process, the early engagements with practitioners did not guarantee that their project would be selected. This was particularly difficult to do in cases in which practitioners showed great enthusiasm for the research and a keen interest in participating in a case study. The primary example of applying the principles of accountability and responsibility is the fact that we recognised that the pre-proposal engagements with societal actors were taking place outside the bounds of procedural ethics and that we needed to take full responsibility for everyday ethics decisions at this stage of the process. This applied to both of us in our capacity as student and supervisor, respectively. Jessica had a vested interest in one of the NGOs that were engaged early in the PhD process, which required paying attention to the principles of integrity and academic professionalism. This vested interest was a result of having previously worked with that NGO and of having pre-existing relationships with the staff. In selecting case studies for the PhD, Jessica had to ensure that these existing relationships did not influence selection of case studies unduly by unfairly favouring one case study over another. The selection of case studies was based on several criteria, including the social, ecological, and agricultural features of the cases in relation to the research questions and framing, and the tenure arrangements of the land in question; we recognised up front that an entirely objective selection of cases (which would have been required in a positivist research methodology) would not suit our TDR principles. In order for the transdisciplinary knowledge co-production process to be of value to both parties, the willingness of participants to join in, and the ease of working relationships between researchers and partners, also had to be taken into account. Acknowledging and reflecting on this vested interest upfront is an example of integrity and academic professionalism. These examples illustrate that although there is a distinction between procedural ethics and everyday ethics, there is in fact a continuum between them whereby the guiding ethical principles as set out in procedural ethics documentation can and should be used to inform everyday ethics (Rossman & Rallis, 2010), and this becomes especially important in TDR.

Jessica also committed to taking responsibility for and considering any additional ethical concerns which may arise because of a transdisciplinary approach in which social engagement with human participants is more intense than in conventional research, which is also recognised as a challenge in participatory action research (Smith, 2008). This brings with it, for example, the need to manage research fatigue (Clark, 2008): Jessica was committed to building trusting relationships and good communication with research partners and participants wherever possible to allow for open communication channels and feedback, so that she could track research fatigue and respond accordingly. Furthermore, in taking an explicit transdisciplinary approach, her role as a researcher was slightly different from that of more conventional research in that she was both a researcher and a 'change agent'. This means that she has a value standpoint regarding the kind of transformative social change she would like to see (Parsell et al., 2014). She was committed to being open and honest with research participants about this and took a reflexive stance in her dual role. Another important strategy here was continually to reflect on and discuss these challenges with supervisors and others with similar experiences, as described in the next section.

In developing an ethical sense, one of the most important practices is reflexivity, and we consider this an important lesson learnt. Reflexivity is considered a tool for ethical research practice, particularly in the field, where researchers do not have access to procedural ethics committees or experts (Guillemin & Gillam, 2004; Parsell et al., 2014). Reflexivity is recognised as a cornerstone of effective qualitative research, but it is usually considered a tool for ensuring rigour in research rather than a practice for ethical research (Guillemin & Gillam, 2004). Guillemin and Gillam (2004, p. 274) provide a brief review of the concept of reflexivity in qualitative research and draw together various definitions in their interpretation of the concept as: 'a process of critical reflection both on the kind of knowledge produced from research and how that knowledge is generated'. This requires a continuous practice of critical scrutiny and interpretation of the research process, not just of the methods and the data but also of oneself as the researcher and of one's research partners and participants, and one's relationship to them (Guillemin & Gillam, 2004; Rossman & Rallis, 2010). Jessica brought reflexivity into her research practice through frequent journaling, joint reflections with other researchers in the communities of practice described next, and through regular discussions with her supervisory team about not only *what* she was researching, but *how* she was researching, *why* she was interested in particular case studies, and *whether* she was achieving the kinds of inclusion she had hoped to achieve.

Recognising research, and in particular ethical research, as reflexive practice puts relational matters into the foreground, and trustworthiness becomes far more important than technical or procedural ethical matters (Locke et al., 2013; Rossman & Rallis, 2010). In fact, procedural ethics is founded on the premise that research is being done on participants with whom we have no prior relationships, and plan no future engagement (Ellis, 2007). However, a relational approach to research ethics is crucial in TDR because of the importance of the relationships between researchers and their researcher partners whilst doing 'science with society' (van Breda et al., 2016). By taking a relational approach to ethics, open and honest communication and negotiation with research participants become crucial skills and practices for researchers (Guillemin & Heggen, 2009). Merely 'ticking the boxes' of procedural ethics is insufficient (Israel, 2015): '[R]relational ethics requires researchers to act from our hearts and minds, acknowledge our interpersonal bonds to others, and take responsibility for actions and their consequences' (Ellis, 2007, p. 3). In Jessica's PhD, we found this to be particularly important in the early pre-proposal stages. At this stage, the research activities were not focused on data collection, but rather on getting to know the stewardship practitioners, understanding their projects and the context they work in, and getting a better sense of the questions emerging from their practice. This was the beginning of Jessica's building of a 'transdisciplinary epistemic community' (van Breda et al., 2016) premised on shared research interests, relationships of trust, and open channels of communication. This relied both on existing work which Jessica had developed whilst working as a stewardship practitioner and on her ability to build new relationships along the way. Building such new relationships takes time and is not always successful; without the existing relationships which helped the pre-proposal phase gain momentum, it would have been difficult to develop an effective transdisciplinary epistemic community within the timeframes of a PhD (van Breda et al., 2016).

Lessons from Participating in Transdisciplinary Research Communities of Practice

One of the ways in which we managed the ethical challenges faced during this TDR project, was through conversations arranged to share insights and lessons with researchers experiencing similar challenges in their work. Jessica is involved in two such 'communities of practice': (1) an international network of young scholars called the Social-Ecological Systems Scholars and (2) a local, university-based group called the Rhodes University Transdisciplinary Research Group (TDR Group). Participation in these groups provided valuable opportunities for joint reflection and discussion about ethical challenges, and about how best to engage in and build relationships with research participants and stakeholders in diverse contexts.

Discussions with other researchers in the TDR Group revealed that many other TDR scholars have also had pre-proposal engagements with societal actors outside the bounds of procedural ethics. The strategies they employed to deal with the everyday ethics challenges they faced during these engagements included open communication with research participants about purpose and intent of research, request for feedback and consent from research participants, and ongoing reflection and discussion with the research supervisor and peers on ethical issues. These insights illustrate that TDR does indeed bring with it distinct ethical challenges, and that strategies are required to guide and inform ethical practice in this field. Among the most important of these is fostering conversation: both between transdisciplinary researchers grappling with these ethical challenges and between researchers and research participants. We also consider it important to foster conversations between researchers working in TDR projects and the institutional RECs, which could aid in broadening the community of practice of ethics for TDR (Wolf, 2010).

Recommendations and Conclusion

Through reflection on our experience, and through discussions with other transdisciplinary scholars, we have identified several strategies that transdisciplinary researchers can employ to deal with the challenges of procedural ethics outlined in this chapter. First, we propose that individual researchers take responsibility for working towards the development of an 'ethical sense'. This means internalising the guiding principles of ethical research and making them part of everyday ethics practice, and taking responsibility for relationships developed during engaged research processes (see the earlier section 'reflections and lessons'). This could aid in shifting the responsibility for considering the consequences of research actions from a distant ethics review committee to the researcher in the field, and thereby moving ethics from procedure to practice. Second, we encourage researchers to identify and to participate in a community of practice grappling with similar ethical concerns which can facilitate collective reflection and discussion with peers. This is an important part of developing the ethical sense described above and of ensuring accountability as a researcher, whilst contributing to scholarly debate not only on the content of research, but also on the process. Third, we believe it is crucial for scholars to develop a practice of reflexivity in all aspects of research, but particularly in the ethical aspects of research. This means continually asking questions not only about what is being researched, but also about how it is being researched, as well as reflecting on our own personal assumptions and value standpoints. Without such reflexivity, researchers may risk over-reliance on procedural ethics, may take insufficient responsibility for their actions in relation to others, and may not cultivate the open-mindedness necessary for meaningful knowledge co-production. Finally, we argue that taking a relational approach to ethics may be important in building ethical practice competency in individual researchers. We recommend that researchers pay attention to the importance of open and honest communication and negotiation with research partners and participants around issues of ethical concern, and to the role of relationships of trust and respect in developing truly ethical research practice.

Based on our experience, several changes can be identified that could enable institutions of higher learning to develop research ethics clearance procedures that align with the emergent field of TDR and similar research approaches. It is important that institutional ethics committees recognise that most research ethics decision-making takes place beyond the bounds of procedural ethics (Farrimond, 2013; Rossman & Rallis, 2010). Therefore, there is a need to assist researchers who are 'thinking ethically on their feet' in the field. This is true both in the early stages of TDR when researchers engage with societal actors before receiving ethical clearance, and also once the formal, ethically approved field work begins (Miller, 2013).

We suggest the following four recommendations for institutional RECs to address. First, we recommend that RECs recognise everyday ethics as the primary location in which research ethics decisions are made. The power of ethical decision-making lies in the hands of researchers in the field, not with ethics committees. Second, we suggest that both students and their supervisors take responsibility for developing an ethical sense to guide their everyday decision-making. Training can play an important role in laying the foundations for this, and RECs could facilitate this training. Third, potentially, RECs can play a role in facilitating collective reflection and discussion on the challenges of everyday ethics faced by researchers, for example, by setting up 'communities of practice' for reflecting on ethical challenges. Fourth, we recommend that institutions consider piloting a pre-proposal ethical clearance procedure or 'everyday ethics preparation' process. A complementary approach may be for ethics committees to be open to ongoing engagement with transdisciplinary researchers, both before and after formal ethical clearance is given for proposals. This kind of process may be valuable also in providing opportunities for dialogue to increase mutual understanding between researchers working in TDR projects and members of RECs, something which is often lacking (Wolf, 2010). However, there are also potential drawbacks to formalising ethics in the early stages of TDR, for example, RECs may not be comfortable with approving research proposals that include engagement methods which allow for flexibility, because these may be open to abuse and result in unintended negative consequences for participants. It is important to remember that the ultimate purpose of RECs is to protect human participants in research (Wolf, 2010).

In conclusion, the balance of responsibility for ethical research practice lies as much with institutions as with individual researchers. What we propose is that individual researchers take more responsibility for their own everyday ethical decisions and work towards developing an ethical sense, while higher education institutions position themselves to better support transdisciplinary researchers as they navigate these challenging ethical research processes. The role of researchers in society is shifting, and, in order to remain relevant, institutional RECs themselves may need to adopt an engagement-oriented approach in order to ensure that research continues to be conducted ethically and responsibly.

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7

Non-human Animals as Research Participants: Ethical Practice in Animal Assisted Interventions and Research in Aotearoa/New Zealand

Catherine M. Smith, Emma Tumilty, Peter Walker, and Gareth J. Treharne

In this chapter we outline the need for further development of ethical frameworks to guide research on the role of animal-orientated health, therapeutic, and service interventions. We discuss findings from our own research with non-human animals in therapeutic settings and the benefits of human–canine interactions for human health. We highlight how these stories from the field reveal a need for ethical frameworks that recognise the symbiotic relationships between humans and non-human animals with the animal as partner in the potential well-being benefits of those relationships. Past literature on animal assisted therapies (AAT) offers little indication about researchers' experiences in negotiating research ethics processes. We explore how these processes frame research on the relationships between humans and non-human animals and use the ethical review system of Aotearoa/New Zealand as an example whilst also highlighting issues that may vary internationally. We draw on the distinction between moral relationism and moral individualism to propose an ethical framework that goes beyond animal welfare legislation and recognises a range of capacities of non-human animals and therefore a range of obligations of humans towards these non-human animals; as Herriot (1998, p. 273) posed: 'If having a soul means being able to feel love and loyalty and gratitude, then animals are better off than a lot of humans'. We also outline the need for an

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updated theory as further non-human animal capacities are identified. We argue that researchers should aim not just for the omission of harm to non-human animals but active provision of capabilities to flourish as well as responsiveness to non-human animal distress in overt and subtle forms during research involving humans and non-human animals.

Rethinking Ethical Principles When Critical Research Involves Non-human Animals

Ethical frameworks require development to support growing research into animal-orientated health, therapeutic, and service interventions. The four principles of ethics traditionally used in human health and health research are as follows: autonomy (ensuring personal freedom), beneficence (ensuring benefit), non-maleficence (preventing harm), and justice (ensuring fairness) (Beauchamp & Childress, 2001).[1] Whilst researching the influence of dog-walking on human health and well-being, two of the authors, Catherine Smith and Gareth Treharne, identified insufficiencies in the human-orientated ethical framework used by research ethics committees. The application of ethical principles was not considered for the non-human animals involved. They were also surprised by a suggestion that in order to pursue future studies wherein dog-walking would be used as a therapeutic 'intervention', ethical approvals would be required from two ethics committees: human research and animal research. This challenge led to critical reflection on attitudes towards the status of non-human animals in society and resulted in consultation and collaboration with two other chapter authors, Peter Walker and Emma Tumilty, whose work identified the need to enhance ethical strategies for animal-orientated health, therapeutic, and service interventions. Together we asked ourselves: what status do non-human animals with health, therapeutic, and service roles have in human society? What relationships do humans have with these non-human animals? How is the well-being of these animals protected and enhanced? How are these animals protected by the four principles of ethics when involved in research? Each of these questions is addressed in what follows.

What Status Do Non-human Animals Have in Human Society?

Human relationships with domesticated animals are over 12,000 years old (Manning & Serpell, 2002). This is a history of the mixed relationships humans have had with non-human animals depending on culture and geography; often problematic dominance has been justified by religious or scientific philosophies (Newmyer, 2006). Human understanding of the inner lives and needs of animals is still fragmented. Whilst these relationships can appear mutually beneficial, they require ongoing development and reflection (Kim, Hong, Lee, Chung, & Lee, 2015). Catherine and Gareth explored the therapeutic benefits of dog-walking from a human perspective but realised that the methodological approach did not cater for exploring mutual therapeutic effects other than from the human participant perspective.

In Aotearoa/New Zealand, humans are required by law to register companion dogs (who become the owner's property). The 'position' or 'status' of the companion dog means different things to different people. Any dog might be considered a working tool, a family member, a status symbol, or a fashion accessory (Carr, 2014). Some dogs can be considered as having dual status as work tool and sentient companion (e.g. farm dog, or mobility dog 'owned' by an organisation yet lifelong companion for a human with disability). Legally, a companion dog is property. However, one US Supreme Court judge ruled that although non-human animals were legally owned property, they were not like other property.[2] In 2015, the New Zealand Animal Welfare Amendment Bill declared all animals 'sentient' beings, recognising the capacity of non-human animals for positive and negative affect, warranting additional freedoms to promote positive non-human animal affect status (New Zealand Ministry for Primary Industries, 2016). Whilst considered a progressive step, this adds to confusion regarding the status of non-human animals. In the eyes of the law and according to some dog-owners, dogs are Objects, but how can sentient beings or Others[3] also be seen as Objects?

The companion dog is becoming increasingly important to humans (Carr, 2014). For example, more dog-walkers are seeking greater access to traditionally human-only spaces for their canine 'family'. It can be argued that this honorary status is context-dependent. Following the Aotearoa/New Zealand Canterbury earthquakes (2010–2012), and often due to very stressful circumstances, some dog-owners surrendered their dogs to rescue organisations and some chose to euthanise their (healthy) dogs for a number of reasons (Potts & Gadenne, 2014).

As we (Catherine and Gareth) reflected upon the relative 'status' of companion dogs, we were led to the work of Walker and Tumilty (n.d.) who were investigating non-human animals in an animal assistive therapy setting. Drawing on the work of authors such as Todd May and Lori Gruen, Walker and Tumilty (n.d.) explore non-human animal status in the context of moral individualism and moral relationism and how we should relate to Animal-Others. Moral individualism states that a non-human animal's worth is derived intrinsically from the essence of that being (May, 2014). Moral relationism conceives of non-human animals' worth as being determined solely by their relationship to morally relevant beings (humans) (May, 2014). Moral relationism underpins existing animal welfare models, meaning that the degree of worth of a given non-human animal is determined by the type of relationship it has with humans (e.g. the distinction between food-animal versus companion animal). Essentially, the difference between these two moral standpoints is that, in a relationist approach, the status of the non-human animal is determined by humans and can vary from a treasured family member to a food item. In an individualist approach non-human animals are recognised as sentient beings with their own innate status or essence. Lori Gruen (2015) proposes an 'entangled empathy' in an approach to the Animal-Other, which recognises the needs and desires specific to each non-human animal rather than a human-imposed value structure. This entangled empathy is not relationism as described earlier but *relational*, in that it requires recognition of and responsivity to the Other, as Other (rather than Object). It does not define the Animal-Other's worth in relation to ourselves, but rather asks us fully to consider the Other, recognising our differences and existence together. We believe that this moral standpoint can help us to identify how non-human animals might be better protected and engaged in mutually beneficial settings.

Interest in animal law is burgeoning (especially in the US) as social and emotional capabilities of companion animals are better understood (Berns, 2013). In 2006, the US Pets and Evacuation Transport Standards granted the same rights to companion animals following a disaster (Grimm, 2014). Animal rights, however (or the lack thereof), are often framed from human perspectives (protection and welfare) and not 'imagined' from the perspective of Others. This confusing conflict between the status of a non-human animal (from our field story: a dog) in the eyes of the law (Object/atypical Object) and the differing status of the dog in the eyes of human owners (Object and/or Other) creates dilemmas concerning ethical positioning for research about how companion dogs influence the health and well-being of 'owners'. Some animal rights advocates are pushing for legal recognition of specific non-human animals as persons. This, however, fails to establish rights for all non-human animals and focuses specifically on non-human animals for whom public support can be easily garnered, for example, great apes.[4] The European Union, as with Aotearoa/New Zealand, recognises non-human animals as sentient (rather than persons with rights), and various states in the union have different degrees of animal protections.[5] To establish legally a non-human animal's moral status as an individual—a person—would mean that many currently acceptable practices would have to be abolished (vivisection, food animals, etc.). By only recognising sentience, legal jurisdictions can support an animal welfare approach that seeks to minimise 'unnecessary' harm, but fails to go as far as a full animal rights approach which would require the recognition of bodily freedom and integrity.

If critical researchers are to take on the philosophical stance that non-human animals are individuals with rights and needs relevant to their own innate essence, then we need to consider also the philosophical principle of autonomy with regard to research involving non-human animals in therapeutic settings. In the next section, the authors draw on the work of Walker and Tumilty (n.d.), which explores non-human animal relationships in therapeutic and service settings and proposes changes to welfare legislation and codes of welfare.

What Therapeutic Relationships Do Humans Have with Non-human Animals?

In order to explore the question of the therapeutic relationships that humans have with non-human animals, the authors first explore relationships in the context of animal assisted interventions (AAI) and then ponder the relevance of this work for exploring the mutual benefits of dog-walking. A *Life* magazine story from 1956[6] shows one of the earliest AAIs at the University Hospital in Ann Arbor (USA) where staff incorporated time with non-human animals (ducklings, kittens, and puppies) for the children in their paediatric wing to help them manage pain, distress, and discomfort.

Today, AATs fall roughly into three categories: highly trained service dogs, emotional 'comforters', and 'activity'-based interactions. Service dogs now assist humans with visual and hearing impairments, autism, epilepsy, and other long-term conditions (Cummins, 2013; Manning & Serpell, 2002). They provide everyday support by being a constant and useful helper in the person's normal activities. They may alert the person to an impending episode (e.g. of epilepsy) or enable wide and effective interaction (Burrows, Adams, & Millman, 2008; Evans & Gray, 2012). These dogs are highly trained and generally bred specifically for the purpose of service (Knol, Roozendaal, Van den Bogaard, & Bouw, 1988).

Aside from highly trained service dogs, therapeutic interactions with non-human animals are found in hospitals, hospices, residential care facilities, libraries, prisons, and university halls (van Pelt, 2010).[7] These animals are generally not bred or trained for purpose but are sourced opportunistically (volunteers and their companion or farm animals, for example) with the objective of providing emotional comfort (Walker & Tumilty, n.d.).

In activity-based AAIs, animals provide emotional and physical support through regular activities with humans. Simply riding and walking with horses is one form of therapeutic intervention; psychotherapy and relational exercises (talking and interacting with horses) is another.[8] Animals in these instances can be dogs or horses bred for purpose, but are also donated or volunteered by their owners and are often trained for human–animal interactions and activities.

Whilst AAIs are described positively in common discourse, human safety is prioritised and non-human animal safety is indirect. This is highlighted by language: for example, non-human animals are referred to as a 'resource' when specifying welfare codes (Walker & Tumilty, n.d.). The fundamental questions of whether we should be using non-human animals in this way is never raised, but is in keeping with our general societal attitudes to non-human animals and why the need for more thoughtful and engaged ethical thinking towards Animal-Others is called for.

AAIs carry risk for non-human animals from direct injury, neglect, stress, or misappropriate selection (Evans & Gray, 2012; Taylor, Fraser, Signal, & Prentice, 2016). While service dog organisations assess affinity between non-human animals and potential new humans, little is documented in less formal settings. Mutual pleasure from AAIs should not be assumed for the non-human animals in AAI (Davis, Nattrass, O'Brien, Patronek, & MacCollin, 2004; Evans & Gray, 2012).

How Is the Welfare of Non-human Animals Protected and Enhanced?

Currently, all non-human animals (whether they are engaged in AAI or not) are, in many countries, protected by welfare codes that encompass five freedoms: freedom from hunger or thirst, freedom from discomfort and inadequate shelter, freedom from disease and injury, freedom from distress and pain, and freedom to display normal behaviour (Ministry of Primary Industries, 2016; Serpell, Coppinger, & Fine, 2006) It could be argued that these five freedoms prevent harm and to a certain extent promote benefit. The interpretation and application of these freedoms are human dependent. For example, a family acquiring a service dog for a child with autism may not be aware of a dog's basic needs if they have never owned a dog (Burrows et al., 2008).

We propose that welfare codes should be driven by a fundamental shift towards an understanding of the non-human animal as a sentient Other (rather than object), leading to a redefinition of the human–animal relationship and supported by a shift in language. This proposed shift in non-human animal welfare has implications for research. Whilst it could be argued that current welfare guidelines provide a framework for non-maleficence (prevention of harm), they do not necessarily promote beneficence for the non-human animal. Therefore, in current frameworks, we cannot know or begin to explore whether AAIs are mutually beneficial for human and non-human animals. Mellor (2016) suggests an expansion, or more accurately a greater recognition, of complexity and a positive framing of the five freedoms, but does not address the basic question of a non-human animal's status. It is our view that tinkering with definitions of welfare and cruelty without addressing what is the moral status of an animal fails to shift thinking substantially, thereby encouraging humans to see non-human animals as tools to be used and so narrowing our ethical imagination and obligations.

In 2014, the International Association of Human Animal Interaction Organisation (IAHAIO) produced a white paper which defined AAI (and its subgroups) and specified guidelines for human and non-human animal well-being (IAHAIO, 2014). While the white paper did not offer specific guidelines for AAI research, non-human animal well-being specifications are detailed therein that promote positive experiences for non-human animals; also it details specific roles for non-human animal experts. This is the first document to recognise therapy animals not as therapy Objects but as individual Others with needs and desires. Further work is required to complete the transition from moral relationism to moral individualism.[9] To ensure meaningful care of non-human animal well-being in intervention settings, we advocate for research and practices that address:

(1) Explicit use of language that promotes the moral status of the non-human animals.
(2) Explicit definition of the relationships (and contingent responsibilities) in a non-human animal's life.
(3) Recognition that understandings of non-human animal capacities are constantly evolving, and therefore that explicit acknowledgment, and a mechanism to incorporate new research and evidence for non-human animal needs in any set of guidelines or legislation, is required.
(4) International advocacy to create mandatory rather than voluntary guidelines or legislation for non-human animal well-being generally and to service animal well-being more specifically.

Using language that reflects the view that non-human animals are individuals with varying needs and capacities prompts us to pay attention to non-human animals in a different way. Recognising these capacities and needs will give rise to the re-examination of responsibilities in the context of human–non-human therapeutic relationships and partnerships. Ultimately, the authors hope these steps will facilitate an ongoing positive shift in human attitudes to Animal-Others and how we relate to them.

How Are Non-human Animals Protected in Research?

Catherine and Gareth were advised by their university human ethics committee that dog-walking-as-a-physical-activity intervention would require ethical approval from both animal and human ethics committees. It is not clear, however, against what standards animal ethics committees review such projects (like the dog-walking story from the field included below) given that their mandate to date has largely focused on non-human animals being used in either vivisection activities or teaching settings.

Catherine's and Gareth's early collaborative research focused on promoting sustained and enjoyable engagement in physical activity for people with long-term health conditions, during which the benefits of dog ownership and dog-walking was a recurrent theme. In 2012, they em-'barked' on a dedicated dog-walking research programme. From the literature, they found that dog-walking was predominantly investigated as a means of increasing human physical activity levels. Dog-owners who perceived that dog-walking was an essential activity for their loved companions walked more and achieved higher physical activity levels than non-dog-owners and those who did not walk their dog (Christian et al., 2013). There was little evidence that dog-walking addressed holistic health indicators. In this context, the dog was positioned as what Carr (2014) would call a 'recreational tool' (p. 6); Catherine and Gareth wanted to use a research design that uncovered more information about how dog-walking might influence health and well-being for humans and dogs through the lens of a co-sentient relationship (positioning the dog as a sentient Other). They subsequently selected a qualitative approach underpinned by the mobilities paradigm which is described as: 'analysis of the role that the movement of people, ideas, objects and information plays in social life' (Urry, 2007, p. 17). Catherine and Gareth employed walk-along interviews and participatory analysis sessions with individual dog-owners to capture data about dog-walking and health.

Despite this effort to capture something of the Other, Catherine and Gareth found themselves repeatedly prioritising the health and safety of the human participant and researcher (e.g. with regard to physical safety and risk management relative to the environment, the technical equipment, interactions with humans who were not participants, etc.). Further critical reflection identified two ways in which the research might alter perceived mutual benefits of dog-walking for humans and dogs. The first explored how the methodology impacted upon usual routines, experiences, and behaviours and, the second, how this approach manipulated trust and compromised usual (and intimate) human–canine interactions. Each is discussed below.

Changing Usual Routines, Experiences, and Behaviours

Whilst the mobile methodology and methods described are purported to be more ecologically meaningful than traditional methods (such as seated interviews), many instances were observed in which the researcher's presence interrupted the flow of the usual dog-walking routine. Meeting the participant and the dog at their home was at times awkward. The researcher might be greeted enthusiastically by a dog at the start of a walk. If enthusiasm was not well controlled by the owner, this had implications for trust-building with the participant (the second observation). More often, the participant chastised the dog for being over-enthusiastic, accompanied by words such as 'Sorry, he's not usually so naughty'. If we take a relational stance and think how this chastisement might feel to the dog, then we can understand that this might be unexpected or worrisome and take away from the anticipated pleasure of a walk. Asking the participant to control the dog might have compromised this relationship of trust and limit the participant's comfort about sharing experiences on the dog-walk. Pragmatic recommendations for dealing with this dilemma in future studies included the researcher's learning subtle and unobtrusive verbal and non-verbal commands in order to minimise any loss of pleasure for dog and human. The researcher could also prepare ahead of a dog-walk encounter via a series of questions to a participant, for example, 'Can you tell me a little bit about your dog's personality and how are she/he is likely to greet me when I come to the house? Will she/he be outside or inside?' and to further reassure: 'Please don't worry if your dog is a little enthusiastic—I'm used to being greeted in that way'.

During the dog-walk, dogs were often curious about the new 'walker', another potential way in which this kind of research could influence usual routines and behaviours. Catherine and Gareth again experienced the dilemma of balancing a neutrality that did not influence routine and engaging with the dog in a way that pleased both dog and owner. How a researcher's presence might influence regular dog-walking routines is another ethical consideration. This has certainly been discussed for human-only walk-along and go-along interviews and a number of strategies have been suggested as to how to minimise this (Garcia, Eisenberg, Frerich, Lechner, & Lust, 2012). On dog-walk-along interviews we noted times when dogs misbehaved; participants were divided between interactions with their dogs, other humans, and researcher questions; and when walking and talking minimised some of the multisensory pleasures of walking for the human. If, however, we recognise the dog as a sentient being with essential needs (including pleasurable experiences), we also need to consider minimising the intrusiveness of the researcher so that both humans and dogs can enjoy those experiences. Minimising impact upon the pleasurable experiences of both human and dog align well with the ethical principles of beneficence and maleficence. We suggest being proactive with human participants as being one way to overcome this: 'Please feel comfortable to engage with your dog as usual—place her needs first and don't feel as if you have to finish every point or sentence. We can follow up on these at our participatory analysis session'.

Trust and Compromising Usual Human–Canine Interactions

The qualitative research paradigm privileges participants' worldviews (Chandler, Anstey, & Ross, 2015). From an ethical perspective, it can be argued that the sharing of experiences, beliefs, perspectives, opinions, hopes, and dreams is privileged information sharing and differs in nature from volunteering for intervention testing, measurement, or numerical quantification associated with quantitative research. In dog-walking research, Catherine and Gareth felt that by including the participant's dog in data capture, the human participants readily shared information. Whilst much is written in the literature about ethical considerations and care around single participants and participant dyads, for example, where a person and a human partner (spouse, caregiver) are co-participants (Bjornholt & Farstad, 2012), nothing (to our knowledge) has been written about ethics in relation to the dyad of participant and dog. If participants are willing to share personal and meaningful information more quickly because their dogs are involved, we wonder whether researchers should include a statement about trust in the participant information sheet. For example:

> We recognise that people build relationships with dogs and trust them in a way that differs from relationships with other humans. As a result of this there might be things that you say during a dog-walk-along interview that are sensitive and/or confidential. We remind you, therefore, that you have the opportunity to reflect on and clarify information at several stages of the study and can ask for information to be removed.

As the dog-walking study programme continued, we became more aware of the regularity with which humans talk to their dogs on a dog-walk. In some cases this is the only way in which some humans share some thoughts with another sentient being. Whilst this is significant for the human, does absence of this discourse impact negatively on the dog? Whilst there is no empirical evidence to answer this question, anecdotal observations of Reading-to-dogs programmes suggest there are mutual benefits for both humans and dogs: for example, more confident human readers and more settled and calm shelter dogs (Humane Society of Missouri, 2015).

In summary, most ethics review committees will ask for identification and resolution of physical and psychological safety issues, and anonymity for human participants. Dog-walk-along interviews raise new considerations for researchers in respect of these issues—what considerations should be made in practising ethically with dogs? We have made some pragmatic suggestions and identified existing literature that partially helps to answer these questions. Many questions still remain and require further reflection and debate as this field of mobile studies continues to evolve.

Non-human Animals as Co-participants (Dyad)

We return to the complex and unresolved dilemma of non-human animal status. Earlier, we examined welfare considerations for non-human animals involved in therapeutic interactions with humans and concluded that these considerations are predominantly driven by moral relationism which places the status of non-human animals involved in therapeutic settings as that of a ‘tool’ or object. A shift to a morally individualistic position is warranted because humans understand the innate needs, desires, and experiences of non-human animals. This shift places the non-human animal as a co-worker or co-participant and challenges existing morally relativistic ethical frameworks described previously.

Companion dogs are an ideal study model for the possible development of morally individualistic well-being and ethical frameworks. From Catherine’s and Gareth's work in the dog-walking field, we envisage dogs and humans as co-participants in studies of AAT including the positive effects of health and well-being between a human animal and a non-human animal in the current framework of a companion animal. For Catherine and Gareth, this is particularly timely as they consider using dog-walk-along interviews to research how 'Borrowers' of dogs experience health and well-being.

For research that explores human–animal therapeutic interactions and interventions, we recommend review by lay or academic committee members (from both human and animal ethics committees) with experience in therapeutically based human–animal interactions. Our vision would be the establishment of national committees competent to make ethical judgements and recommendations from a morally individualistic perspective, and which would consider the non-human animal as participants to whom ethical principles apply.

As discussed through the chapter, such human–animal interaction ethics committees could use a model that recognises the dog (or non-human animal) as a co-participant; this model could be underpinned by traditional principles used by human ethics committees and making some alterations to treat non-human animals as sentient beings and to account for the human–animal relationships. The recognition of sentience is leading to changes in the law around status. This challenges us to look critically at the autonomy of non-human animals in therapeutic settings. How can we use moral individualism to explore non-human animal consent, for example? How can we ensure no loss of pleasure or no increase in psychological harm? How can we use our results to help promote justice for companion dogs? In Table 7.1, we make preliminary suggestions for trialling and testing, all of which require further discussion.

Conclusion

In this chapter we have provided background on non-human animal assistance (therapy, activities, and interventions), described the moral and legislative landscape in Aotearoa/New Zealand as it pertains to non-human animals, including an ethical review of research, and related this to research work in the field with companion animals. This fieldwork described the important role of the dog in Aotearoa/New Zealand society and ethical issues that arose in conducting data collection with dogs during the activity of dog-walking. We suggest a revision of ethical review as it relates to non-human animals in this setting, especially given the growth in the AAT field. Ethics review committees are required to see Animal-Others as participants to whom human ethics principles must apply, rather than as tools or objects where harm reduction for human benefit is the only consideration. Such committees will recognise not only welfare and sentience, but also the capacity of Others to feel and express pleasure, displeasure, enjoyment, willingness, and reluctance. In addition, the envisaged committee will consider how research proposals contribute to the wider well-being of non-human animals through the tenet of justice, for example: urban policy and planning, protective legislation, and access. It is our hope that further development in this area will lead to the enhanced well-being of

Table 7.1 Application of ethical principle to human and non-human animals

Principle	Human–animal application	Non-human animal co-participant application
Autonomy	Autonomy is addressed through the practice of informed consent. Participants, with full knowledge available to them, should not be forced to take part or do things they do not wish to do (Beauchamp & Childress, 2001). Proxy informed consent is provided by another in research where participants are unable to consent individually (e.g. a child). Individuals lacking capacity for consent are still asked to assent to the various steps of the research, that is, agreeing to either that which they have to do or that which is done to them (Beauchamp & Childress, 2001).	Future studies should be framed to capture the health and well-being benefits of both humans and non-humans. Research teams should draw on animal experts when designing studies. Ethical bodies should include clear guidelines acknowledging non-human animals as participants with a moral status. Proxy informed consent can be provided by the human with assent being provided by the non-human animal defined by acceptable standards for the specific animal/species. The humans could be asked how they recognise their non-human animals' different emotional states and, by proxy, let the researchers know if they perceive their non-human animals' distress. Researchers should also draw on animal experts to ensure their knowledge is appropriate. Data collection could be temporarily or permanently suspended if the animal does not wish to engage in the therapeutic activity.

(*continued*)

Table 7.1 (continued)

Principle	Human–animal application	Non-human animal co-participant application
Beneficence/Maleficence	Beneficence requires benefit for the participant in taking part (Beauchamp & Childress, 2001). Non-maleficence requires no harm to participants by taking part (Beauchamp & Childress, 2001). This is conceived at the individual level, that is, what will happen to each particular participant.	A usual dog-walk with minimal intrusion by the researcher. Non-human animal's well-being outcomes captured as data. Reimbursement for participation, for example, animal care gift vouchers or food/toy treats. A usual dog-walk with minimal intrusion by the researcher. Information sheets can include phrasing such as 'as a co-participant, you will be able to recognise when your dog is enjoying engagement in the research process and when s/he is not. You are free to discontinue engagement in the research process at any point if you feel your dog is unduly distressed'.
Justice	Justice requires researchers to measure the benefits and burdens accruing to participants as a whole, the community and society (Beauchamp & Childress, 2001).	In this case, what is the outcome for non-human animals in research participation, does it improve or worsen the overall welfare or status of their species? Researchers could use study results in a way that promotes more beneficent societal attitudes towards companion dogs, for example, access to more dog-walking spaces.

non-human animals involved in research and service settings and ultimately to a more empathetic entanglement of humans and Others in society at large.

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Notes

1. Other ethical principles can be and also are used either to expand these four or to use a different framework altogether.
2. For more information see: *Harvard Magazine*—http://harvardmagazine.com/2016/03/are-animals-things, March–April 2016.
3. We draw here on Levinas' work on intersubjectivity between self and Other (Levinas, 1969).
4. See in the USA—http://nypost.com/2015/04/21/judge-reverses-human-rights-status-for-chimpanzees/—and in Argentina—https://www.washingtonpost.com/news/speaking-of-science/wp/2014/12/22/orangutan-granted-rights-of-personhood-in-argentina/?utm_term=.19c52155ea4f.
5. Available from: https://ec.europa.eu/food/animals/welfare_en.
6. Available from: http://time.com/3491397/animals-make-a-hospital-happy-classic-photos-of-critters-helping-kids/.
7. College students: http://www.nytimes.com/2015/10/05/us/four-legged-roommates-help-with-the-stresses-of-campus-life.html. Residential homes: http://www.carehome.co.uk/news/article.cfm/id/1557257/pet-therapy-brings-the-joy-of-animals-to-care-homes.
8. The international organisation for riding for the disabled, Federation of Riding for the Disabled International (http://www.frdi.net/), includes both physical and psychological interventions. The Equine Assisted Growth and Learning Association (EAGLA) is an example of a purely psychological intervention—http://www.eagala.org/.
9. It is worth noting that such a shift necessarily raises questions regarding the underlying presumption of the use of non-human animals in these forms of activities and even as companion animals—if animals have a moral status akin to our own, how do we then justify their participation in such activities?

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8

Critical Enquiry in the Context of Research-Ethics Review Guidelines: Some Unique and Subtle Challenges

Will C. van den Hoonaard

Researchers devoted to doing critical enquiry are disenchanted with the place of such enquiries in the light of international trends in research ethics policies (see, e.g., Bell, 2015; Dingwall, 2016; van den Hoonaard, 2011). In the first part of this chapter, I focus on the broader place and meaning of critical enquiry that seeks, firstly, to highlight how current social relations premised on capitalism are unsustainable and, secondly, to alleviate these social and economic inequalities. I then discuss the prevailing norms of contemporary research ethics review, using the example of the Canadian *Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans* (*TCPS 2*) (Canadian Institutes of Health Research, Natural Sciences and Engineering Council of Canada, & Social Sciences and Humanities Research Council of Canada [CIHR et al.], 2010). The *TCPS 2* represents the formal, collective guidance of Canada's three research agencies; it was first developed in 1998, with subsequent revisions as a 'living document' in 2010 and 2014, known as *TCPS 2* (see Zimmerman, 2017). I go on to argue that research ethics review assumptions are a source of disenchantment for critical researchers, but also that a deeper reflection on the language of the *TCPS 2* reveals an appreciation of critical research. I then discuss the fate of critical research once it enters the realm of formal research ethics review and how the regulatory processes themselves underpin the neutral-normative framework of ethics codes which often explicitly or implicitly requires apparent neutrality of researchers. In other

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words, this framework claims to make space for critical research, but this is a constrained space which is restricting the enactment of reflexivity and creativeness in critical research.

The Place and Meaning of Critical Enquiry

The many sociologists who engage in critical enquiry would claim that all sociology, by its very nature, is critical. Michael Burawoy, past President of the American Sociological Association, said that 'without critique[,] sociology is lost' and informs us that an established journal devoted to critical sociology 'is a pillar of our discipline' (Critical Sociology, n.d., p. 4). Critical sociology is so intrinsic to the field that it would be quite impossible to provide the long list of all those who are engaged with it. The informal birth of critical sociology stems back to Karl Marx, whose approach rested on the dictum: 'Philosophers have hitherto only interpreted the world in various ways; the point is to change it' (Marx, 1845/2002, p. 65). The real impetus of critical sociology stems back to the 1950s, when students and scholars began to challenge the dominant paradigm in sociology, which led them to believe that 'social science [should be] used in the "war on poverty" [where] inequality was the bi-product of a system promising greater prosperity' (Association of Critical Sociology, 2017, p. 1). More specifically, however, as the Association for Critical Sociology (2017) points out, the earlier conception of critical sociology revolved around the problem of capitalism. If sociologists today embark on any study of contemporary society, they must inevitably face the disjunctures caused by the 'problem of neo-liberal capitalism' (Association of Critical Sociology, 2017, p. 1), which would also call into question any system that supports racism and other forms of oppression. One might suggest that the ideology that guides decisions by members of ethics committees might well be neoliberal capitalism, hindering critical sociological research (see, e.g., Charmaz, 2017).

When so few are able to 'control the means of production and of subsistence,' the mission of critical sociology is not only to understand that these capitalist social relations are chronic and environmentally unsustainable, 'resulting in longer and deeper crises that inflict ever greater pain on more and more of the world's population' (Association of Critical Sociology, 2017, p. 1), but also through its critical analysis to bring about the necessary change to alleviate these social and economic inequalities. Racism, ableism, ageism, sexism, and cisgenderism intersect with and sustain these inequalities. Borghi (2017) argues for the importance of seeking to understand how the social sciences can emphasize ‘the crucial role of agency, actors’ critical capacities and voice’ in the information society in building ‘an effective exchange and collaboration’ to lead us to ‘reconceive research in terms of a human right to actively participate in the knowledge-making process’ (Borghi, 2017, p. 1). Under those conditions, Borghi (2017) argues that social science perspectives cultivate the capacity to offer ‘a promising way for developing a sociological analysis’ (p. 12) and for enquiring into these transformations.

The heart of critical enquiry relates thus to critiquing the status quo of the powerful, emancipating the powerless, giving voice to the marginalized, and analyzing power relations and social inequality (see, e.g., Pérez, 2012). By contrast, the conventional neutral-normative conception of sociology is grounded in the belief that researchers can produce objective knowledge and that this belief, in turn, is based on the valorization of the neutrality of researchers and thus research (Hammersley, 2000, p. 1). Critical sociologists challenge this particularly prevalent view in the social sciences and have begun advocating discursive and reflexive modes of engagement with the social worlds.

Some scholars have concluded that the term ‘critical sociology’ is a pleonasm (use of more words than is necessary) because every attempt at doing sociological research should have elements of critical enquiry. Howard S. Becker (1986) raised this issue in the context of studying social structures. Those in power have the freedom to tell the world what questions to ask; the powerless typically have no such freedom. Any good sociological research should be inherently critical, as I suggest. For example, Arlie R. Hochschild’s *The Time Bind: When Work Becomes Home and Home Becomes Work* (1997) offers a well-researched study of a business that claims to promote the importance of home-family life. Hochschild, however, was not swayed by a business that invited her to study their policies about families and the workplace. She found widespread obduracy in the traditional business values that underplayed the importance of the family in the lives of women employees especially.

As mentioned above, the predominant approach to social sciences enquiry in the past involved a detached and disinterested form of research that privileged objective knowledge and the value of the apparent neutrality of researchers. With the erosion of the form of research that seems distant from lives of research participants that is embedded in neutral-valued research, a more passionate and even militant approach to solving the problems of the status quo, the powerless and the marginalized, and social inequality has come to the fore. The former frame of reference decried the explicit application of research findings; the latter seeks it.

The Prevailing Norms of Contemporary Research Ethics Review

The neoliberal capitalist stance referred to above spills over into the realm of research ethics committees, which now must deal with a research perspective (critical enquiry) that runs counter to conventional neoliberal wisdom and falls entirely outside the frame of conventional research objectives. I argue that not only is research ethics review out of step with contemporary modes of social research, but that the ethics review process cannot, in particular, perceive the subtleties that attend to critical enquiry. These subtleties hardly rise to the surface in ethics committees when they deliberate on critical sociological research. To a large extent, the medical research ethics world has remained out of reach of this new turn in science. In the world of research ethics review, it is my experience that the discursive and reflexive modes of understanding research inherent in critical enquiry are still not accounted for. For example, ethics review templates acknowledge and affirm the notion that knowledge must be 'objective' and adhere to the value of neutrality. The adoption of a critical approach to the study of human society is seen as confrontational and poses a potential problem for formal, bureaucratic ethics codes in which research 'templates' rather than a programme of research to change the world are usually the norm. Stacked against the opportunity to conduct critical research, university ethics committees hesitate to approve critical research, particularly when the research is considered 'controversial.' Cultural expectations about research, relationships with research participants, and our own taken-for-granted knowledge may also hobble our attempts to conduct critical enquiry.

The study of any social phenomenon implicates a 'hierarchy of credibility' (Becker, 1986, pp. 83–102). People at the top of an organization are more likely to be believed than those in lower positions (Becker, 1986; see also Hammersley, 2000). As long as the sociologist reflects the often taken-for-granted view that the voices of those at the top are more worthy than those at the bottom, the research is likely to follow the dictates and interpretations of those who have power in organizations. Those who run soup kitchens, prisons, schools, or hospitals have been treated as having much more pertinent and relevant things to say about the people for whom they are trustees than are the homeless, inmates, students, or patients. Ethnographies require that attention be given to those at the bottom rung of the hierarchy of credibility who are, after all, living experts in those settings. 'Whose side are we on?' has become a rallying cry for every sociologist who does not want to be caught in this web of faux credibility (Becker, 1986, p. 39). And there is an increasing body of critical scholarship from the perspective of those considered lower in the 'hierarchy of credibility' (see Section 4).

I recall several instances during my research on the experiences of social scientists with research ethics review that illustrate how alive and well the hierarchy of credibility is in my kind of research, and how critical enquiry remains an 'outsider' to formal research ethics review processes, whether it comes to the study of the political context of research ethics review, the discouraging of research on the bureaucratic processes in ethics review (van den Hoonaard, 2011, pp. 13–14), or prohibiting a researcher from using audio recordings, transcription, classroom observation, focus groups, and video recordings as these constitute an 'unacceptable risk to the subjects' (van den Hoonaard, 2011, p. 240). With an interest in recording the experiences of the social scientists, a Canadian national organization dedicated to promoting research ethics review invited a colleague and me to participate in a debate at one of their plenaries on the 'pros' and 'cons' of research ethics review. The organization provided us (as critics of ethics review) with black cowboy hats to wear during the debate; the proponents of research ethics review wore white hats. As another example, a US Institutional Review Board (IRB) forum carried a posting on its email distribution system that asked what the useful gatherings were that IRB members could attend to learn about the work of IRBs. When I suggested that it also might be useful to attend meetings organized by those who had difficulties with IRBs, the IRB forum ignored the suggestion. Similarly, it is quite unusual to find any references in the 'official' IRB platforms and explanations in the large body of critical literature that speaks of these difficulties (perhaps amounting to some 350 articles and some half-dozen books; see, e.g., Bell, 2015; Calvey, 2017; Dingwall, 2016; Emmerich, 2013; Gontcharov, 2014; Hedgecoe, 2016; Israel, 2017; Miller et al., 2012; Newmahr & Hannem, 2016; Schneider, 2015; Schrag, 2010; Stark, 2012; van den Hoonaard, 2002). The 'contra' literature seems to have no credibility in the face of the 'formal' accounts of IRB experiences. In the absence of places that hold any literature critical of research ethics review, researchers see their struggles with ethics committees as *personal* challenges, rather than as something that is shared by many researchers that might lead to systemic changes.

The Canadian Tri-Council Policy Statement (TCPS 2): An Illustration

In this section, I present extracts from the Canadian *TCPS 2*. While these extracts denote the essential neutral-normative nature of that document, they also reflect a similar approach taken in research ethics codes in other countries, especially in Anglophone countries which derive their policies from restrictions imposed by US research authorities and their guiding document, the Belmont Report (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1978). Chapter One of *TCPS 2* entreats the researcher to meet 'high scientific and ethical standards' and implores researchers to use 'rigorous analysis […] and adherence to the use of professional standards,' sentiments that would be common to all research ethics codes and research methodologies, although the hegemonic conceptualization of all research as having to meet 'scientific' standards goes to the heart of the marginalization of critical research methods.

While the *TCPS 2* states that 'research often entails risks to participants and others' and that 'these risks can be trivial or profound, physical or psychological, individual or social,' the question of whether these 'risks' pertain to the powerless only is unanswered. It is unlikely that researchers would disagree with 'the dual moral obligations to respect autonomy and to protect those with developing, impaired or diminished autonomy' (CIHR et al., 2010, p. 8), but it leaves silent the influence of research on the powerful. Critical researchers should note, with some satisfaction, that the *TCPS 2* does recognize 'individuals in a position of power.' The real challenge in the context of the demands of the *TCPS 2* (p. 35) is to estimate or know what 'may cause them [individuals in power] some harm.' The nature of social science research, especially exploratory research, is that the researcher cannot know the precise nature of those potential harms in advance. The organizational structure that works around those individuals in power is less likely to affect these individuals than those who occupy a marginal status:

> REBs should also be aware that some research, involving critical assessments of public, political or corporate institutions and associated public figures, for example, may be legitimately critical and/or opposed to the welfare of those individuals in a position of power, and may cause them some harm. There may be a compelling public interest in this research. Therefore, it should not be blocked through the use of risk-benefit analysis. Such research should be carried out according to the professional standards of the relevant discipline(s) or field(s) of research. Where an individual in a position of power is invited to be

> interviewed or gives access to private papers and thus becomes a participant as defined by this Policy […]. In such cases, the balance of risks to those who are the object of the research is mainly considered along with the potential benefit of new knowledge to society and the indirect benefits to the population affected by the public, political or corporate institutions to which the participant belongs. (CIHR et al., 2010, p. 36)

Frequently, *TCPS 2* speaks of 'the *design* of research' (CIHR et al., 2010, p. 10, my emphasis), giving it a formalistic and formulaic approach. The *TCPS 2* also asserts that 'groups may benefit from the knowledge gained from the research, but they may also suffer from stigmatization, discrimination or damage to reputation' (CIHR et al., 2010, p. 10). This assertion leaves the critical sociologist in a quandary. Challenging society's concentration of surplus, for example, could involve the potential stigmatization of a privileged group. Deciding what groups can or cannot bear the risk of research findings requires cultural and subjective assessment. Such decisions can vary considerably over time. Would such a mandate apply to all groups, regardless of their social and economic standing? Is there, in other words, an unequal distribution of risks to which researchers must pay attention? Chapter Two of *TCPS 2* addresses the magnitude or seriousness of the harm, including research in 'sociology or cultural anthropology, that may present risks that go beyond the individual and may involve the interests of communities, societies or other defined groups' (CIHR et al., 2010, p. 31). What inferences are critical researchers to make of such an assertion? Would one have to consider the harm to such groups as the powerful? Will this statement discourage researchers from embarking on research that envisions a restructuring of society? In an enlightened narrative space, researchers and members of ethics committees might well bend their concerns towards the larger issue of the structure of society, rather than just the impact of research on any one organization, group, or individual research participant who happens to be part of the study.

Researchers also read about the 'legitimate' social requirements of research in *TCPS 2*, but do such requirements mitigate against a sociology of advocacy, of critical enquiry? How far does formal research ethics review go in permitting researchers to understand such troubling issues as terrorism (Atran, 2007), workplace settings (Bamber & Sappey, 2007), or the illicit drug trade (Bell & Salmon, 2012)? Even more 'conventional' research topics engender obstacles, whether the study of farm children (Cummins, 2006) whose work is an integral part of farms, or the study of homeless people (Cloke et al., 2000) which might demonstrate a government body's failure to face up to their needs. Probing enquiry touches more social and economic facets than is originally foreseen.

Critical Enquiry in TCPS 2

Chapter Three of *TCPS 2* concerns the process of obtaining consent from groups or individuals who have been invited to take part in research. It is also the only place in *TCPS 2* where one would find substantial guidance about critical enquiry:

> In critical inquiry, permission is not required from an institution, organization or other group in order to conduct research on them. If a researcher engages the participation of members of any such group without the group's permission, the researcher shall inform participants of any foreseeable risk that may be posed by their participation. (CIHR et al., 2010, p. 35)

In some cases, the broad sweep of critical enquiry makes it impossible to know any 'foreseeable risk' to particular individuals. Members of ethics committees do not have personal knowledge of the circumstances of the lives of research participants. As a consequence, they invent those circumstances and ascribe the worst risks, in order to be 'safe' when reviewing the research from an ethical perspective.

The following paragraph, also found in Chapter Three of *TCPS 2,* unusually reinforces the endorsement of critical research that falls outside the norm with respect to the idea of consent:

> Where the goal of the research is to adopt a critical perspective with respect to an institution, organization or other group, the fact that the institution, organization or group under study may not endorse the research project *should not be a bar to the research receiving ethics approval*. Where social sciences or humanities researchers seek knowledge that critiques or challenges the policies and practices of institutions, governments, interest groups or corporations, *researchers do not need to seek the organization's permission* to proceed with the proposed research. If institutional approval were required, it is unlikely that research could be conducted effectively on such matters as institutional sexual abuse or a government's silencing of dissident scientists. Important knowledge and insights from research would be forgone. (CIHR et al., 2010, p. 35, my emphases)

The following paragraph continues to provide this unconditional waiver to conduct critical enquiry:

> Researchers and REBs should be aware that institutions, organizations or other groups under study may have requirements for allowing access to their sites and to participants, and that some of these may have established mechanisms or

> guidelines e.g., school boards, Aboriginal communities […] correctional services, and community groups. […] Nevertheless, REBs should not prohibit research simply because the research is unpopular or looked upon with disfavour by a community or organization, in Canada or abroad. Similarly, REBs should not veto research on the grounds that the government in place or its agents have not given approval for the research project, or have expressed a dislike for the researchers. (CIHR et al., 2010, p. 36)

Those engaged in critical enquiry are more likely to want to explore more than one institution or organization. And when conducting critical research with more than one institution or organization, the following ethics precept might be more challenging than anticipated:

> However, individuals who are approached to participate in a research project about their organization should be fully informed about the views of *the organization* regarding the research, if these are known. *Researchers shall inform participants* when the permission of the organization has not been obtained. Researchers engaging in critical enquiry need to be attentive to risks, both of stigmatization or breach of privacy, to those who participate in research about their organization. In particular, prospective participants should be fully informed of the possible consequences of participation. (CIHR et al., 2010, p. 36, my emphases)

To explore multiple organizations, researchers (and ethics committees) must be aware of the numerous layers of informing research participants about whether or not the research has not been approved. The *TCPS 2* provides no guidance on the possible reluctance of participants to engage in the research, and this remains a genuine problem if the research is perceived as problematic. Moreover, when critical researchers attempt to uphold anonymity and confidentiality, the risks of consequences for participants would be only hypothetical. However, because not all research participants partake in the work of the institution(s) at the same level of responsibility or intensity, it would be a challenge for researchers to accord the participation of all research participants the same weight of consent. The following advice in the *TCPS 2* recognizes anonymity and confidentiality as a potential solution, but there are serious limitations on how anonymity and confidentiality can be maintained when doing field research in some settings (van den Hoonaard, 2003). Interestingly, the *TCPS 2*'s typical expressed need for researchers to use consent forms is not seen as a problem:

> REBs [Research Ethics Boards] should, however, legitimately concern themselves with the welfare of participants and the security of research materials in

> such circumstances. When participants are vulnerable to risks from third parties (e.g., authoritarian regimes, gang leaders, employers) on account of their involvement in research, researchers should ensure that copies of field materials are kept in secure locations. When sharing research materials such as consent forms or transcripts of field notes with participants, researchers must honour their commitment to protect the anonymity and confidentiality of participants to ensure that their human rights, and the ethical principles set out in this Policy, are not compromised. In general, regardless of where the researchers conduct their research, researchers and REBs should concern themselves with safeguarding information while it is in transit. (CIHR et al., 2010, p. 36)

Despite these assurances, it is not uncommon for ethics committees to ignore the role of social structure as part of the findings in research. Sociologists and critical researchers from other disciplines are often committed to the framework that numerous patterns of behaviour point to a systemic or routinized societal pattern. While, no doubt, some behaviours seem to exemplify individual penchants (abuse, for example), a critical approach highlights the systematic nature of such behaviours.

How the Beliefs in the Regulatory Processes Underpin the Neutral-Normative Framework: On Discretion and Dignity

What is often overlooked are situations that should, on the one hand, compel researchers to promulgate discretion in the research setting, and, on the other hand, acknowledge the dignity of the readers of their research. The former relate to doing covert research; the latter to disciplining one's overt enthusiasm for one's findings.

Covert ethnographic research is not mentioned in *TCPS 2*, but it can be a valuable tool in critical sociology, especially in circumstances that touch on injustice, discrimination, or violation of human rights (see, e.g., Chap. 26 by Marco Marzano, this volume). Discretion is a much-vaunted attribute in covert research in private or semi-public settings, but it is quite likely for a research participant to ask a researcher, point-blank, if one is doing research. A truthful reply might satisfy the researcher's heart, but it could also spell the end of this particular research stint. The experience of many researchers is that the truthful answer is what is required, and that the freedom to continue studying the setting is typically not disturbed.

The ethical extension of critical enquiry touches on the tone and manner of writing up one's findings. The art of good writing requires the need to leave the dignity of the reader intact, that is, to allow readers to make up their own mind about the argument that the researcher has presented. This form of disciplined writing cannot be abandoned just because of a researcher's fervent belief in the findings. After all, the endpoint of critical enquiry is not the researcher's own analysis, but the manner in which the reader of one's assertions or findings is convinced. The dignity of the reader means that the researcher must leave enough room for such independent assessment of the enquiry and its findings. This situation became quite apparent to me (van den Hoonaard, 1987) when I read an ethnography about the seal hunt near Newfoundland, Canada. The ethnographer was detailed and convincing in his findings, and would have had me on his side, except that towards the final stage of his book, he started to castigate those who were against the seal hunt. In that one brief section of the book, he 'kidnapped' my own judgement, preventing me from making up my own mind.

The variations that attend to judging the ethics of research applications are surprisingly diverse. In my ethnography on the workings of Canadian research ethics committees, *The Seduction of Ethics* (van den Hoonaard, 2011), I report the processes by which, for example, the size or number of grants held by an applicant can be a factor in speeding up an application or slowing it down for some ethics committees. What the above extracts from the *TCPS 2* bring to mind is the moral cosmology of ethics committees and their staff. What drives the ethics review world are not only regulatory functions, but also deeply held perceptions and beliefs, a sort of 'emotion work' (Hochschild, 1983, pp. 17–18), feelings that staff and members of ethics committees 'feel obliged to create, nurture, and sustain while being part of the ethics-review process' (van den Hoonaard, 2011, p. 97). Their devotion to the goodness of regulation procedures may reflect Ann Hamilton's observation that 'regulators seek a lack of ambiguity […] that is "consistent with Weber's observations about the goals of bureaucracy"' (Hamilton, 2002, p. 241): people prefer the simplicity that rules provide.

Conclusion

There is no sweet place for critical enquiry in research ethics codes such as the Canadian *TCPS 2* (CIHR et al., 2010). On the one hand, ethics codes rely on the use of templates derived from biomedical research and advocate a science that values neutrality (Charmaz, 2017; Hammersley, 2000; van den Hoonaard, 2011). On the other hand, critical enquiry advocates a robust research topic and method that criticizes the status quo, analyzes power relations, speaks of emancipating the powerless, and seeks to remove social inequality.

The tone of advocacy or partisanship in critical sociology and critical research widely creates its own ethical dilemmas. We have noted that the *TCPS 2* does make room for critical enquiry, but there are still other elements about which ethics committees are silent or default to the neutral-normative framework of purportedly objective research. While acknowledging that objective knowledge is impossible to achieve, the question of bias in research lurks in the background of all critical research. Are ethics committees capable of spotting these biases? And while ethics committees do understand reflexivity, reflexivity sometimes occurs after a spell of having done some research, making the researcher turn back to the data and maybe even reconceptualize the research.

There are relevant passages in the *TCPS 2* that clearly acknowledge critical enquiry, and the researcher must rely on anonymity and confidentiality—crucial ingredients in any research that touches power relations. These passages, however, do not acknowledge power differentials among research participants when the researcher is told to make research participants aware of the research. Some participants occupy a central role in organizations and others do not; likewise, this issue of power extrapolates to critical research which is not definitively located in an organization or institution but which also addresses power relations. The critical researcher must recognize that in such a layering of different responsibilities, the process of finding whose consent is more valuable will vary considerably. The question of fostering the dignity of research participants in critical enquiry pertains to doing covert research in which anonymity and confidentiality are key. With the intention of maintaining the dignity of readers, the researcher should be encouraged to convey findings in such a manner that the reader is left with the courtesy of deciding the value, relevance, and findings of that particular critical enquiry.

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Section 2

Blurring Boundaries

9

Introduction: Blurring Boundaries

Phindezwa Mnyaka and Catriona Ida Macleod

In this section, we pay attention to the ethical dilemmas that arise when researchers find themselves stepping outside their understood roles as researchers when engaging with participants. As with all relationships, research encounters presuppose particular boundaries, depending on the methodology employed and the research questions posed. While the objective outsider positioning of researchers that demands strict researcher–participant boundaries is generally eschewed in critical research, most research maintains a similar presupposition that particular boundaries will be maintained. The research process, particularly in qualitative research, is typically envisioned as a means of generating knowledge about an aspect of the participants' lifeworld. In the context of fieldwork, however, this can translate into fragmenting those experiences from the participants' everyday life and from other aspects of their lives, a fragmentation that may not make sense to participants.

'[T]he inevitably human dimension of qualitative research' (Perry, Thurston, & Green, 2004, p. 135) means that in the process of collecting data, the researcher may be recognised by participants as more than an information gatherer and be pulled into performing roles outside those designated by the research approach. Researchers may be ill-prepared for such an occurrence,

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which may complicate ethical agreements regarding anonymity or may be experienced by researchers as unanticipated 'emotional labour' (Hubbard, Backett-Milburn, & Kemmer, 2001, p. 121). Additionally, such intersubjective encounters that extend beyond the scope of the research question have a bearing on the process of interpreting and writing. How the data collection unfolded and the interpersonal processes that went into producing the data are crucial to the analytical work that can be undertaken in critical research.

The authors of the chapters in this section explore the blurring of these boundaries and the implications for ethical practice. Drawing on the dilemmas faced in the field, this introduction explores how researchers consider: (1) intimacies in the process of research, (2) the positioning of researchers as agents of change, and (3) the oscillation between 'insider' and 'outsider' status. We conclude by posing critical questions about the often-unspoken assumption of research as transaction.

Researcher Subjectivity and Intimacies

Critical research is often conducted by people who also occupy the professional role of medical, psychological, or social work clinician. Frequently, the clinical role precedes the researcher role, implying the need to reflect on the transition in roles and the accompanying differences in expectations of the two roles (Mendenhall, 2007; Wallace, 2005). In addition, participant misconceptions about which role is being undertaken by the researcher require management (Hiller & Vears, 2016).

Hay-Smith et al. (2018, this section) reflect on a typology of dual-role scenarios experienced by clinician-researchers which they had developed with the aim of enabling reflection on ethical and methodological considerations when carrying out health research. They speak to the multiple ways in which clinician-researchers may be pulled into acting out a dual role as clinicians in research settings. This may include, for example, participants disclosing intimate information that was not sought: an issue for the researcher in fieldwork and teamwork that may have clinical implications. This has legal and methodological implications, as the authors note, compounded by the health professional's ethical and legal obligation to a duty of care; this may complicate the research process as an opportunity to gather data.

Clinicians' deeply ingrained training to disclose as little of themselves as possible may result in the clinician-researcher assuming the familiar role of clinician which allows emotional detachment. By contrast, Harvey's adoption of the psychoanalytic interview method (2018, this section) assumes the centrality of the researcher's subjectivity in the generation of new knowledge. Drawing on Freud's concepts of transference and countertransference, she notes how the psychoanalytic interview accesses the participant's conscious and unconscious dynamics through the *conversations* between researcher and participant. The researcher's own affect in this context becomes in turn a source of information about the participant's internal psychological processes. Far from forming a barrier to research, the researcher's own subjective responses and thought processes form essential material for analysis. This shares homologies with what Walshaw (2010) calls the authoring of oneself into the research account. For Harvey, while the psychoanalytic method entails the researcher contemplating and remaining aware of her own feelings, the researcher may in turn feel a transferential push to respond to participants (e.g., when she is asked to speak to her participants about her own disability). Here, what the participants experience as a shared condition of 'difference' poses its own challenges to the very methodology that is invested in researcher subjectivity.

While the psychoanalytic interview relies on establishing a psychodynamic relationship between the researcher-analyst and the participant, in large part this takes place within the confines of demarcated spaces that remove both parties from the flow of everyday life. By contrast, Akhurst et al. (2018, this section) consider the implications of blurring boundaries when researchers are immersed in communities under study. Drawing from their experiences of research on sexual activity and HIV/AIDS in a setting that entailed living as guests in family homes, and thus being privy to an intimate space that may ordinarily be beyond the reach of other researchers, the authors indicate an inevitably subjective involvement in the lives of their participants. For the authors, while such a degree of intimacy translates into rich data, it also asks the researchers to consider the ethical implications of occupying such a generative space. As noted by Molyneux and Geissler (2008):

> Fieldworkers who are based in 'the field' face significant challenges in mediating between the very different priorities and concerns of well resourced research institutions and low-income communities. In the process, they do not simply neutrally observe and adhere to formal externally derived ethical rules, but instead play a vital, creative, and under-recognised role in research and ethics practice. (p. 688)

In Akhurst et al.'s research (2018, this section), the very act of living as temporary residents meant being drawn into intervening in personal matters that lay outside the research project and which were not being covered by predetermined codes of ethics.

For Barker and Macleod (2018, this section), the difficulties that arise from negotiating such codes when accessing participants' intimate lives arise in part from considering that however we as researchers choose to position ourselves in relation to our research participants, they encounter and position us in ways that we may not have anticipated when writing an ethics protocol. Ethical protocols presuppose particular positions taken up by researchers and participants, and will implicitly construe ethical gestures by assuming that all participants occupy those positions. Drawing from their ethnographic study on an anti-rape protest, and particularly the experiences of participation in the protest by women who had experienced sexual violation, the authors argue for the necessity of envisaging ethical decision-making as relational and ongoing. This argument is in line with that put forth by Geissler, Kelly, Imoukhuede, and Pool (2008), who advocate for kinship-like ethics: 'not just as a quasi-legal frame but also as an open, searching movement' (p. 696).

For Barker and Macleod (2018, this section), ethics protocols represent participants through the realm of rationality which may elide precognitive and embodied ways of knowing. Their own experiences suggest the necessity, instead, of seeing 'the face of the other' by acknowledging the other as fellow human being rather than research participants whose task is to respond to predefined research questions. Similarly, Ezzy (2010) suggests moving away from what he calls 'masculine metaphors of conquest: probing, directing, questioning, active listening' (p. 164) because this often translates into the researcher's maintaining control, directing, and shaping the conversation. For Barker and Macleod (2018, this section), encountering participants who express such personal experiences draws attention to the ethicality of such gestures when one is called on to respond, in this case, the researcher responding affectively to the participant's narrative or, pragmatically, to calls for help.

Researchers as Agents of Change

Developments in qualitative research, such as the increasing popularity of participatory action research and a range of critical theoretical frameworks, have shifted the emphasis from the researcher as information gatherer to the researcher as change agent. A number of chapters in this section reflect on the possibilities and complexities of this positioning.

Barker and Macleod (2018, this section) argue for the need to negotiate ethics by considering researchers as interlocutors with a responsibility towards their participants. This poses a challenge to scholarly practices of retreat and abstraction, generalisation, and reading from afar. As Ezzy (2010) argues, '[T]he emphasis on rational cognition and intentional action allows humans to avoid, or underestimate, the role of emotions in shaping their actions' (p. 163). Thus, Barker and Macleod propose that bearing witness may itself constitute an ethical response in contexts in which emotions are certain to arise in the research process. When Barker was positioned as counsellor in her interviews with rape survivors, she drew on her experience of pastoral therapy to rephrase her questions so as to shift participants' personal narratives in a supportive direction. This marks a subtle but important shift away from considering ethical practices as preventing and preempting harm to ethics as a responsibility that may require sensitive decision-making *in situ*.

While Barker and Macleod did not set out to be change agents themselves, others do. Being cognisant of this as an aim of the research does not negate the possibility that similar ethical dilemmas may appear. Paphitis and Kelland (2018, this section) provide an account of research undertaken with the explicit intention of generating change for participants. As Taylor (2014) demonstrates, 'As broad and inclusive notions of activism dislodge the boundaries between academia and activism, they have enabled scholars to challenge the idea that it is necessary to keep activism separate from research and to explore why and how activism and research might be combined' (p. 305). From the start, Paphitis and Kelland's project was action oriented and sought to generate strategies to alleviate the negative impact of menstruation on girls and their schooling. The authors positioned themselves as researcher-activists and considered their research participants as co-activists when undertaking a needs assessment that would inform subsequent practical intervention. While Hay-Smith et al. (2018, this section) demonstrate a typology of the constraints that may be imposed by occupying dual roles in research, Paphitis and Kelland seek out both roles. In their chapter they reflect on how the research process itself may be experienced as a constraint in the context of activism, as this entails implementing necessary empirical steps to generate knowledge.

Curiously, then, while scholars such as Maxey (1999) challenge the very binary of academia and activism by insisting on a notion of activism as discursively produced, configuring academic research through its practical components (namely conceptualising, drawing up a research design, implementing the design, etc.) seems to reproduce that binary. While an agreement of informed consent in part assuages the anxieties around potential abuse, generally the researcher sets the research agenda. Similarly, Anyan (2014), in writing about the qualitative interview specifically, argues that participants' prescribed roles may conceal a built-in discourse asymmetry.

A different sense of ethical responsibility thus emerges here whereby researcher-activists assume a meta-level perspective on inequality and power beyond the research task by their consideration of the unequal distribution of resources in a setting marked by deep class, gender, and race divisions. Thus, Paphitis and Kelland (2018, this section) question the adequacy of ethical protocols which declare an investment in the well-being of participants but imply adhering to research requirements that slow down the process of generating change. Put simply, the authors ask us to consider how one might configure empirical research through the realm of ethical practice when one prioritises change over data, while simultaneously generating data in order to effect change.

Moreover, Paphitis and Kelland (2018, this section) reflect on how a researcher-activist stance has a bearing on the power relations between researchers and participants. Thus, in the use of a community theatre intervention to demonstrate the experiences of menstruation for girls and to generate dialogue, the authors consider whether their intricate involvement as agents of change meant that learners might have felt unduly coerced into taking part in research activities. Here, the role of researcher who subscribes to ethical protocols of volunteerism may be in conflict with that of an agent of change who desires collective participation as an integral part of effective change. Indeed, what is suggested is that while the empirical research may have been construed as a base from which to stage practical interventions, it generates its own effects in the process.

This is in contrast with the experience of Akhurst et al. (2018, this section), who had to steer away from their frequent positioning as such agents in the low-resource community in which they undertook their research on sexual activity and HIV/AIDS. As their chapter demonstrates, by virtue of being identified as researcher, one may encounter assumptions that one is able intervene in socio-economically significant ways. Thus, the chapter is suggestive of what might be a collusion of research and the discourses of development in low-resource settings, which may have the effect of reinforcing racialised and classed notions of ‘research for change’. How a ‘problematic subject’ in need of ‘intervention’ is produced in academic discourse is steeped in racial, classed, gendered, ableist, and heteronormative configurations, which in turn circulate within developmental work, thus constructing subjects in need of research for change versus those about which information is simply collected.

Researchers as ‘Insiders’ and ‘Outsiders’

For authors of chapters in this section, negotiating the researcher/participant subjectivities that are produced in the research act is interwoven in oscillating social positionalities as outsiders or insiders in their varying research contexts. Not only are such statuses that cohere around a range of social identifiers constructed in the process of generating knowledge, but they also have a significant bearing on projects, both in the field and in the sphere of analysis and synthesis. Equally, our authors trouble distinctions between the field as site from which data are collected and the detached research office, university, conference, and so on where such material is given narrative form.

For Harvey (2018, this section), the field is the intersubjective encounter generated in the psychoanalytic relationship. It is an invention that is co-created by all participants in the interview act. Her own disability status, while disclosed at the beginning of the interview to minimize participant defence mechanisms, means being regarded as a member of an imagined community, which at times dislodges her status as a researcher when participants reverse roles by asking her to speak about her disability or ask her for practical advice. Harvey's experience is a reminder of how the very category of researcher remains fluid and is performed for the duration of the interview. According to Rabe (2003), one way in which researchers may be positioned as insiders is when they occupy positions of relative power. The psychoanalytic interview, invested as it is in engaging conscious and unconscious utterances and actions of the participant, lends itself to reproducing such power differentials: the analyst-researcher is complicit in the construction of research-knowledge, and much of this analytical labour (and research notes) remains with her. While Harvey's disclosure of her disability is intended to create a space of sincerity and openness, it also, to invoke Barker and Macleod's terminology (2018, this section), brings her own face into the research interview in ways that complicate those power differentials. Thus, while this implies additional emotional work for the researcher, the question remains whether the configuration of the researcher in this case as a 'source' of information for the participant assists in offsetting or further complicating those differentials.

According to Rabe (2003), access to knowledge can also generate the insider/outsider dichotomy: 'The insider is perceived as the one with 'inside knowledge' which the outsider does not have' (p. 151). Hay-Smith et al.'s chapter(2018, this section) is suggestive of how the clinician-researcher's clinical knowledge complicates her ethical commitment to respecting the participant's privacy outside the research framework, particularly when the clinician is able to deduce important medical information about the participant to which the latter may not be privy. Should a clinician-researcher respond as a clinician and share necessary clinical information, and thus act as an agent of change by virtue of her insider status? Or should she operate within the parameters of her ethical contract with the participant by adhering to a devised set of research questions? As they note, participants often position clinician-researchers as capable, knowledgeable, and able to intervene, suggesting that like the psychoanalytic interview, rather than existing as a stable imagined space that one enters and leaves, the field is a dynamic space that troubles preconceived ethical responsibilities.

For Rabe (2003), participants themselves are often posited as having ‘insider’ knowledge to which the researcher is granted access. However, Akhurst et al. (2018, this section) trouble a simple emic–etic approach to knowledge production by suggesting that participants may supply readymade responses which they imagine the researcher *wants* to hear. Arguably, this is more than participants simply invoking particular discourses (which in their case is a discourse of social development), but is suggestive of how the research process is undertaken as a performance for the benefit of the researcher. How might researchers then rethink the notion of ‘living in a community’, undertaken for the sake of enriching data? What implications might this have for the researcher who selects aspects of his or her ethnographic data in the process of writing? That is to say, if aspects of the ‘official’ research interview may be questionable to the researcher, what are the ethical implications of reading all the encounters with the participants, including those that lie outside the terrain of research, as constitutive of the ‘field’? How might social scientific discourse, and aspects of it that circulate in policy work, NGO work, development work, and so on, unwittingly ‘train’ would-be participants to encounter researchers in a predetermined manner, thus troubling the notion of the field and research office/seminar/conference as distinct spaces?

The extent to which participants in all our authors’ chapters bring layered aspects of their lives to the research is telling, and challenges the conception of research as a *pause* outside the flow of everyday life. To what extent do ethical protocols imagine research as a self-contained exercise that ‘reads’ the world under study, rather than considering how the very act of ‘doing research’ is intertwined with what the researcher construes as the ‘social’ space under study? Paphitis and Kelland (2018, this section) note how the use of community theatre incorporated other actors into the larger research project in ways that might undermine the female learners’ sense of anonymity by encountering relatives and familiar faces. Similarly, in her interviews with mothers of disabled children, Harvey (2018, this section) is reminded that such ‘real-life’ experiences are difficult to configure as a fragment of participants’ lives, which are not necessarily experienced by participants in a fractured manner. Thus, while Akhurst et al. (2018, this section) chose to immerse themselves in their participants’ lives by living in the research setting, this means negotiating the field as a performative space, necessitating potentially some discernment, filtering, and selection. Yet, the researcher who intends to focus on distinct aspects of her participants' lives, paradoxically and unexpectedly, is privy to a wider frame.

Conclusion: Blurring Boundaries in Transactional Encounters or Relational Interactions?

Underpinning the above-mentioned sites of negotiation for researchers is the notion of research as constitutive of power relations both in those moments in which research activity takes place and in the various institutions and socio-historical sites which researchers occupy, marked as they are by histories and dynamics of class, race, gender, ability, and sexuality. Adhering to ethical protocols becomes, thus, more than simply minimising the potential for harm (a future-directed gesture). Such adherence is precisely the site in which power is continually negotiated. The very preemptive measures required in ethics protocols may be, in a paradoxical fashion, their own expression of the researcher's authority. On the one hand, they minimise the potential for abuse of power, but on the other, they allow the researcher to direct the research. To what extent are even critical paradigms, invested as they are in questioning power relations, able to extricate themselves from such circuits of power relations in the ethical practices that constitute them?

Authors in this section grapple with the implications of the multiple roles that they may be called upon to perform in the research encounter and the attendant relationships with participants that these roles invoke. In thinking through the complex dynamics of the blurring of boundaries, the question of whether research may be seen as a transactional encounter (information in exchange for individual or communal benefit) or as a relational interaction (researcher and participant on a journey of exploration) may be posed.

Paphitis and Kelland (2018, this section) draw attention, for example, to how power is manifested by the popular understanding of research as a transaction. For the authors, undertaking research in the spirit of activism means remaining critical of how research is configured frequently in transactional terms. As they note, '[T]he transactional nature of the relationship has largely remained even where we have shifted to paradigms in which the subjects of research have been characterised in more active terms, being seen as participants' (p. 195).

Arguably, the extent to which participants trouble the researcher's detachment and the instances in which researchers are asked to extend beyond their academic roles are moments in which the researcher's authority is dislodged temporarily. They are also moments in which a future-driven set of ethical protocols may be compromised. When some participants, in the experience of Akhurst et al. (2018, this section), expect financial remuneration, the material manifestation of the notion of transaction is revealed, suggestive as it is of economic processes. Additionally, one might consider how the assignment of roles, or the performativity of the project, is itself tied to the notion of research as a transaction characterised by an existing script for would-be role players. Thus, while Paphitis and Kelland (2018, this section) make use of theatre, Akhurst et al. (2018, this section) encounter a social space that takes on the form of performance which inevitably draws the researchers into existing roles.

Paphitis and Kelland propose then the notion of relational research in collaborative work to reinforce the extent to which all parties share responsibilities in the design and implementation of research as well as in the dissemination of results. Might such a framework be applicable even outside the parameters of participatory and community-engaged work? Moreover, does it do away with the asymmetry between researchers and participants? Seemingly, it is at those moments of ethical ambiguity that power is negotiated when it is the researcher who experiences *subjection* and constraints.

Chapters in this section reflect on the challenges that arise when researchers find themselves positioned in unexpected roles by participants, or in the process of research, beyond simply that of accumulating information. Such occurrences complicate one's existing ethics contract or agreement that may not anticipate such positioning. As the chapters suggest, what constitutes an ethical response in such instances wherein boundaries are blurred may need to be negotiated in that dynamic space of fieldwork engagement. On the one hand, blurring boundaries does imply that ethical agreements undertaken prior to research are rendered incomplete, thus generating anxiety about unanticipated harm. This dilemma also opens up, however, the potential to dislodge, at least temporarily, the researcher's authority as director of a research project. Responding sensitively and creatively to participants' needs, wants, and desires suggests a move towards a relational research agenda.

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10

Blurred Researcher–Participant Boundaries in Critical Research: Do Non-clinicians and Clinicians Experience Similar Dual-Role Tensions?

Jean Hay-Smith, Melanie Brown, Lynley Anderson, and Gareth J. Treharne

Clinician-researchers have two roles and identities: clinician and researcher. In research with patient-participants the clinician-researcher may feel that the two roles blur in such a way that the 'boundaries' between the two roles are not easy to discern for them or their participants (Hay-Smith, Brown, Anderson, & Treharne, 2016). The experience of dual-role is typified by feeling internal conflict (e.g. am I acting as a researcher or as a clinician here?) and difficulties in clarifying roles to others (Yanos & Ziedonis, 2006).

In 2016 we published a typology of dual-role experience specific to clinicians (i.e. registered health professionals) involved in research with patient-participants (Hay-Smith et al., 2016). We postulated there were some underlying feelings or events that precipitated the clinician-researcher dual-role experience and systematically reviewed reports of clinician-researcher dual-role experiences to develop a typology of these catalysts. Having identified ten common catalysts of dual-role dilemmas in our typology, we concluded that dual-role experiences were probably inevitable in research in patient settings involving clinician-researchers, and that the typology could be used as a framework to tackle the ethical challenges of dual-role tensions in research planning, implementation, monitoring, and reporting.

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In the process of developing the typology, we started to see other possible configurations of dual-roles, such as educators researching with students or a member of a profession undertaking research within their profession. In the body of literature screened during typology development, we noticed that critical researchers (Lyons & Chamberlain, 2006; Stainton-Rogers, 1996) and researchers of 'sensitive' topics (Dickson-Swift, James, Kippen, & Liamputtong, 2007) also reported the ethical dilemmas of the researcher role, including boundary blurring (Dickson-Swift, James, Kippen, & Liamputtong, 2006). This chapter examines our observation of possible parallel concerns for non-clinician researchers in detail. We ask whether critical and sensitive topic researchers can experience blurred role boundaries similarly to clinician-researchers. We consider whether this is as foreseeable and unavoidable in critical and sensitive topic research as it is in clinician research, and whether the clinician-researcher dual-role typology is useful as a template for unpacking some of the ethical challenges associated with blurred role boundaries for critical researchers. Awareness of the challenges and likely catalysts may help support the planning and conduct of robust critical research for non-clinician researchers.

The Typology of Catalysts for the Experience of Clinician-Researcher Dual-Role Dilemmas

The systematic review methods we used to search for, screen, select, and synthesise the data about clinician-researcher experience of dual-role tensions are fully documented elsewhere (Hay-Smith et al., 2016). Papers included either research reports of investigations of clinician-researcher dual-role or autobiographical accounts of dual-role experiences written by clinician-researchers. Thirty-six papers contributed data for thematic analysis (28 autobiographical accounts, 8 investigations); most were nursing research (27 out of 36 papers) and 26 out of the 28 autobiographical accounts were reflections on dual-role experience in qualitative research projects. For each reported instance of dual-role tension in the included studies, the coding focus was on what happened (the event) and what the researcher felt and thought about that event.

Two overarching catalysts for clinician-researcher dual-role tensions were derived: 'Clinical Patterns' and 'Connection' (Hay-Smith et al., 2016). Dual-role tension was provoked when the researcher acted as a clinician in the research setting for the benefit of the patient-participant, or the carer, or health professional colleagues. Patterns of clinician behaviour included the use of clinical skills, clinical reasoning, or the provision of access to clinical resources. Dual-role tension was also manifested when the researcher–participant connection began to blur and mirror a clinician–patient-type bond. While the primary relationship was researcher–participant, both parties had experience of the clinical context and this easily potentiated a clinician–patient-type connection in the research setting. A clinician–patient-type relationship was reinforced if the researcher was also thinking and behaving in ways congruent with the clinical role. We concluded that for clinician-researchers the experience of dual-role tension is probably inevitable consequent upon their ingrained orientation towards patients' needs, an orientation that is carried into the research setting. There are five sub-categories in each overarching theme and these are briefly elucidated in Table 10.1.

Table 10.1 Summary of the typology of clinician-researcher dual-role tension

Overarching themes and sub-categories	Description
Clinical patterns	Dual-role tension is provoked when the researcher acts or is expected to act as a clinician in the research setting for the benefit of the patient-participant, or the carer, or health professional colleagues. Patterns of clinician behaviour include the use of clinical skills, clinical reasoning, or providing access to clinical resources.
1. Clinical queries	The patient-participant makes a straightforward request for information or reassurance and the researcher uses clinical knowledge to address the question or offers an alternative resource.
2. Perceived agenda	When the researcher has clinical knowledge and behaviours the patient-participant may ask a question that appears to contain an 'agenda' (e.g. request for referral), or another person with vested interest (e.g. referring clinician) asks for research-generated clinical information about a participant that would usually be communicated between professional colleagues.
3. Helping hands	Researchers feel they are asked or are expected to use hands-on clinical skills to help patient-participants or to help colleagues provide patient care. There is a desire to help, whether it is acted on or not.
4. Research or therapy?	Researcher is concerned that patient-participants confuse research and therapy because the researcher's behaviours are typical of clinical behaviours (e.g. listening empathically, undertaking clinical tests).
5. Uninvited clinical expert	The researchers 'automatically' use their clinical knowledge or reasoning in the research setting. They may discover an incidental clinical finding or use clinical expertise to make a research-related decision on behalf of a patient-participant.

(*continued*)

Table 10.1 (continued)

Overarching themes and sub-categories	Description
Connection	Dual-role tensions manifest when the researcher–participant connection begins to mirror a clinician–patient-type bond. Blurring of clinician and research roles, and development of a clinician–patient-type relationship, is reinforced when the researcher thinks and behaves in ways congruent with the clinical role.
1. Clinical assumptions	Common clinical ground creates opportunities for assumptions of shared understanding between the researcher and patient-participant.
2. Suspicion and holding back	The researcher suspects that the patient-participant is holding something back because, as clinician, the researcher could have an influence on the patient's current or future clinical care.
3. Revelations	Patient-participant revelation of more intimate information than was expected or sought by the research suggests the participant has assumed the researcher–participant relationship is synonymous with a clinician–patient relationship.
4. Over-identification	As the trust relationship develops in the research encounter, the researcher finds it difficult to discern the boundary between researcher–participant relationship and clinician–patient relationship or being too connected to the clinical self 'blinds' researcher to the phenomenon being explored.
5. Manipulation	The researcher intentionally fosters clinical trust in the relationship with the patient-participant to advantage the research.

Are Blurred Role Boundaries Likely in Critical or Sensitive Topic Research?

During eligibility screening for the review (Hay-Smith et al., 2016) we excluded a number of papers that appeared to report blurred role boundaries, and attendant ethical or methodological concerns, but did not meet our review criteria of clinician-researchers conducting research in patient settings. Composite examples of excluded papers were studies conducted by clinician-researchers with participants who were not patients, (e.g. clinical psychologists engaged in research with domestic violence perpetrators), studies conducted by non-clinicians with patient-participants (e.g. a social scientist engaged in research with women attending a repeated miscarriage clinic), or by non-clinicians in studies in which the participants were not patients (e.g. a researcher who has experienced addiction issues engaged in research with users of addiction services). We observed that many of the excluded papers reported research with social justice aims or research addressing private, sensitive, highly charged aspects of participants' lives and therefore asked ourselves if blurred role boundaries also might be likely in such research.

We reasoned that parallels were likely because much critical and sensitive topic research is undertaken within a context of the non-clinician researcher's orientation of caring for the community in which the research was conducted. For clinician-researchers the challenge is clarity between their clinician and researcher roles and delineating clinician–patient from researcher–participant relationships. For critical researchers the 'equivalent' may be clarity between activist and researcher, or socially conscious community member and researcher, and distinguishing a researcher–participant relationship from something like friendship (Dickson-Swift et al., 2006). Thus, critical research might be just as likely to generate tensions between duty of care and methodological rigour as research undertaken by clinician-researchers, where the researcher is oriented towards patient needs. If blurring of role boundaries is predicable in critical and sensitive topic research, as it is for clinician-researchers, then the existing typology (Hay-Smith et al., 2016) may have some use as a framework for unpacking some of the ethical challenges in critical and sensitive topic research too.

Illustrative Examples of Blurred Boundaries in Critical Research, and Research on Sensitive Topics

Using the typology as a framework we examine five exemplar 'stories from the field', written by critical or sensitive topic researchers. The search for 'informative' examples started by reviewing the 'nearly but not quite' exclusions from the original review. Based on a combination of reference list checking, backward and forward citation chasing, and some supplementary searching, we easily gathered a pool of 20 accounts of ethical dilemmas experienced in critical research and research on sensitive topics that were related to the nature of researcher–participant relationships. From these we selected five 'informative' examples (Blythe, Wilkes, Jackson, & Halcomb, 2013; Hodgson, Parker, & Seddon, 2006; Mitchell & Irvine, 2008; Richman, Alexander, & True, 2012; Sinha, 2017).

We do not claim that the examples are representative of critical or sensitive topic research, in terms of methodology, methods, topic, participant groups, or researcher background. The primary reason for their selection was the 'richness' of the accounts—detailed writing about events and researcher feelings and thoughts that conjured a clear picture of the dual-role tension(s). Four examples were autobiographical (Blythe et al., 2013; Hodgson et al., 2006; Mitchell & Irvine, 2008; Sinha, 2017) and one was primary research (Richman et al., 2012). This was similar to the representation of autobiographical and primary research in the original typology. Each illustrative example is described briefly below.

Hodgson et al. (2006) published their reflections on their experiences of interviewing people in police custody suites who had been arrested and tested for opiate or cocaine use. The study was part of a larger research project investigating a drug testing pilot in the criminal justice system in the United Kingdom. Issues raised in the paper included the particular difficulties of site access, researcher identity and partisanship, and specific ethical dilemmas associated with seeking informed consent and breaches in trust.

Mitchell and Irvine (2008) reflected on their experiences of interviewing people who had experienced mental ill health and had claimed an incapacity benefit, about the experience of employment. Both researchers, who had had personal or family experience of mental ill health, were employed by a UK Social Policy Unit to work on this government-funded study. Some of the ethical challenges faced by the authors occurred while negotiating consent, finding appropriate responses to their own and participant emotions, developing rapport, and what responsibility they had for follow-up and support of participants.

In their qualitative study, Richman et al. (2012) reported findings from interviews with community research workers recruited from research organisations in the United States. The study aim was to explore community research workers' experiences of navigating the tensions in fieldwork and what enabled or impeded responsible research conduct. The researchers found that community research workers had difficulties in reconciling research norms with their obligations to their community; their proximity to their community (the reason they were desirable as research workers) provoked role conflict and affected data quality and usefulness.

The primary author of Blythe et al. (2013), and her research supervisor co-authors, reflected on the challenges of 'insider' research. Their insights derived from a feminist storytelling study of Australian women's experiences of providing foster care. The primary author was a foster carer. Four challenges of insider research were discussed: assumed understanding between researcher and participant, how to ensure analytic objectivity, the need to manage researcher emotion, and dealing with participant expectations of research outcomes.

Sinha (2017) provided a reflexive account of the challenges of research on sex work. Her study in India aimed to understand how sex workers who were not based in brothels perceived their HIV risk within the broader context of other risks in their lives. A middle-class Hindu, she found her study participants were bothered that she (being middle class and not a sex worker) would be stigmatised by association with them; Sinha's reflections focus on the effect of stigma on the research process, in particular while making contact with participants and establishing rapport.

Applying the Typology of Dual-Role Tensions to Illustrative Examples of Critical Research and Research on Sensitive Topics

Under two headings, patterns of researcher behaviour (parallel to 'Clinical Patterns') and the relationship between researcher and researched (parallel to 'Connection'), we collate instances of events and researcher thoughts and feelings, drawn from the critical and sensitive topic examples, to illustrate role tensions. Using the original typology as an analytic framework, we note and discuss the similarities with and contrasts between the boundary blurring experienced by clinician-researchers and critical researchers or researchers of sensitive topics.

Patterns of Researcher Behaviour

Providing Participants with Information

Researchers may offer information or provide pathways to useful information resources in both clinical (see clinical queries, Table 10.1) and non-clinical research settings, as part of the researcher–participant transaction. For example, Mitchell and Irvine (2008), anticipating a lack of mental health support for some interviewees, had prepared a list of local resources and services which they gave to those who expressed a need for more information. Sinha (2017, p. 9) 'immersed' herself in the daily lives and problems of the women sex workers , and this included helping them 'seek consultation from doctors' and 'obtain information about schools and residential homes for their children'. While clinician-researchers may question whether answering clinical queries blurs the boundary between research and clinical care, we noticed that information exchange was considered by critical researchers to be an appropriate means to support participants (Mitchell & Irvine, 2008) and an appropriate form of reciprocity (Sinha, 2017). It is possible, therefore, that non-clinician researchers may be less concerned than clinician-researchers about boundary blurring when addressing questions or giving information. Nevertheless, the 'sensitivity' of clinician-researchers to sharing information as a source of possible role tension prompts us to pose the question for critical researchers: what are some of the commonplace, mundane, and everyday researcher behaviours (such as information sharing) that, if unquestioned, could potentiate blurred role boundaries?

Agendas

In the illustrative examples there was no immediate parallel for the clinician-researchers' concern about being 'exploited' if a participant sought a clinical response (e.g. expedited referral) beyond what was deemed appropriate in the research setting (see perceived agenda, Table 10.1). A possible explanation is that where a clinician-researcher is bothered about a possible participant agenda, non-clinician researchers may see instead a legitimate expectation for joint benefit.

Third-party agenda, however, was evident and ethically challenging in critical research. Sinha (2017) experienced problems with some non-government organisation (NGO) staff who were unable to distinguish the boundary between the NGOs' sexual outreach project and the research that recruited sex workers who had contact with the outreach project. For instance, NGO staff asked her for the names of women who took part, or why the names of some women referred to the study were not on the list of those interviewed. Concerns for the women's safety and anonymity led Sinha to seek participants independently of the three NGOs she had initially approached as recruitment sites. Perhaps it may be useful for critical researchers to ask what potential there is for third-party agendas in their research, and how these could be managed 'up front' (e.g. contractual negotiations with funders about access to data). A more dynamic response may be needed for situations arising 'in the field' such as Sinha changing the recruitment process once the research began.

Helping Out

Physically helping, or wishing to help, was also a source of dual-role tension for clinicians (see helping hands, Table 10.1). Instances of helping participants, and cases of helping third parties (e.g. 'staff'), were apparent in the illustrative examples too. Sinha (2017) helped the sex workers with technologies (such as mobile phones and automatic teller machines), completion of written forms, and buying medicines. In this context, helping was considered a way to demonstrate reciprocity and genuine engagement with women and of generating trust by being part of the women's lives. However, Hodgson et al. (2006, p. 259) reported that researchers collecting data in custody suites often had their role misunderstood and confused 'with Arrest Referral Workers, and more occasionally with Solicitors or Appropriate Adults'. This meant some researchers 'were asked to fulfil duties outside their remit' which included being given the keys to collect or return prisoners to cells. While initially seen as positive, 'in that custody staff trusted us to carry out their duties', on reflection, it was considered 'unprofessional and put researchers in a difficult situation'. Thus, helping may not be 'benign' for non-clinical researchers in that some actions may have legal implications or put the researcher at risk.

The typology suggested that 'helping' is something the researcher wants to do, and choosing not to help can be uncomfortable and also worrisome if not helping might affect the research (such as upsetting people the researcher relies on to recruit participants). Critical researchers may find it helpful to consider the ways they could be asked to help in the particular context of their research (e.g. in hospitals, NGO offices, schools, etc.) and establish boundaries and narratives to explain why they might be willing to help or not help if those boundaries are questioned.

Research or Therapeutic Behaviour?

Another tension for clinician-researchers is their behaviour in research when their interaction with participants could veer towards 'therapy' (see research or therapy, Table 10.1). This was a concern that arose for Mitchell and Irvine (2008). They expected and indeed found that asking participants about mental ill health and its life consequences—personal and work—precipitated heightened emotion for some participants. Being cognisant of the need to avoid taking on a 'pseudotherapist role' (p. 35), they considered in advance how to respond appropriately, 'how to offer practical or emotional support, and the potential positioning of the researcher as therapist or "friend"' (p. 34).

Given the nature of critical and sensitive topic research, we hypothesise that this is no less likely to result in the need to respond appropriately to participant emotions than clinician research, and that dealing with heightened emotion always has the potential to precipitate a blurring of the research–therapy boundary. Dickson-Swift et al. (2006) call this the research–counselling–therapy boundary and found many examples of it in their study of boundary issues in qualitative research on sensitive topics. Taking a lead from Mitchell and Irvine, we ask what practical preparation the researcher might need in order to manage possible participant distress, what strategies are available to monitor the research–therapy boundary, and what are the agreed signals (e.g. researcher feelings, researcher behaviours) indicating that the boundary is blurring? In addition, as modelled by Mitchell and Irvine (2008), useful preparation also may include finding out about local services and resources that relate to the particular aims of the research (e.g. awareness of agencies and resources relating to mental ill health and employment).

Acting as 'Expert'

Finally, with respect to patterns of researcher behaviour, there is acting (or feeling the impetus to act) as an 'expert'. We found a parallel for this in Richman et al. (2012). In their exploration of challenges faced by community research workers recruited because of their proximity to the communities in which data are collected, Richman et al. (2012) reported one community worker's experience:

> Dawn felt badly about having information that might be useful to a participant but that she was not supposed to share:
>
> > As I'm looking for yeast [infections] I can see other things, like maybe if they have trichomoniasis and I feel horrible … that I cannot tell this person that they're walking around with a disease. … It kills me. I keep asking, can I say anything? They say, nope, remember everybody's a number, act like you didn't, like it's not there. (pp. 22–23)

This replicates the doubt about, or acceptability of, acting on a diagnosis or observation 'incidental' to the research experienced by clinician-researchers (see uninvited clinical expert, Table 10.1).

We speculate that one reason it may seem difficult not to draw on one's expertise as a researcher and act in the, apparent, best interests of a participant is that not acting runs contrary to other patterns of behaviour. For example, consistent with forging a 'good' relationship with the research participants, the researcher may offer information, answer some questions, and help participants with aspects of their daily life yet find that other actions are outside the limits of helping. Critical researchers may well be asked to demonstrate that they are 'expert' in the topic they are researching in order to make connections with participants and may also need to express the limits to their expertise or to set boundaries to the role of expert that they are willing or able to take on.

Relationship Between Researcher and Researched

Assumed Understanding

Parallel with clinical assumptions reported by clinician-researchers (see Table 10.1), we found documented examples of assumed understanding in one of the illustrative examples. Assumed understanding, attributed to 'insider' research, was one challenge noted by Blythe et al. (2013). The primary researcher (a PhD candidate, woman, and long-term foster carer) found that woman foster carers in her study made comments 'such as "You should know that", or "You know what I mean"' in interviews (p. 11). Blythe interpreted these utterances as a signal of omitted information based on assumed understanding.

For critical researchers, as for clinician-researchers, we feel it is likely that there are pros and cons for shared understanding based on shared experience. While rapport and trust may be enhanced by feelings of connection through shared experience, there is also the risk of unchecked misunderstanding or incomplete understanding. Researchers who recognise their 'insider' status are most likely to incorporate reflexive practices that challenge what they know and why, yet at the same time are at greatest risk of making assumptions about events and practices that are normal or usual for themselves. Critical researchers can incorporate checks and balances that help identify assumptions through further interactions with participants (or the group in question) as well as input from supervisors or colleagues.

Suspicion as Barrier to Connection

Non-clinician researchers report being bothered by apparent 'suspicion' of the research or researcher in ways that are similar to the tension experienced by clinician-researchers (see suspicion and holding back, Table 10.1). Hodgson et al. (2006) noted that participants were suspicious of the researchers after they were asked to act in the manner of custodial staff (see also the section on helping out). By contrast, Sinha (2017) found that the women taking part in her research were suspicious not of the researcher but of the NGOs for being overzealous in assisting with recruitment of participants. For example, one sex worker said to her:

> I don't like the way they keep showcasing us in front of anyone who comes to the project. They can provide general information but why should they escort these people and introduce us as 'sex workers.' I don't like this practice of theirs. You can't trust these other people and there is no way to control what these other people are going to do with the information. You tell me? (Shristi, 28 years) (p. 6)

Sinha (2017) considered that taking time to build rapport, founded on respectful and trusting relationships, was essential to ensure the genuineness of the women's consent to participate. We do not disagree with her reflection, yet at the same time ask whether, in order to overcome suspicion and develop rapport and trust, the critical researcher may be tempted to behave in ways that blur boundaries between researcher and researched in a way that provokes dilemmas rather than productive critical research? A critical researcher might ask what, for example, are the ethical implications of coming out as a researcher after prolonged covert relationship building before recruitment of participants begins?

Revelations

For clinician-researchers' dual-role tension often followed the revelation of 'intimate' information in the research that was not expected or sought, but was typical of what they would hear in a clinician–patient relationship (see revelations, Table 10.1). Hodgson et al. (2006) furnish several instances of revelations in a researcher–participant relationship that posed an ethical dilemma. In one instance, a researcher had significant concerns about a participant's suicide risk and experienced tension about whether disclosure to custody staff was warranted. Hodgson et al. gave other examples of participant disclosure that could precipitate similar unease—'what should the researcher do if they are told during an interview about an intention to commit a serious crime? Or that the respondent has concealed a weapon?' (p. 260).

What we observed is that in both clinical and non-clinical settings it seemed researchers are most likely to feel conflicted about their primary responsibilities when immediate and significant risk to participants, or others, is exposed. The dilemma is how to take further action, which seems warranted, when this would breach previous assurances of research confidentiality. In such circumstances, clinician-researchers may feel justified in taking a decision to put patient needs first based on clinical ethics and have the advantage of established pathways for referral or reporting. Critical researchers may wish to ask themselves what 'bar' they set for negotiating a breach of research confidentiality (and whether they would ever 'override' a participant's wish). If a breach of research confidentiality is deemed likely or becomes essential, it is important for researchers to be aware of the likely agencies or pathways to manage revelations by participants.

Over-Identification

The investigation of community research worker experiences undertaken by Richman et al. (2012) was riven with examples of workers who strongly identified with research participants and, in the words of one participant, 'crossed the line' (p. 23). Clinician-researchers also found it difficult to discern the boundary between researcher–participant relationship and clinician–patient relationship as trust developed between researcher and participants (see over-identification, Table 10.1). Richman et al. (2012) called this boundary blurring 'going beyond', and reflecting on one worker's experience, the authors said:

> Harmony, for instance, said: 'I'll talk to you at least once a week or once a month; you can still keep calling me.' Harmony's cultural proximity to the target population of her study gave her very personal motivation: 'Statistics show that African-Americans and Latinos are the highest rate infection and that's my population, that's my people. I need them to stop getting infected [with HIV].' Harmony did not describe this as a boundary issue, although others certainly would have. (p. 23)

Transference involves the redirection of one's feelings or interpretation of one experience onto another (Finlay, 2002). The risks of transference are potentially greater in some designs and settings than in others and possibly higher if the researcher feels 'inside' to the research (see also the section on assumed understanding, above). We contend that the emotional and physical proximity, duration of contact, and the behaviours in which a researcher engages to build rapport are dynamic and interactive components of the connection between researcher and participant. While health professional codes of conduct give clinicians guidance for boundaried clinician–patient relationships, the boundaries may be less well articulated for non-clinician researchers. Perhaps the question for critical researchers is whether a boundaried relationship can be established that is productive for the research and respectful of the community's needs and goals.

Manipulation

The potential for a researcher intentionally to foster clinical trust in the relationship with the participant in order to advantage the research was of concern to clinician-researchers (see manipulation, Table 10.1). Similarly, the illustrative examples reflected on concerns about the potential for manipulation and how to guard against it, rather than on examples of manipulation.

Participant remuneration was a particular issue that provoked disquiet about the potential for exploitation and the ways in which payments might be coercive for people held in police custody suites (Hodgson et al., 2006) and woman sex workers (Sinha, 2017). Another anxiety raised by Mitchell and Irvine (2008) was whether anything they planned or did would fabricate a connection with participants with mental ill health that ‘commodified and commercialized’ rapport, making this ‘a skill that can be turned on and off as and when required’ (p. 37).

We conjecture that the heightened awareness of potential for manipulation is because clinician-researchers, and critical and sensitive topic researchers, are alert to the potential vulnerability of the participant population and power imbalance between researcher and researched. These vulnerabilities and the potential to feel or to be seen to be manipulating participants may only become evident once in the field, and therefore requires an ability to respond in the moment and rethink planned research practices that contribute to this.

Parallel, not Equivalent: Reflections on the Original Typology and Its Utility in Non-clinician Research

We embarked on this chapter having noticed some parallel methodological and ethical concerns arising from an experience of blurred role boundaries in two literatures: clinician research and critical or sensitive topic research. Applying an existing typology of dual-role experiences in clinician-researchers (Hay-Smith et al., 2016) to five illustrative examples drawn from critical research and research on sensitive topics, we asked: (1) might the typology offer a useful template for understanding some common catalysts of blurred boundaries for critical and sensitive topic researchers? and (2) whether blurring of role boundaries is as foreseeable and unavoidable for critical and sensitive topic researchers as for clinician-researchers?

Using the typology, we found parallels for the ten catalysts of dual-role tensions in the critical and sensitive topic research literature. This suggests some usefulness for the typology by helping critical researchers and researchers of sensitive topics to consider some likely indicators of boundary blurring. Thus, one use of the typology might be as a discussion framework when designing and conducting research. It might assist in anticipating some sources of blurred boundaries, provide a prompt for debriefing dual-role tension experiences during research, and enable a structure for reflection. With regard to the potential for blurred role boundaries in critical and sensitive topic research, we speculate this is as inevitable as it is for clinician-researchers. Critical researchers are likely to demonstrate behaviours (such as providing information and support for study participants, helping participants or others in the research setting, empathic listening, and using expertise to benefit study participants) that promote rapport, trust, and relationship with their participants. In advancing the connection with participants, however, researchers also may start to question if they have become too 'close' or are too much the 'insider' so that the researcher–participant boundary has begun to blur.

The limitation of holding up the typology of dual-role tension experienced by clinician-researchers as a mirror to the wider context of critical research and research on sensitive topics is that the original typology was generated from papers collected and selected using systematic methods, and the illustrative examples were purposively selected to demonstrate possible parallels. There may be other important stimuli for boundary blurring and accompanying ethical and methodological tensions, experienced by critical researchers or those researching sensitive topics. At the same time, this chapter contributes to the debate about the nature and catalysts of boundary blurring in critical research. Clinician-researchers couch the challenge in terms of the clarity between their two roles, clinician and researcher, and delineating clinician–patient from researcher–participant relationships. It is less clear what roles critical researchers were trying to distinguish—activist and researcher, socially conscious community member and researcher, or friend and researcher perhaps?

Another difference was that clinician-researchers seemed to problematise blurred boundaries, seeking a solution or a way to keep their clinical and research roles clearly separated. In their vocational and professional training clinicians are educated to disclose little of themselves to patients and to uphold relationship boundaries with patients consistent with the code of ethics of their registering body. Thus, clinician-researchers may be more inclined to problematise behaviours that, in non-clinician researcher contexts, might be perceived as innocuous or even necessary for developing a relationship with participants (e.g. sharing information and helping participants in various ways). Clinician-researchers may feel they have to question any behaviour—no matter how commonplace or straightforward—that fosters connection if it might blur the distinction between researcher–participant and clinician–patient relationships for them and their participants.

By contrast, non-clinician critical researchers may be socialised to understand the 'distance' between themselves and research participants differently. While non-clinician researchers can draw on published ethical norms from research institutions, funders, and academic research disciplines, the guidance about what constitutes a 'professional relationship' between researcher and participant may be less clear cut than the 'rules' governing clinicians' relationships with patients. Arguably, the clinician-researcher is constrained in the relationship with participants in ways that the non-clinician researcher is not. There may be pros and cons to this. Perhaps non-clinician researchers can be 'participant' or 'immersed' in their research in a way clinician-researchers find difficult (or prohibited) when they apply their health professional ethical principles in research. However, there may be risks and consequences for the non-clinician researcher in closeness of engagement and emotion 'in relation to their understanding of their self and identity, and their capacity to perform in a fashion that they would themselves regard as professional, and these effects can be long term' (Holland, 2007, p. 207).

Conclusion

Some parallels in the ethical dilemmas of boundary blurring for clinician-researchers and non-clinician critical researchers are evident. Fundamentally, however, non-clinician researchers situate their tensions within a context of how to engage with their participants while 'being professional', and clinician-researchers' issues are embedded in the dialogue of maintaining the boundaries of a 'health professional' in research with patient-participants. Nevertheless, the typology of catalysts for the clinician-researcher experience of dual-role tension may have some resonance for critical researchers and researchers of sensitive topics. As the illustrative examples we selected demonstrate, non-clinician researchers also grapple with blurred role boundaries and the ways researcher behaviours and physical and emotional proximity can contribute to this tension.

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11

Blurring Boundaries Between Researcher and Participant: The Ethical Use of a Psychoanalytically Informed Research Interview

Clare Harvey

This chapter is a reflection on the challenges of remaining ethical when collecting participant information and using the psychoanalytically informed research interview (adapted from Stromme, Gullestad, Stänicke, & Killingmo, 2010; Cartwright, 2004; Kvale, 1999). Specific ethical tensions can arise when participants relate to researchers as confidants and advice-givers; the work then becomes emotionally demanding and should be approached carefully. I attempted to manage encounters ethically with participants by using examples from my study on maternal subjectivity[1] in which I interviewed able-bodied mothers raising visibly physically disabled children. I interviewed each woman twice on how she makes sense of who she is now that she is also a mother, specifically to her disabled child. I too have a visible physical disability.[2] I am also a mother to two children, and my daughter has the same disability as mine. Another relevant particularity is that I am a practising psychoanalytic psychotherapist and psychoanalytic-researcher.[3]

I felt prepared to conduct the interviews as I had diligently reminded myself of ethical research principles, including beneficence and non-maleficence, from my training and experience. It became apparent, however, from the first encounter with a participant that this research required additional ethical engagement. I thought participants may respond to me openly due to our shared similarities, including motherhood and disability. Also I anticipated that my disability might cause participants to withhold thoughts and feelings

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for fear of offending me. I informally addressed my disability with participants at the beginning of our first encounter, discussing my interest in motherhood and disability stemming from personal experiences. Given the visible nature of my disability I felt it helpful to address it from the beginning to try to avoid participants becoming psychologically defended which could have curtailed the depth of information they provided. I also decided to conduct repeated interviews, hoping this would facilitate a relationship of trust and ameliorate the possibly silencing effect of my disability. Dependant on the nature of the project, this would be likely to extend to researchers with other particular physical characteristics such as gender and race, and with participants from marginalised populations and minority groups. Thus, some of the ethical tensions raised in this chapter may be applicable to researchers in other fields using other qualitative methods.

My two identities of disabled and mother to a disabled child, in particular, played a significant role in the data collection process.[4] Unexpectedly, participants turned the interview relationship around asking me questions about these particularities. These interfaces inverted the researcher-participant relationship, blurring the roles. Since there were many of these types of interactions, I faced unforeseen ethical tensions. These included participants relating to me as a confidant and potential advice-giver.

Certain ethical issues related specifically to disability studies also arose, notably, the ethics of 'doing' disability research. As Goodley (2017) states, it is important that disabled people direct the research agenda so as to avoid disabled people becoming objects of research because of their disability. I was acutely aware of this agenda in myself even though my participants were able-bodied. I feel I managed to avoid such an objectification. Because participants, at times, 'researched' me, however, I became the object of their study, causing me to question how helpful my study is to disabled people. Thus, the boundaries between abled and disabled also became blurred at times. The participants' need to flip the research around speaks to parts of the disabled community's need to feel understood by others whom they deem share similar experiences.

The blurred interactions left me uncertain as to whether I should/could answer participant questions. If I did divulge personal experiences what would this mean for the participants and the research? How would it affect the researcher-participant relationship? I decided to share information cautiously and answer participants' questions. These responses were well received. A deep rapport and sense of safety seemed to be established between the participants and myself at the time and for subsequent interviews. My willingness to answer questions seemed to leave participants feeling less emotionally exposed as they shared more information and made ongoing contact with me after the interviews. Further, I felt that I had offered something to the participants as they had gifted me so generously with their personal accounts. Constantly reflecting on these ethical tensions by applying my training and experience as a psychotherapist, as well as within my own psychoanalytic psychotherapy, was critical. However, before I deliberate on the ethical tensions, let me outline the research method.

The Psychoanalytically Informed Research Interview

The method that I used applies psychoanalytic theoretical concepts and practices in an attempt to collect nuanced, including unconscious, material. Freud (1923), who originally developed psychoanalytic technique, described the foundation of psychoanalysis as mental life consisting of the conscious and unconscious. Unconscious thoughts only become conscious once the person is encouraged to reflect upon them deeply (Stromme et al., 2010). Stromme et al. (2010) consider how unconscious defence processes often influence a participant's subjective account. This psychoanalytic method aims to access conscious and possibly unconscious intrapsychic processes, fantasies, and defence mechanisms associated with the focus of the research (Cartwright, 2004). Thus, I chose this method as I believed it would generate a woman's deep psychic functioning when her child is born with a disability.

This research interview is based on the psychoanalytic listening perspective, depicted by Freud (1923, p. 239):

> …the attitude which the analytic physician could most advantageously adopt was to surrender himself to his own unconscious mental activity, in a state of evenly suspended attention, to avoid so far as possible reflection and the construction of conscious expectations … to catch the drift of the patient's unconscious with his own unconscious.

A central emphasis of this method is the contextual nature of meaning (Cartwright, 2004). Knowledge is created in the transactions between researcher and participant. Kvale (1999, p. 96) describes this as 'human emotional interaction'. Thus, the researcher plays a central role in accessing and understanding the participants' experiences. The goal of this relationship is for the researcher to collect the participant's story of a particular phenomenon. The outcome is a version of the participants' experiences comprising a structured interpretation of the collated responses. As it is a working relationship there are predetermined roles for each person to play. Defining and maintaining this relationship is complex, presenting an ongoing challenge that needs to be renegotiated throughout the research (Mitchell & Irvine, 2008). A balance needs to be continuously striven for between the dangers and benefits of being too close to or too distant from participants (Dickson-Swift, James, Kippen, & Liamputtong, 2006).

As with most human interactions, the researcher-participant relationship is an intersubjective one. Consequently, this has an impact on the interview process and on the nature of the material collected. The intersubjective nature of this encounter shares similarities with the psychotherapist-patient relationship (Stromme et al., 2010). The concept of transference-countertransference plays a significant role in this method. Freud (1910/1953) introduced the concept of *transference* as the patient consciously and unconsciously re-experiencing emotions towards persons from his or her early life in relation to the psychoanalyst. Contemporary psychotherapists also acknowledge the role of a person's current relationships, including with the psychotherapist (Ogden, 1994).

Freud (1910/1953) coined the term *countertransference* to denote the psychoanalyst's reactions to the patient's transference. Countertransference includes the psychotherapist's conscious and unconscious feelings and thoughts towards the patient, which are based on characteristics of the patient, and of people in the psychotherapist's current and past life (Hayes, 2004; Joseph, 1985). It is recognised that both elements are interwoven and is described as the *transference-countertransference situation* (Ogden, 1994). Thus, psychotherapists (and researchers) are encouraged to take responsibility for personal emotional reactions.

Engaging with how the participant 'uses' the researcher in the transference-countertransference is indispensable in accessing participants' unconscious material. Thus, this method is different from other qualitative interviews in which researchers reflect conscious emotional states, and do not necessarily attend to information accessed through the transference-countertransference situation. In order to use this method to its full extent, researchers should be experienced psychoanalytic psychotherapists trained to access information through the transference-countertransference situation (Harvey, 2017). Indeed, attending to personal and participants' feeling states provides a wealth of information regarding participants' psychic functioning (Cartwright, 2004; Stromme et al., 2010). The theoretical assumption is that internalised intrapsychic relationships are repeated in every person's interaction with others (Stromme et al., 2010), including with the researcher. According to Brown

(2009), there is a central intersubjective nature to psychic life as *both* individuals in an interaction operate on one another's unconscious. The intrapsychic and the interpersonal are intricately intertwined, hence meaning is co-created. The nature of creating this meaning suggests certain ethical tensions, particularly when applying psychoanalytic concepts outside a psychotherapy space. I felt prepared to manage potential ethical tensions specific to this method written about by others (Birch & Miller, 2000; Kvale, 1999; Long & Eagle, 2009), including engagement with participants' unconscious material outside a psychotherapeutic setting. I was to use my psychoanalytic-researcher skills of containment and empathic listening to conduct a debriefing session with each participant immediately after every interview. I was also crucially aware that this form of research is not to be confused with psychotherapy, and I was to remain in my role as researcher. These ethical deliberations did arise, and yet they were manageable with mindful psychoanalytic reflexivity.

The blurring of roles between participants and myself proved to be challenging, however, and required further thought. Additionally, because this method encourages the researcher to work with the, often unconscious, transference-countertransference situation, the emotional labour of participants seeking advice and comfort from me was tangible.

Blurring of Researcher-Participant Boundaries

Part of the complexity of research encounters involves participants entering into the encounter with their own expectations regarding the process and the role the researcher will play (Mitchell & Irvine, 2008). Gabbard and Hobday (2012) describe patients as unconsciously recreating their internal relations in the transference-countertransference relationship with their psychotherapist. I suggest that the same occurs in the nature of the research relationship using the psychoanalytic method I employed, with researchers needing to be mindful of this blurring.

When the participant and researcher share identities and experiences, it can result in the participants identifying with the researcher. This was my experience as I was cast into unexpected roles in the interviews. I was initially uncomfortable with the extent of the blurring of identities between the participants and myself. Each participant turned every interview around to ask me questions about my disability, mothering my disabled daughter, and my experience of being mothered. I was aware of the strong transferential push to answer participants' questions. I soon realised the necessity of remaining conscious of my feelings so as to reflect on the participants' internal experiences and to respond meaningfully lest my emotions contaminate the research (Fonagy & Target, 1997). While such identifications with researchers can occur in other forms of qualitative interviews, this blurring seems particularly complex when using psychoanalytic practices and an intimate connection is formed focusing on conscious and unconscious communications. I perceived three different roles in which the participants positioned me depending on their identifications or dis-identifications with me at the given moment of interaction.

Identifying with a Disabled Person

Participants identified with me as a disabled individual, and thus as similar to their disabled child. This seemed to be a positive, facilitative experience for them. One participant voiced this directly and repeatedly: 'it [the interview] is absolutely welcoming because I don't have that interaction with any other dwarfs' and 'I've never been able to speak to an actual person that has dwarfism in an adult state'. This form of identification comforted me since it felt that I was researching disability in an ethical manner by aligning with disabled people.

'I don't get to speak to a lot of people with the same condition as my daughter … it's so nice to actually get to speak to somebody because I know you would probably relate to me ten times better than anybody else can' was another participant's identification with me as similar to her child due to our disability. These types of encounters were emotionally demanding for me as I was forced to engage with my disabled particularity, something I was not entirely expecting as I entered the interaction as a researcher. The participants' identifications with my disability aspects did not afford me the role of 'pure' researcher and I was left feeling perplexed and frustrated. I was acutely aware of my overriding thought: Was this going to be yet another encounter centred on my disability at the expense of my other particularities, most notably, as researcher?

Due to my countertransferential responses to the participants' needs for engagement over our foregrounded shared experiences, the helper in me was ignited. I could relate to their desire to connect with someone similar to their child, an experience that is hard to come by on a frequent basis. However, I was concerned that I may not be able to access the information I had hoped for. Yet, it soon became apparent that this intersubjective aspect of the research encounter provided rich, albeit unanticipated, information. The fact is that I, as the researcher, was not related to as an 'expert' in these interactions because the participants directed the research, thereby reassuring me that these encounters were ethical.

Interestingly, when participants identified with some of my specific characteristics, they seemed to feel comfortable about sharing intimate stories as they felt I particularly understood them. One participant stated: 'Well I'm sure … you get it all the time' when referring to how non-disabled individuals stare at her child in public. Another woman remarked: 'I feel that maybe you can relate better to me than anybody else can because you have probably been there, in those situations [the same as those her daughter has been in]' and 'I think you know exactly how I feel … you've been there, through all of what I'm still busy going through'. Yet another participant described relating her mothering experiences to me: 'I can sort of relate better because I know you've got some frame of reference [of disability] … so talking to you is probably easier than me just talking to someone who looks completely baffled'. These identifications with me were manageable as I constantly engage in how I feel about being disabled in my own psychoanalytic psychotherapy. Additionally, I am accustomed to people relating to me as disabled. Even so, a part of me wished that I could be afforded a solely researcher role, to hear participants' stories without at times bringing my own disability to the foreground of the encounter. This was something with which I needed to engage on a personal level.

One participant referred to my disability, and my life as a disabled person, throughout our encounters. Interestingly, she assumed that my mother is able-bodied, and thus she was identifying with her. I was identified with her daughter: 'you see with your disability … your parents knew'; 'You see now in your case with your mother, she wouldn't have felt in any way responsible'; 'I don't know if your Mom ever did this, but this is something I have done' and 'If you think of any of the issues you've gone through over the years … probably similar to her [her disabled daughter]'. This participant repeatedly referred to my disability at the expense of relating to me in my entirety. I was left feeling ambivalent, annoyed with being othered. I felt she presumed to know how I experienced things. I was reminded of the many times I am related to as only disabled. I was also empathic towards her need to focus on my disability in an attempt to address her daughter's disability. This type of emotional engagement is personal and demanding for a researcher. I argue that this identification with my disability helped these women feel that they could disclose at times previously untold stories feeling genuinely understood, and their experiences validated. This was exciting and I felt privileged. It required, however, the constant demand of engagement on my part of maintaining the boundary between encouraging participation, and containing the emotional encounter for both the participant and myself.

Kleist and Gompertz (1997) discuss how participants can confuse the role of a researcher with that of 'expert helper'. There were times in which I experienced participants as furnishing me with a superior status as a disabled person, creating the relational scenario of wanting me to provide guidance on certain issues. Some questions that participants asked included: 'So what was she [my Mom] like to you?'; 'Did your parents offer it [limb lengthening] to you?'; 'Have you found that it's a common response [from my other participants] … or if it's my specifics?'; 'I wonder if she [my Mom] felt the same way [as she does]?'; and 'I'm hoping for the opportunity where I get to meet, through your research, other parents that can share their experiences with me'. I consciously chose to empower participants when they asked for information by answering their questions, and this left me feeling less guilty about the often one-sided research relationship. Indeed, researchers often feel highly privileged by the willingness of participants to share their most intimate thoughts. This can leave researchers feeling ambivalent, simultaneously excited by the quality of the research material, yet guilty about the level of detail a participant has shared (Dickson-Swift, James, Kippen, & Liamputtong, 2007). Accordingly, many researchers feel the need to self-disclose to give their participants the experience of being appreciated and validated (Dickson-Swift et al., 2006), as well as wanting to repay them (Mitchell & Irvine, 2008). I was also aware of my advocacy for disabilities, and thus wished to provide some assistance to participants through sharing my knowledge and experiences.

While identifying with me as a disabled individual was a mainly positive identification for the participants, this did not stop the women from sharing very difficult emotions. This is not the focus of the current chapter; for a discussion on this, please see Harvey (in press).

Mother to Mother

Some participants asked me for parenting advice that was disability related and related to their struggles at the time. One participant's able-bodied child felt her mother's attention was too focused on her disabled sibling. She asked me: 'Are you an only child? If you don't mind my asking'. And after I had answered, she asked: 'And how was your brother and sister with you?' Two of the participants asked me specific child disability–related questions. 'I want to pick your brain about something' ranged from asking questions about grommets, bicycle choices, to car seats. These types of questions felt fairly manageable due to their limited personal and emotional requirements, and to my countertransference of the participants' genuine need for practical guidance. I could also respond without moving the focus of the interview onto me.

One mother asked: 'How do you deal with [it] when people point 'n laugh?' This was also a concern for another participant: 'What's it like when you go out as a family?' as she reported how people stare at her child and ask questions about why she cannot walk. These types of questions were more personally demanding to engage with since they required connection with a sensitive topic related to the visibility of my disability. Further, the responses I could give to participants were complex and not particularly encouraging, which left me feeling ambivalent about how to respond.

One woman asked about how my mother managed in raising me: 'I'm worried that when she [her daughter] grows up, what would she think? Because you want them to think positively of you [as her mother]'. This was a difficult and direct question to approach, and I was aware that we were both experiencing strong feelings. The participant seemed to need me to reassure her that she would have a good relationship with her daughter. I chose to reflect and contain this comment so communicated that I heard her real concerns that she is doing the best she can as a mother. Consequently, she shared more of her maternal experiences.

Although these questions were unexpected, my psychotherapeutic default, and expectation, of always thinking before answering was vital. My responses were always given after internal deliberation based on the ethical principle of beneficence, the protection of the research project, and my own level of comfort. Accordingly, the participants experienced me as retaining appropriate boundaries, as one participant expressed: 'I was going to ask you and then I was "okay maybe I am just being too inquisitive, I will ask eventually"'. And: 'You came to research me, not me you; but I eventually said something'.

Given that motherhood is often part of many women's overarching identities, it can enhance the relational connection between mother-participants and mother-researchers (Ribbens, 1989), which was the case in my research. One participant asked: 'how do you deal with it now, especially with having a dwarf [same disability as her child] baby?' She later remarked: 'I don't get to speak to many people that have children with Achondroplasia'. My countertransference to these types of questions made me realise how easy it would have been for me to fall into an acquaintance type role, casually discussing the highs and lows of mothering. Additionally, I could have slipped into a parent-guidance type role as I wanted to share some aspects that I thought may be useful for these mothers as I identified with their feelings of loneliness and confusion, but I was always aware that these encounters were about *their* experiences.

Relating to a Psychotherapist and Researcher

At times participants identified with me as a successful professional, and this seemed to elicit hope in them for their own child's future. One participant reflected that having met me she had realised: 'When he's [her disabled son] an adult … there is a way forward; that you're studying at … [University]'. It seems that her identifying with my perceived success, despite my disability, gave her hope that her child would also be able to achieve. I was happy that I had instilled some hope in her as a person, and as a mother, but was also acutely aware of her anxieties regarding her child's future.

Another woman remarked: 'you'll know more about why' when reflecting how she had not initially wanted to bond with her daughter because of her disability. I was struck by how honest a disclosure this was, and how perhaps this mother shared such personal thoughts with me as I have psychoanalytic knowledge—perceiving I would be non-judgemental. I was mindful of my empathy for her sense of guilt and struggle as she navigated her journey as mother of a disabled child.

The careful engagement with these various identifications seemed to help build a researcher-participant relationship that encouraged the sharing of nuanced information. This required a particular thoughtfulness so as to remain ethical.

Psychoanalytic-Researcher Reflexivity

Long and Eagle (2009) suggest that once a person is trained in psychotherapeutic skills, these cannot be dispensed with in order to conduct research. It is my contention that these skills are essentially helpful in eliciting meaningful information from participants. Although researchers are not making psychotherapeutic-type interpretations (which assist in patients' awareness of their unconscious communication), the psychotherapeutic style of engaging and following up responses often can inadvertently elicit highly nuanced material. Thus, the revealing nature of such interviews is arguably unavoidable, and in fact invaluable.

Further, Long and Eagle (2009) state that a researcher and participant form a different type of relationship from that which is established between psychotherapist and patient. Thus, access to a participant's unconscious dynamics is limited. I argue, however, that transference-countertransference operates in *every* relationship, and is present from the outset in any encounter. Hence, paying attention to these dynamics in the research relationship is ethical and beneficial to both individuals, and to the overall research endeavour. It would be unethical to attempt to ignore them.

The mindfulness that was required of me in my research suggests that various psychoanalytic-researcher skills were crucial throughout my encounters with participants. I relied on my unconscious and conscious responses as an instrument (Freud, 1912/1959) of data collection and engagement. Pertinently an ongoing emphasis on my self-awareness acted as a restraint on any of my omnipotent tendencies to impose knowledge onto the encounter. Researchers need to remain conscious that the research process is firstly about the participant. I think of this self-awareness as *psychoanalytic-researcher depth reflexivity.* Reflexivity is crucial when using this research method. I argue for an interpersonally deep and ongoing engagement with one's thoughts and feelings. Frosh and Baraitser (2008, p. 350) are quoted in this vein: 'the priority is reflexivity, understood as an interactively critical practice that is constantly reflecting back on itself and is always suspicious of the productions of its own knowledge'. Reflexivity is not a method; rather, it involves a researcher's self-examination and consciousness of personal emotional responses. Reflexivity requires a researcher to 'keep an honest gaze' (Frosh & Baraitser, 2008, p. 359) on what he or she contributes to the entire research process. This practice requires the researcher to engage in extensive professional reflections (Stromme et al., 2010) in an attempt to understand the nature of interactions with participants. Psychotherapists are expected to display this inward attention with patients. Thus, working with one's countertransference comes relatively naturally to psychoanalytic-researchers using this method. Using subjectivity objectively (Elliott, Ryan, & Hollway, 2012) was an ongoing approach that I took in my research through engaging with it in personal psychoanalytic psychotherapy, confirming that researcher subjectivity is a potential resource for bringing the researcher close to an in-depth account of the material (Parker, 2005), and for engaging ethically with participants.

One can adhere to a level of accountability to the participants' stories by creating enough psychic space from the participants in order to think about the interaction (Hollway & Jefferson, 2000). Cartwright (2004) states the importance for a researcher to engage meaningfully in personal motivations for studying a particular phenomenon and the associated feeling states. This process, initiated before the interviews and continued throughout the research process, assists in limiting potentially adverse effects in interviews and maintaining accuracy in interpretation of research material. Thus, the researcher's subjectivity is actively engaged with in personal psychoanalytic psychotherapy, and in research supervision sessions with a psychoanalytic-researcher, in order to reach greater understanding of the participants' stories.

Holland (2007), as well as Long and Eagle (2009), warns of the shortcomings if this interplay of individuals and research process is not considered. Researchers need constantly to be attuned to their subjective position, and to be mindful of transference-countertransference as both a source of potential blockage to accessing participant information and as a source of rich material if they are sufficiently comfortable in this internal milieu. Further, it is psychoanalytically oriented training that often results in researchers being empathic to the point of eliciting participants' unconscious material. This is unavoidable, but, if dealt with in a thoughtful manner, it can be empowering and can elicit sincere disclosures.

Making clinical-type journal notes (Cartwright, 2004; Stromme et al., 2010) immediately after each interview was also invaluable. These reflective notes contain personal impressions and feeling states that arose during, and after, each interaction with a participant. Engaging with my psychoanalytic-research supervisor about these challenging interactions with participants was also immensely beneficial. Marks and Mönnich-Marks (2003, p.3) suggest 'integrated intervision', which is a combination of formal and peer supervision. Pacing interviews to create enough time between interviews to process my emotions was another useful strategy.

Final Thoughts

I have reflected on my experiences and challenges in collecting participant accounts using the psychoanalytically informed research interview in my project on maternal subjectivity when raising a physically disabled child. The research process was permeated with surprises as participants turned the interviews around, wanting personal and emotional engagements from me. I have argued this is because we share certain particularities and life experiences, including motherhood and disability identities. The unexpected ethical tensions, of participants relating to me as a confidant and advice-giver, and the subsequent emotional labour, was something I felt ill-prepared for from my research training. However, my training and experience as a psychotherapist, as well as my psychoanalytic psychotherapy, became crucial as I was able continually to engage with and reflect on this process to protect the participants, the research endeavour, and myself. At times I consciously shared personal experiences with participants and these were well received. This steady flow between carefully navigated identifications and distancing between myself and my participants ultimately benefited all involved. Further, the growing call within disability studies for researchers to be mindful that disabled people are not objectified by doing research on 'them', instead of *with* disabled individuals, was addressed. The blurring of disabled and abled contributed to my study's ethical stance.

I have argued that I successfully navigated the blurring of numerous identifications in my research because I relied on psychoanalytic-researcher reflexivity, consciously working with transference-countertransference in these complex emotional encounters. The end product was rich and unanticipated information; particular participant subjectivity was generated through the intersubjective psychoanalytic relationships that the participants and I created.

Alongside these ethical tensions, I also experienced unexpected personal benefits through conducting the interviews. Occasionally, stepping out of a researcher role was not only because the participants had provoked me towards this, but because I felt I needed, and wanted, to do so. Thus, I chose to share information and personal experiences related to the topic of the participants' stories. I understand that this was linked to my feelings of guilt related to the often one-sided research relationship and my wish to give back to participants. This relational position appeared to be well received by the participants, and consequently, I felt satisfied. Certain participants requested they stay in contact with me, with some sending text messages and one sending a disability-related video after our interviews. Further, I feel that I may have given each participant an experience that went beyond psycho-education. Our interactions seemed to provide participants with a unique opportunity which quietened some of their anxieties in relation to their disabled children and their mothering role. Our encounters appeared to provide participants with a comforting snapshot of their child's, and their own, future self. It is my assertion that this is not always the experience for qualitative researchers, and I maintain it is because of our shared aspects of identities and experiences that this occurred, and my conscious use of psychoanalytic-researcher reflexivity so as to ensure this sharing remained ethical.

It is my contention that researchers need to uphold researcher-participant boundaries, but boundaries that are not rigid and that allow for self-disclosure where appropriate permitting a mindful blurring of boundaries and intersubjectivity. I found it helpful to take my cue from the participant, and what felt appropriate to the specific encounter. There is not one set of standard practices that can be followed, and researchers need to be sensitive, responsive, and flexible to the needs of each participant. Thus, researchers are required to be mindful of the intersubjective identifications between themselves and each participant so that ethical psychoanalytic research can be conducted.

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Notes

1. This study was granted ethical clearance by The University of the Witwatersrand's Human Research Ethics Committee in 2014.
2. I have Achondroplasia, a form of human dwarfism. The clinical manifestations include an average sized body, disproportionately short limbs, and a large head (Horton, Hall, & Hecht, 2007).
3. The term *psychotherapist* will be used throughout the chapter to refer to *psychoanalytic psychotherapist*.
4. The term *data*, although not strictly a psychoanalytic term, is used to signal rich, clinical-type information that is collected from participants within the intersubjective encounter using the psychoanalytically informed research interview.

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12

Bearing Witness to ‘Irreparable Harm’: Incorporating Affective Activity as Practice into Ethics

Kim Barker and Catriona Ida Macleod

A cornerstone of research ethics is the consideration of harm. The facets of harm considered include potential harm that participation in research can evoke, the balance of harm and benefit, and the remediation of harm where it does occur. On the basis of this, it is recognised that research with people who have experienced trauma requires careful consideration. Ethics committees view such people as ‘vulnerable’ populations and require researchers to put mechanisms in place to ensure either that no further harm is caused to the participants through participating in the research, or that where harm does occur, it is remediable. Researchers are tasked with demonstrating experience in conducting research and/or working with ‘vulnerable’ populations as well as an ability to deal with the research encounter in a sensitive manner.

Constructing a particular group of people as inherently vulnerable and in need of special care profoundly shapes the relationship between a researcher and potential participants before they have even met. In this chapter we question whether such positioning of researcher and researched supports or complicates ethical research practice. The ethical concerns we reflect on here emerged during the course of my (Kim’s) PhD research journey (supervised by the second author, Catriona) about participation in an anti-rape

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protest.[1] I was particularly interested in how women who had been raped or sexually assaulted made sense of the protest and of their own experiences of participating. I was also curious about any impact that their participation may have had on their ongoing sense of well-being.

In preparing the ethics protocol for the study, I paid attention to potential ethical challenges in accordance with the University's Code of Ethics. Despite this careful process and the project having gained ethics clearance, I was not prepared for the dynamic and reciprocal positioning I encountered in relationships in the field or the 'ethically important' moment-by-moment decision-making that this demanded of me. Drawing on examples from this research and from the work of Margaret Wetherell and Emmanual Levinas, we show how ethical decision-making with those who have experienced 'irreparable harm' is always relational and dialogical, both in direct interactions with participants and in the ways in which we, as researchers, approach our data. Using an understanding of affective activity as practice, we argue that ethical conduct in relationships with research participants who have experienced trauma requires seeing the face of the other, hearing and responding to the narratives told even when these are not directly relevant to the research question, and deep reflection on the process of bearing witness to the suffering of others.

Background to the Study

The context of this feminist-inspired ethnographic research was the Silent Protest at Rhodes University. This is an annual protest against sexual violence which consists of a series of carefully choreographed events over the period of a day and an evening. Students participate in large numbers (in the year of this study there were over 1500 participants, approximately 20% of the student body). Silence is a key feature of the protest and this is largely achieved through the taping of protesters' mouths with black gaffer tape. The taping offers a vivid and provocative image of resistance to the multiple silences that arise in response to an experience of sexual violation. The protest takes place in the context of high levels of gender-based violence. South Africa has the highest statistics for sexual violence for a country not at war: it is estimated that one in three South African women will be raped in her lifetime (Moffet, 2006).[2] Given the prevalence of rape and the over-stretched public health sector, therapeutic/supportive services (generally one-on-one or group counselling sessions) are inadequate or unavailable.

While individual or group counselling is an important service, it often fails to offer victims/survivors[3] a contextualised awareness of the collective and decidedly political nature of sexual violence, which is that rape is 'one of the multiple ways in which people wield power over each other' (Du Toit, 2005, p. 253). Individualised therapeutic responses inadvertently construct the victim/survivor as the one with the 'problem' and place the responsibility on the victim/survivor to 'recover' whilst failing to address the culpability of the perpetrators or the social context in which their actions were made possible. In contrast (or in addition) to individualised models, researchers and practitioners have found that communal processes have been helpful in the recovery of people subjected to sexual violence. These include public acknowledgement of the traumatic event, some form of community action that assigns responsibility for the harm and takes steps towards restitution (repairing the injury), and constructing meaning in relation to the experience that transcends the limits of personal tragedy, such as joining with others in social action (Herman, 1997). The Silent Protest potentially offers those who have experienced sexual violation access to such communal processes. These include participation in a communal event that highlights the gendered power relations underpinning sexual violence and an opportunity to 'break the silence' by openly acknowledging their own experience either through wearing a t-shirt which says 'rape survivor' or 'survivor', or by speaking publicly about their experience at a facilitated Breaking the Silence event.

In the light of this, one of the principal aims of my research was to explore ways in which women who have been subjected to sexual violence ascribe meaning to their participation in the Silent Protest. The key informants for this component of the research were 29 women. Most participants were students at the University and a few were staff members. Participants ranged in age from 18 years to late 50s. Some had participated in the Silent Protest over several successive years, a few had key roles in organising the protest, and some were participating for the first time. All had experienced some form of sexual violation. Most had been raped. I conducted multiple semi-structured audio-recorded interviews with the participants which lasted anywhere from half an hour to two hours each, as well as group sessions with those who chose to participate in this component of the research in addition to their individual interviews.

Vulnerability and Ethics Clearance

People who have experienced sexual violence are usually described in research contexts as a 'damaged' and 'vulnerable' population that requires the institution of protective measures (Sharratt, 2011). Researchers in the field point out that sexual violence may have substantial and enduring negative effects on victim/survivor's physical and psychological well-being (Callender & Dartnall, 2011). In addition, victims/survivors of sexual violence are persistently stigmatised worldwide, often being blamed in subtle or explicit ways by family members, police, medical professionals, and the justice system, and being subjected to further dishonour, marginalisation, and even death (Callender & Dartnall, 2011; Campbell, Self, Wasco & Ahrens, 2004). Women's experiences of being subjected to sexual violence are, therefore, in the interests of self-preservation, very often hidden from public view (Campbell et al., 2004).

With this in mind, I thought carefully about the potential impact of my interactions with the research participants in the conceptualising phase of the research, and a number of measures were put in place. I took note of the concern that where participation in research requires victims/survivors to revisit their experiences of sexual violence, they might have strong responses of anger, sadness, or anxiety and that flashbacks and/or nightmares may be triggered in some instances (Draucker, 1999). Participants, therefore, were informed carefully through the informed consent process that the research was not about their experience of sexual violation itself and that they would not be asked to speak about it.

Researchers have argued, however, that the very measures designed to protect survivors of sexual violence often have the effect of muting or constraining their expressions (McKenzie-Mohr & Lafrance, 2011). Indeed, as indicated by Jewkes, Watts, Abrahams, and Penn-Kekana and Garcia-Moreno (2000), many participants may welcome the opportunity to talk to someone about the violence they have experienced. I anticipated, therefore, that participants might volunteer information about their experiences of sexual violence, despite not being asked explicitly about this. I was aware that these situations needed to be handled sensitively. I had been practising as a pastoral therapist for seven years and had facilitated retreats and workshops for a lot longer, working predominantly with women. My experience meant that I was both aware of and alert to signs of distress and traumatisation and was able to respond to these timeously. I was clear in my mind, however, that my identity and positioning as researcher was different from that of therapist. I was approaching my relationships with research participants with the aim of listening, learning, and understanding rather than of attempting to facilitate change.

In the Field: The Unravelling of Our Rational Intentions

In preparing the ethics protocol and addressing the concerns noted above in consultation with Catriona, we carefully positioned both myself as interviewer and the research participants as being rational, intentional people who would operate within the boundaries laid out in the detailed informed consent form we devised. Participants were invited to participate in various aspects of the research process such as interviews, discussion groups, and taking photographs on the day of the Silent Protest of moments which represented significance for them. The consent form provided details of each aspect and allowed the participants to choose their levels of involvement. We assumed, as is generally the case, that the giving of informed consent was a process of information provision, clarification, and cognitive decision-making. However, there were two major processes that both we and our department's Ethics Review Committee failed to take into account. The remainder of this chapter explores the lessons we learnt by working through these processes.

The first crucial lesson was that however I, as researcher, chose to position myself in relation to my research participants, they encountered and positioned me in ways that I had not anticipated while writing the ethics protocol. What the women chose to share with me and how they chose to engage with the research process invited me into subject positions that I could then accept, refuse, or re-negotiate, and each choice that was made had an impact on the participant, the researcher, and the research relationship. Secondly, I realised that my encounters with my participants were never purely rational or cognitive. Affect, embodied sensing, and intuition—that ineffable gut-level knowing which apparently defies logic—profoundly influenced my research practices and my responses to my participants, as well as my participants' responses to me and to the research process. Apart from demonstrating that I could respond appropriately to any distress which might arise as a result of the research engagement, affect and emotion had not been considered relevant in our official accounting for ethical research practice. Each of these realisations will be dealt with below.

Encountering Participants

In the research interviews, I met with real women in real bodies that had been violated. Each participant had her own unique story, very often intensely painful, told through those very bodies that had suffered and/or were still suffering. Most of the women chose to tell more than was asked. Many chose to share the story of what had happened to them, and, for some it was the first time they had done so: this was what they needed and/or expected from the research encounter. It may be that, due to the focus of the research being participation in the Silent Protest where the emphasis is on breaking silences and speaking out, some of the research participants chose the medium of the research interview as an opportunity to do just that. Whether or not they narrated the violation, however, each participant invited me into a relationship in which they asked me to see them, hear them, attend to them, and acknowledge them as fellow human beings rather than as research participants whose only value existed in the responses they offered to pre-defined research questions.

I had a choice about how to respond. Guellemin and Gillam (2015) call such encounters 'ethically important moments', that is, moments when the decision made, or the approach taken, will have important ethical ramifications, and yet the researcher does not feel uncertain. It is, perhaps unexpectedly, fairly clear to the researcher how she needs to respond or proceed. Like medical sociologist Arthur Frank (2000), it was clear to me, as the interviewing stage began, that I needed to engage respectfully with the participants' invitations to see and to hear them. The way in which they engaged with me, however, and what they shared, positioned me as compassionate witness rather than as researcher. As a result, my responses to many of the women I interviewed felt in some way transgressive of the detached researcher role anticipated by the ethics protocol.

In responding to participants' invitations to witness the trauma they had endured, I began to ask questions that were not directly related to the research question but were informed by the narrative therapy tradition which I draw on as a pastoral therapist. In contexts in which someone has experienced trauma, this line of questioning and listening involves a dual focus, asking about, and listening for, what happened to the person *and* what they did in response: the choices they made to act in ways that may have been big or tiny, visible, or utterly unnoticed in order to stay safe and/or minimise the impact of the trauma. Such questions help the person to recount the narrative from an agentic position and to recognise herself as having been active and responsive even when she felt most powerless.

In my discussions with Catriona as supervisor, we spoke about whether this line of questioning crossed the researcher-therapist boundary. We agreed that I could not, and should not, act differently in the space provided by the research interview. Not to use the knowledge and experience available to me potentially to shift the spontaneously narrated stories of trauma in a direction that might be more supportive of the narrator's well-being was, we believed, an untenable ethical position. In addition, hearing the stories of violation evoked a helplessness and despair in me which echoed the helplessness and despair expressed by many of the women in the telling of their stories. Thus, both my own and the women's well-being was enhanced by pursuing a line of questioning which emphasised survival and resilience.

We did debate the boundaries that needed to be constructed in such encounters to protect both myself and the participants from exaggerated expectations of the relationship they were co-constructing. We agreed that at the end of a session in which participants had revealed details of sexual violence, I would speak through the person's thoughts regarding counselling and make it clear that while I could refer the participant, should she wish this, I could not play that role.

As with most aspects of the research encounter, this proved more difficult in practice than in discussion and, despite these measures, some participants did position me as a counsellor. About a month after the Silent Protest and just after the second round of interviews, I received a call from a University residence warden. One of my research participants was having a panic attack and had been rushed to the Accident and Emergency Department of the local hospital. She had begged the warden to call 'her therapist' (me) and ask her to come. On receiving the call, I stopped long enough to wonder which ethical boundary I was crossing. Then I went. No other action, in my view, was ethically permissible, given the distress that the participant was experiencing. Responding as a caring human being was the priority. My presence helped to calm the young woman who was later discharged. She continued to meet with me on a regular basis and the relationship shifted to one of mentorship and then friendship.

Through these kinds of encounters, we came to understand that the researcher is not fully 'in control' of research ethics. The research protocol details everything that the *researcher* will do in order to ensure that the research is ethical, but this does not and cannot account for the unavoidable reality that research is a relational and dialogical encounter with participants who often respond in unexpected ways, and in which ethical responses and ways of being require moment-by-moment, real-time decision-making. In this dynamic process of decision-making, the rational intentions portrayed in ethics protocols intertwine with affect in complex ways. It is to this that we turn to in the next section.

Affect in Research

Affect, embodied sensing, and intuition informed the processes referred to above, as well as others, as much as cognition. How does one then account for ethical research practice when the influences which shape it are complex and, to some degree, pre-cognitive and embodied, and not directly knowable? In line with what has been called a 'turn to affect' in the social sciences in recent years, there is an increasing acknowledgement of the role played by affect in ethical decision-making (e.g. Guzak, 2015). There is also robust debate about the very nature of affect and its relationship to emotion, to discourse, to embodiment, and so on (see e.g. Leys, 2011; McAvoy, 2015; Wetherell, 2012). Space does not allow for a full explication here of this debate. Suffice it to say that in the context of understanding the processes which unfolded in my research, I found Margaret Wetherell's (2015) notion of 'affective practice' useful. Wetherell (2012, 2015) offers a convincing critique of the fairly simplistic characterisation of affect as the inevitable triggering of one or other of a set of universal and innate basic emotions by a particular stimulus. In contrast, Wetherell (2015, p. 146) proposes that we understand 'affective activity' as a practice. The patterned realisations of affective practice can be represented as a 'complex flow' which draws together culture, society, biology, and memory, and is evoked within a particular configuration of relationships, at a particular time, and in a particular material and sociopolitical context. In the context of research ethics, affective practice is able to encompass both expected and unexpected reactions of researchers and participants to the research context.

In Wetherell's (2015) words, a practice approach 'positions affect as a dynamic process, emergent from a polyphony of intersections and feedbacks, working across body states, registrations and categorizations, entangled with cultural meaning-making, and integrated with material and natural processes, social situations and social relationships' (p. 139). Affective practice is therefore an action, a movement that opens up the possibility of improvisation, whilst at the same time there is the sense that this has been done before. Affective responses are always situated and are, therefore, shaped and constrained by previous experience and knowledge interacting with the current material and temporal context. We can be trained in certain affective practices which, subsequently, can perform a function of discipline and control, but each new situation requires that the practice begins again and is rendered or enacted anew. Affective practice is a bit like alchemy, sometimes predictable, sometimes not.

Such a practice approach to affective activity has, we believe, significant possibilities in the consideration of research ethics particularly in studies that involve 'vulnerable' populations. The intersection of the researcher's and the participant's history, life experiences, or narratives, discursive investments, reflexive and interactive subject positionings, and embodiment (even at the level of physical health, levels of tiredness, or hunger, and so on) within a particular temporal, material, and sociopolitical context, will inevitably produce complexities and unexpected turns that simply cannot be thought out or managed beforehand. From the moment they meet, researcher and participant engage in relationship construction that will evolve and change constantly as they negotiate power and trust and they decide, moment to moment, how much, and what, of themselves to share with the other.

But what does affective activity as practice mean in concrete terms in relation to the ethics of research? We move on for the rest of the chapter to pose three challenges: the ethics of seeing; the ethics of responding; and the ethics of bearing witness.

The Ethics of Seeing the Face of the Other

Emmanuel Levinas (1974/1991) suggests that it is the face of the other that calls us, as interlocutors, into responsibility towards him or her. When I see your face, a response is required, even demanded. For those who have suffered, this is not a demand stemming from arrogance, hostility, or entitlement, as James Hatley (2000) emphasises when he draws on Levinas in *Suffering Witness.* Rather, it is their very vulnerability that calls to us: the nakedness of a face in which we recognise a fellow being whom we have the capacity to harm or to love. What 'undoes' us as interlocutors, though, is when we encounter the face of one who suffers, or, worse still, who has suffered and whose violation cannot be undone and is irreparable. Our compulsion or urge to respond is then thwarted and we are helpless in the face of the suffering, helpless to undo, and helpless to repair. The feeling with which we are left is one of shame at our own helplessness. This is different from guilt as it is not our fault. Our shame lies in our inability to respond in a way that can put things back the way they were.

This is an intensely uncomfortable response to experience and there are many strategies or tactics we employ as human beings, and also as researchers, for avoiding the face of the other and the demands it places upon us. We can retreat into abstractions, generalisations, statistics, and theories *about* the other. We can avoid *listening to* them in our urgency to *talk about* them. In this sense our ethics protocols can actually help us to avoid our moment-to-moment ethical responsibilities towards our research participants. Protocols require that *we* as researchers set the boundaries and decide, a priori, what is ethical behaviour and what is not. This means that we can avoid the immediate and unexpected obligation of response in the face of the other. All we are 'ethically' obliged to do is to comply with the minimum requirements of our ethics protocol.

When we remain long enough to *hear* the others' story, however, from a place of deep and open listening, it becomes impossible not to *see* their face, to see their vulnerability, and their strength/power, and to recognise both our connectedness and our obligation of care towards them. The participants in my study invited me to see them, to look into their faces, and to hear their stories. In doing so, they asked me to respond to them and their stories and to bear witness to their suffering. While the face calls us into an ethical response, I believe it is the narrative that compels us to answer that call.

The Ethics of Responding: What Do I Say When I See the Face of the Other?

The identification of a population as 'vulnerable' will shape and constrain the ways in which researchers approach research participants, the subject positions participants are invited to assume, and the knowledges we anticipate eliciting from them. In the case of rape victims/survivors, other dominant discourses and cultural narratives in relation to sexual violation compound this categorisation. These include constructions of rape victims/survivors as inevitably 'damaged' tragic figures who have had to endure what is commonly described as the worst possible thing that can happen (to a woman). Rape victims/survivors are expected to be emotionally fragile, potentially unstable, and in need of psychological care, or, at the very least, careful treatment.

Upon listening to the recordings of my early research interviews, I was struck by how my demeanour and the questions I asked were strongly influenced by these dominant narratives and positionings. I treated the participants as vulnerable and proceeded with caution and gravity, as well as some trepidation. I began the research interview process by asking participants carefully prepared and worded questions about their involvement in the Silent Protest, deliberately avoiding narratives of trauma and violation. Although this was intended to protect the participants, it resulted in an awkwardness in the interaction as the experience of sexual violation, in most cases, was referred to initially but was not spoken about openly. Ironically, my caution had the effect of disallowing the very narratives which participants wished to tell. It is testimony to their own determination to speak out that many found their own ways of introducing the narrative of violation into a conversation which had been constrained by my caution. For example, Participant 5 responded as follows when I asked her about her experience of participating in the previous Silent Protest, and I asked if she could describe the day as it had unfolded:

> P5: I can /**ok**/ u::hm, ok well I (..) I well I might as well just say it off the bat because it's probably gonna come up later /**mhh**/ I have experienced uhm (..) sexual u::hm, you know (.) violence [….] mm-mm, and the thing is, for (.) I actually didn't <u>know</u> that it was rape for a long time actually what had happened /**ok**/. I didn't actually (..) constitute it as rape because (..) I kinda (.) it was only when people started speaking about their experiences, I was like 'Oh wait a minute, oh wait wait wait (..) this **is** what actually happened' /**ja**/ because (..) (audible inbreath) the whole time I kinda thought in my head, I'm like (..) I don't know if there is a question coming up where I'll have to speak and tell you about it or can I just go /**just go, it's okay**/ ok. Ok I can even tell you about the whole thing /**ok**/.

These extremely cautious, tiptoeing conversations became increasingly uncomfortable for me as I began to expand my own constructions of rape survivors beyond the sense of vulnerability and trauma. I found that the participants' narratives challenged me to enrich, nuance, and render complex the ways in which I saw and understood them. I was particularly struck by the first research discussion group that I conducted with my participants. There the participants were invited to set the agenda and choose topics for discussion that were pertinent to them. In that context I encountered humour, anger, resistance, critique, and a range of strengths of character that had been hinted at but had never found full expression in the individual interviews. I began to move beyond categories and binaries and to see my research participants as victims *and* survivors, vulnerable *and* powerful, as choice-makers, constant responders, resistors, agents, and activists. For each one, simply coming to meet with me was a significant act of resistance. All were defying powerful taboos and, for many, breaking silences. Simply by turning up at my office they were identifying themselves, at least to me, as women who had experienced sexual violence. Experience had taught them that such a step was risky.

Seeing my participants through this range of lenses allowed me to notice different things and to ask different questions. It was, therefore, the research participants themselves who challenged me into seeing them in ways that supported more ethical and, ironically, more beneficial-to-them research practices than those implied by the 'vulnerable population' status of the ethics protocol. As indicated by Arthur Frank, speaking about one's life in a research setting does more than simply produce an account or report of 'what happened to me' or 'what I know'. It sets processes in motion that can change how participants view themselves (Frank, 2005, p. 968). What we, as researchers, ask of our participants, how we ask, and how we respond to what is told are all therefore of crucial importance.

The Ethics of Bearing Witness

The final element in our threefold ethical challenge is the question of bearing witness: having seen and responded to the face and narratives of participants, how do we, as researchers, tell others about what we have seen and heard (in relationship)? What decisions do we make in representing those who have suffered, even when the research questions, as in our case, were not directly about the suffering per se?

James Hatley (2000), drawing on Levinas and Primo Levi, suggests that when we are entrusted with the narrative of the other's suffering, we are not required simply to give a historical account of the particular events or even to try to understand them. We are called upon in the first instance to witness the suffering:

> By witness is meant *a mode of responding* to the other's plight that exceeds an epistemological determination and becomes an ethical involvement. One must not only utter a truth *about* the victim but also remain true **to** her or him. In this latter mode of response, one is summoned to attentiveness …. In this attentiveness, the wounding of the other is registered in the first place not as an objective fact but as a subjective blow, a persecution, a trauma. (Hatley, 2000, p. 3)

Arthur Frank suggests that the only appropriate mode for receiving such a testimony of violation is *being with* (Frank, 1995, p. 144) and the only appropriate response may be silence. What does this mean in the context of research in which testimony becomes data to be analysed? Frank's challenge raises important questions about what we do with the narratives entrusted to us and suggests that the practice of affect is as important in the ethics of analysis as it is in interacting with the participants. Nicola Gavey (2011) writes poignantly that '[t]he proposal that we regard "experience as text" has haunted me to some extent … In the context of research, it permits a relation of detachment between a researcher and research participant about which I do not think we should ever feel comfortable' (p. 186).

A number of questions arise as we, as researchers, engage with the analytical process: how do our writings invite others to imagine (see or construct) our research participants? What would the research participants think about how they are imagined? What kinds of responses to persons who have experienced sexual violence do those imaginings or constructions evoke? Does our work help readers to recognise and respond in meaningful ways to suffering or to avoid recognising suffering? Does our analysis amplify the voices of those who suffer so that they can be heard on their own terms or does it drown them out in the noise of our own analysis? Does our work contribute to the alleviation or perpetuation of suffering for persons who have experienced sexual violence? Can we bear witness to narratives of irreparable harm without constructing the women who tell them as irreparably harmed? These questions are ongoing challenges as we engage with the data. In the light of our three-pronged ethics challenge, we are aware that we need to invite readers to look into the faces of the other and hear their narratives through the words that they themselves have spoken and the words that we write. We need to challenge our readers to allow themselves to hear the call to respond and not to turn away.

Conclusion

Ethics committees, with their origins in positivist biomedical practices, largely emphasise the role of rational thought, planning, and control in ensuring ethical research practices. Ethics protocols are, of course, essential in holding researchers accountable to basic standards and practices. Having our protocols approved, however, can lull us into believing that once we have ticked all the boxes, such as getting informed consent forms signed and password-protecting our data, we have 'done the ethics'. This can leave us unprepared for those ethically important decision points, or what Paul Komesaroff (1995) calls 'microethical moments' that continuously arise and in which both the researcher and the research participant are confronted with a range of complicated choices and the emotions which those choices evoke.

As the research described in this chapter progressed, we realised that strict compliance with the boundaries constructed at the outset of the research (e.g. researcher/therapist) and a determination to answer the research questions had the potential to shift me (Kim) in the direction of ethical ambiguity, and even unethical interactions. We realised that affective activity as practice is an essential part of engaging ethically with participants who have suffered. Emotion often signals an 'ethically important moment' and has been shown to be crucial for intuitive decision-making (Klein, 1998). I appreciated the fundamental importance, not only to my participants but also for myself as researcher, of seeing, responding, and bearing witness to the women who shared their stories and to the stories that they shared. How we, as researchers, see our research participants (what we see when we look at them, listen to them, think about them) determines how we respond to them and to their narratives. If we see a person as the object of our curiosity and our research, it is easy to keep a professional, uninvolved distance. However, if we encounter someone as the subject of their own complex and nuanced existence, as a fellow human being, if we recognise our interconnectedness and interdependence, the maintenance of distance and a particular role constructed entirely on our own terms becomes impossible. Instead, research participants and researchers begin a dance in which the pace and steps are, and can only be, negotiated rather than imposed. This ongoing negotiation requires a level of alertness and 'ethical mindfulness' (Guellemin & Gillam, 2015, p. 730). It also implies a mutual relationship.

In the process of cultivating 'ethical mindfulness', I found the colleagueship of other researchers and the guidance of my supervisor, as we engaged in honest conversations involving our heads, hearts, and intuition, more useful in grappling with the moment-to-moment dilemmas than was my carefully constructed ethics protocol. As researchers, we need ethics protocols but we need more than that if we are to engage in truly ethical research. We need to admit that we do not always know how to proceed, and to live with that vulnerability long enough to be able to respond to the vulnerability, and strength, of our research participants.

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Notes

1. The Research Projects and Ethics Review Committee of the Department of Psychology on behalf of the Rhodes University Ethical Standards Committee provided ethical clearance for this project in 2012.
2. Women are acknowledged to be the primary victims of sexual assault and my research focuses on women, as the Silent Protest emphasises women's experience. However, the sexual assault of men, boys, and trans people is also a significant problem. A South African study conducted among school-going youth aged 11–19 found that 9% of male respondents reported having been forced

to have sex during the year prior to the study (Andersson & Ho-Foster, 2008). In a further study involving school pupils in 445 schools across 10 Southern African countries, the overall reported prevalence of forced or coerced sex for 16 year olds was 28.8% for girls and 25.4% for boys (Andersson, Paredes-Solis, Milne, Omer, Marokoane, Laetsang & Cockroft, 2012). Another study that was conducted at a clinic dealing with sexually transmitted infection in Cape Town found that 40% of the female participants and 16% of the male participants had been subjected to sexual assault (Kalichman et al., 2005).

3. There is no single word that adequately captures the complexity and fluidity of subject positions taken up by and ascribed to women who have been subjected to sexual violence. Reducing women's experiences and responses to one pole of the simple victim/survivor binary has 'real effects', running the risk of diminishing and totalising their experience (McKenzie-Mohr & Lafrance, 2011). We use the dual form while acknowledging the inadequacy of this signifier.

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13

In the Red: Between Research, Activism, and Community Development in a Menstruation Public Health Intervention

Sharli Anne Paphitis and Lindsay Kelland

From a research ethics perspective, the traditional framework for understanding the relationship between researchers and those who are standardly positioned as the 'subjects' of research projects has been historically a transactional one. The transactional nature of the relationship has largely remained, even when researchers have shifted to paradigms in which the subjects of research have been characterised in active terms as research participants but in which truly collaborative research is still not being done. This transactional framework undergirds the standard informed consent relationship in which: (1) researchers determine a research goal, a series of research activities, as well as the risks and benefits associated with the activities; (2) autonomous individuals consent to participate in the research activities after assessing the risks and benefits of doing so; and (3) the relationship between researcher and participant is terminated after the research activities are concluded (Glass & Newman, 2015) and, in some cases, once the findings have been presented to the participants.

By contrast, when *collaborative* research methods are used in what is broadly referred to as engaged research (encompassing a range of methodological approaches, arguably on a spectrum of engagement and collaboration, such as community-based participatory research, community-based research, participatory action research, and action research), the relationship between the researcher and 'the researched' should be understood in relational rather than

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transactional terms (Glass & Newman, 2015). The relational quality of the interactions between researchers and participants in engaged research stems from the fact that both parties work together as *partners* to co-investigate the research questions, co-plan the research activities, and share in the responsibility for the research goals and the dissemination of the research findings. The relational, rather than transactional, quality of the relationship between the 'researcher' and the 'researched', thus, also derives from the epistemic and democratic aims of engaged research. In seeking both to share the power inherent in the knowledge generation process with research participants, and, through collaboration, to decide on further action to address the challenges identified by all stakeholders, engaged researchers enter into a set of social relations in the research process that are not possible in traditional research paradigms (Boser, 2006).

Institutional Ethics Review Boards have been slow to recognise the fundamental shifts underlying these differing approaches to research and the distinct set of ethical dilemmas that result from a relational rather than a transactional relationship between researchers and research participants engaged in the research. These dilemmas extend well beyond merely the complexities surrounding the process of informed consent, although indeed there are many complications arising from traditional understandings of informed consent emanating from the relationships formed, the democratic knowledge generation process, and the iterative process of engaged research projects. Despite the multiple complexities, much of the recent literature has pointed to the dilemmas arising within the engaged research paradigm rather than analysing or exploring them (Boser, 2006; Glass & Newman, 2015). In this chapter we add to, and complicate, this literature by exploring some of the complexities we faced in our own work so as to aid future researchers in the practical navigation of these spaces. To do this, we unpack and explore from our perspective some of the ethical complexities that arose from pursuing relational interactions with our participants, or co-activists, within our engaged research project.

As with many other researchers involved in engaged research, we shared with our collaborators a deep interest in reaching equity-oriented social and policy goals as a primary outcome of the project (Glass & Newman, 2015), and as a result found ourselves straddling the lines of researcher, collaborator, and activist in working towards these ends. These personal and relational tensions lie at the heart of the ethical complexities explored in this chapter. The explorations themselves serve as a point of reflection on our own work.

Though we have tried in our actions and in our reflections to work collaboratively and with the aim of undoing injustice and exclusion, we are always painfully aware of the fact that 'the very conceptual tools and theoretical lenses we use to illuminate the ways in which we are all complicit (though in different ways and to different degrees) in practices of domination and oppression (and with which we are not aligned and consciously resist) are insufficiently complex and contribute to the reproduction of hierarchical social relationships, even in the very spaces that are dedicated to their transformation, despite our best intentions' (Logue, 2013, p. 54). Our hope, however, is that these honest reflections may serve as a means whereby others who find themselves similarly placed may be able to think through some of the complexities of human social interaction in a world that requires constant reflection and sincere negotiation.

Siyahluma: Activism-Tainted Research, Research-Tainted Activism

Siyahluma, which means 'we are growing' in isiXhosa, is an engaged research project with a number of distinct but interwoven objectives, outputs, and stakeholders. It is situated in Grahamstown in the Eastern Cape of South Africa and brings together researchers and local NGOs in order to address: (1) the menstruation-related challenges faced by school-going girls, most notably a lack of access to reliable and hygienic menstrual products, and a lack of access to reliable information about menstruation; (2) a gap in the research on this topic in South Africa; and (3) sustainable community development and capacity building in the Eastern Cape.[1] Although the project has grown significantly over the years, ultimately working towards these three ambitious aims, it did not start out like this.

The project began after members of our broader Grahamstown community shared their experiences of the negative impact that a lack of access to reliable and hygienic menstrual products can have on the school attendance of young girls. The women who shared this challenge indicated that the primary impact of this lack of access was absenteeism which ultimately impacts on young girls accessing the basic and secondary education they need. This immediately awakened in us a desire to respond to this problem and, importantly, to try and *actively* ameliorate this problem in the lives of young girls in our community. From the outset our aims in what would become an engaged research project were distinctly transformative and action oriented, despite the fact that we are both philosophers by training; we wanted to find a solution to the problem, initially defined purely as access to menstrual products, so that young girls would be able (and comfortable enough) to attend school while menstruating, and to get the education they need.

As philosophers, completely untrained in this field, we began by thinking, from our own perspective, about how this challenge could be addressed actively, initially becoming quite excited about the idea of sourcing funding to distribute menstrual cups to young school-going girls in our community. We were especially taken with this idea because of the environmental and economic benefits of the menstrual cup as a means of managing menstruation as well as their longevity (some lasting up to ten years if taken care of), and soon were trying to make contact with manufacturers of cups to obtain details and quotes. Through consultation with colleagues (who were trained in this area and would become research partners), we realised, however, that in order to address this challenge in a sustainable manner, we would need to do empirical research (since none was currently available), which could be used to inform a successful and sustainable intervention strategy, and, needless to say, the results of our research changed everything.

In order to fully assess the menstruation-related challenges faced by school-going girls, the research team settled on conducting a needs assessment survey of the secondary schools in the province in order to grasp more fully the challenges faced by the girls we wanted to target.[2] The instrument developed targeted a large sample (1035 learners) and provided us with information about: school-going girls' knowledge about menstruation and the sources that provided them with this knowledge; the challenges they face at school as well as at home; the challenges they face during social and sporting activities; the menstrual products they currently use or those they might prefer to use; from where they source these products; as well as the sanitation facilities available at their school; and, importantly, their levels of absenteeism from school while menstruating. This initial research step took a year to complete, and, along with other activists we met along the way, we often found ourselves frustrated by the fact that we were not yet on the ground, practically addressing the challenges with which we had been confronted so vividly.

As remarked upon above, however, the groundwork laid at this stage of the project enabled progress which would not otherwise have been possible to achieve. The data collected indicated that a lack of access to menstrual products was not the only (or even the *primary*) menstruation-related challenge facing school-going girls, and that any intervention into this area required educational interventions that provided girls (and boys) with reliable, non-stigmatised information about menstruation. This lack of information, or indeed the provision of stigmatised information, seemed, when engaging with our data, to underlie a number of the challenges faced by menstruating girls (and women). In particular, the meaning given to menstruation and the secrecy surrounding it, which is compounded by cultural taboos preventing conversations between parents and children about sexuality, has serious ramifications for the lives of young girls. These range from shame and humiliation at the discovery of one's menstruating status, brought about in part by negative connotations associated with menstruation, for instance, that it is dirty, to newly sexualised treatment by male peers and teachers as a result of a socially constructed shift from girlhood into womanhood, which, in extreme cases, can lead to sexual violence. Given this, one of the primary aims of *Siyahluma's* work was to work with local NGOs and members of our community to access and distribute reliable and non-stigmatised information about menstruation to the various, differently situated, members of our community. It is this work that is the focus of our reflections here.

As we moved forward, we saw that deeper research needed to be done on the themes that emerged from our initial study, and that this could only be done by working on the ground, interacting with our research participants in order to gain greater insight into their personal lived experiences. More importantly, we also began to see that educational interventions, focusing particularly on shifting the stigmas, taboos, and biases associated with menstruation, would not be possible if we did not adopt a participatory approach in which our participants came to see themselves as co-protagonists in our efforts for social change.

In order to fulfil our aims we began to work with local stakeholders (including local NGOs and schools, as well as the local branch of South Africa's Department of Basic Education) to develop and implement different educational interventions. In working with a local NGO, we partnered to re-curriculate relevant sections of their Life Skills programme which is run in local high schools. In partnership with a local high school's Grade 12 (final year of high school) drama class, we worked to develop a community theatre intervention on menstruation. In partnership with the Department of Basic Education, we have worked to supplement the Life Orientation work done in primary and secondary schools by teachers in the area. In each case, our aim has been to open up a space in which participants can talk freely about menstruation, ask questions, as well as share and receive open, frank, reliable, and non-stigmatised information on the subject. Each intervention, while driven by the desire to improve education about menstruation, always has been fundamentally underpinned by the project's activist beginnings—by the desire to transform the situation on the ground. Moreover, while we have been driven to bring about social change through our activities, we have also worked to bring about changes in those with whom we work—inviting them to become agents for change along with us.

Through engaging in this work we have come to realise that having an activist agenda can, at times, present researchers involved in this kind of work with various ethical challenges in our roles, both as researchers and as activists; this applies, in particular, to challenges surrounding consent, confidentiality, and anonymity, as well as to participation and power dynamics. In order to elucidate these issues, we shall focus in what follows on unpacking our work in the community theatre intervention and the Life Skills programme.

Activist Persuasions, Relational and Iterative Consent, Confidentiality, and Anonymity

In our community theatre intervention we worked with a Grade 12 drama class at a local school to create a play on menstruation that could be performed to audiences of Grade 7 (final year of primary school) at other local schools. After the play was performed, the Grade 12 girls hosted a post-performance dialogue with the audience, during which the audience were able to ask the Grade 12s questions about the performance and about menstruation in general. The play theatrically unpacked and critically explored the socio-economic issues and challenges surrounding menstruation, and problematised the cultural taboos, stigmas, and common myths about menstruation in our community using a framework of information for self-study provided by us and drawing on their own lived experiences.

This intervention was immensely successful in terms of opening up the kind of dialogical space we see as necessary to undermine the culture of silence surrounding menstruation. The play was performed at two local schools and, during both post-performance dialogues, we saw young girls and boys opening up and keen to learn about the subject from one another, to talk about the challenges related to menstruation, and how to overcome them. We saw how the Grade 12 class had grown in confidence during the process and were able to answer with ease sometimes incredibly sensitive questions posed by the Grade 7 learners. Subsequent to this, we saw the Grade 7 female learners grow in confidence to the extent that they began to answer questions posed by both their male and female peers. We found that the Grade 12s' knowledge about menstruation had improved, not only in terms of biological knowledge, but also in terms of the social and cultural meanings and stigmas associated with menstruation, possibly because of working with one another and the information gained while developing the play.

We also noticed a dramatic attitudinal shift in the Grade 12s when it came to menstruation. When the drama class was initially approached about the educational intervention, they expressed concern about engaging in the project because of the sensitive nature of the subject matter. At a later stage, they were nervous about the prospect of performing in local schools where they might be known.

Their initial alarm at the subject matter and concerns about performing in public were strong indications of the stigma and silence surrounding menstruation, which was consistent with our research findings, and provided further evidence for the need to address these challenges. Simultaneously, they highlight some of the challenges we faced surrounding consent, confidentiality, and anonymity.

Boser (2006) points out that the process of informed consent in engaged research projects cannot be expected to operate in the ways it would do in traditional research projects. Because research activities are negotiated with participants at various stages in the research cycle, full and informed consent cannot be given in advance since the process, activities, and outcomes have yet to be determined. Participants can only consent to join the collaboration with 'the knowledge that this will be a negotiated process and elect to participate or not as the process unfolds' (Boser, 2006, p. 13). Perhaps more importantly, the question of informed consent in engaged research projects is marred by the social and political action aims of these projects themselves, since the processes and outcomes are impossible fully to define or predict, and to consent to in advance (Glass & Newman, 2015). Within the boundaries of such complexity, further distinct issues of consent are likely to arise owing to the challenges arising from the relational interactions between parties in engaged research.

In our own case, even though the Grade 12 class was convinced of the importance of the project and all consented to participate in the process, the girls' consent may be questioned on a number of grounds. Should their initial concerns about the subject matter have been enough to challenge the validity of their consent for us as researchers? Did their teacher, who came to see herself as a co-activist through her engagement with us, ultimately convince them of the need for the project and in so doing undermine their autonomy in consenting?[3] Here, activism—aiming to bring new agents for social change into the world—might have come directly into conflict with our role as researchers in ensuring that the learners were not in any way unduly coerced into taking part in the research activities. The concerns raised by the girls should, in retrospect, have warned us to question more deeply than we did the nature of their consent. Furthermore, for the individual girls being part of a *class* activity would have made it very challenging for any individual to withdraw without drawing attention to herself after the group had decided to go ahead with the project. In this respect, engaged research projects which allow for a level of community organisation in their activities, present us here with an opportunity to interrogate the tension between the rights of an individual and those of a group when operating under a democratic process that privileges the will of a majority (Glass & Newman, 2015). At the same time, however, in this instance, our (as well as the teacher's) desire to address the challenges identified in our research was first and foremost in our minds, and the activist work that we knew was needed prevented us from interrogating the ethical dilemmas surrounding informed consent at the time.

The girls' concerns about performing the play and facilitating post-performance dialogues in schools where they may be recognised or may have an existing relationship with a pupil also raise interesting concerns about the nature of confidentiality and anonymity in engaged research. While this chapter does not contain identifying information about the schools or the individuals involved (aside from ourselves), this is not the only knowledge generation process in the research project. It is not the only knowledge product of the research (the play itself should be seen as an equally important knowledge product), and indeed this is not the only dissemination of the research project to be consumed by the broader public—since the play was performed in local schools. There is a very real sense in which we could give no assurance of anonymity to the Grade 12 girls, and their concerns of being known made this threat clear to us. We negotiated with them about performing the play at schools where they believed they would not be known, but even in doing this, we knew that we could not guarantee their anonymity either at the performance or thereafter.

Similarly, though we can ensure that we do not share any of the intimate details about the personal experiences shared in platforms such as these, the play and the post-performance dialogue were public spaces in which intimate stories were being shared by individuals. While we could not predict the level of intimacy that would unfold in these spaces, we could similarly not give any assurances to any of the participants beyond what is given in any loosely constructed community of confidentiality. Here again, the complexity of our interrelationships with our participants and our dual role as activists and researchers compounded the ethical challenges we faced. We would, in our interactions with our participants, often reveal intimate details about ourselves and our experiences while unpacking the challenges around menstruation and bringing our participants into the spaces we hoped to open up for unconstrained dialogue. Perhaps our role as activists in this space was leading, and our own vulnerability led our participants to share details that they would not have offered so readily had they been working with researchers who had been engaging in the topic from a more detached and less personally invested position.

In spite of these challenges and dilemmas, we were conscious of the concerns raised by the girls and, because the research project was evolving and developing over time, we used a process of iterative consent with the girls, asking for their consent each step of the way and making them aware as far as possible of the potential risks and benefits involved. Interestingly, as the project unfolded, the learners chose to take what they would initially have classified as risks: they not only chose to perform the play at schools where they may be recognised (some of the girls had even attended these schools) but more importantly were not shy to do so, no longer thinking that it was inappropriate to talk openly about the topic. Their initial embarrassment was replaced with a significant amount of pride both in their work and in their capacity to act for social change within their community.

Power, Participation, and Activism

The tension and risk at the heart of engaged research stems from the fact that engaged research projects lend themselves to exploring and attempting to resolve potentially controversial issues faced by communities, such as in our own case in which we explored the challenges faced by menstruating women and girls. Engaged research lends itself to these topics because the process of critical reflection brought about through community dialogue on these challenging issues ‘can receive the benefit of open and frank scrutiny and debate’ (Minkler, 2004, p. 688) by all stakeholders. Since controversial issues may also divide and polarise community members, the choice to work on controversial issues can often put at risk the goals of fostering social cohesion and strengthening community trust and capacity if not handled in appropriate ways (Minkler, 2004).

For engaged research projects with distinctly transformative goals, the choice to work on controversial issues is further complicated by the aim of providing space for communities to re-imagine social interactions through ‘giving precedence, or at least equal weight, to the voices of the least advantaged groups in society, who may not have sufficient power for accurate representation among stakeholder groups’ (Mertens, 2007, p. 222) in research activities. The aim of including those who may be seen as having insufficient representative power within social spaces is to provide a platform for those individuals and groups to become active agents of social change, reflecting the goal of allowing people to tap into and give expression to their ability to evaluate their own assets and use them to shape their actions (Mertens, 2007; Minkler, 2004).[4] However, the use of transformative methodologies in participatory projects where controversial issues are being addressed can often bring about difficult ethical questions and practical strains in relation to cultural tensions within community groups where views, values, and ideologies are not homogenous or even shifting. Since the transformative agenda seeks critically to explore and challenge the assumptions of the status quo, some risk is necessarily entailed for participants in the social and cultural environment of the project, as well as in the process in which an attempt is made to democratise the set of social relations in the community. Within our own project, the tensions between the transformative agenda of the project and the sensitivities involved in navigating complex social spaces played out in both the community theatre initiative and the Life Skills programme.

Importantly, our research revealed that girls felt unable to speak to males about menstruation; they were afraid or embarrassed or had been told to keep it secret from males because it is either inappropriate or a taboo subject matter. This secrecy, we believe, underpins many of the challenges reported by the girls. Simultaneously, our findings revealed that girls felt that they would like the opportunity to be able to engage freely in conversations about these issues with members of the opposite sex. They wanted to share their experiences in order to provide insight into their lives and challenges, or wanted advice from the perspective of someone they trusted, despite their sex. Given this, we, along with our NGO and teacher partners, felt that the play should be performed to groups including both girls and boys. Similarly, in our work with our NGO partner, the Life Skills Programme was run with both male and female learners present. This, we felt, was important in breaking down the stigmas and culture of silence surrounding menstruation and critical to opening up spaces where it would be seen as natural and normal for males and females to engage freely and openly in education and conversation about menstruation.

We were conscious of the fact that opening up these kinds of spaces had the potential to reinforce stigmas and negative associations with menstruation, exacerbating tensions on the topic between the sexes if not handled sensitively. There was, we recognised, a risk of the female learners becoming marginalised by the male learners, and of the relations of power currently present in the group being reinforced by the process (Boser, 2006). It was precisely for the latter reason that together with the NGO partner facilitators we decided that we should not be present in the sessions, as our position as researchers from the university could reinforce existing power relations. Another concern raised by the facilitators was that our different cultural and racial positioning[5] could potentially interfere with the dynamics of the session. In ensuring that the process was facilitated in appropriate ways, then, we had to work closely with, rely on the facilitation skills and expertise of, and trust in, the shared commitment to the overall goals of the project of the NGO partner facilitators, school teachers, and learners themselves. Similarly, we had to trust in the efficacy of the activities we had co-designed to unlock the potential in the learners to come to shared understandings of their own and one another's situations in the process, and their ability to navigate new social relations in the shared space that had been opened up.

In the case of the Life Skills programme, cultural tensions that we had not anticipated emerged. Older male participants who had undergone their cultural initiation into manhood ceremony voiced the fact they should not be talking about menstruation to the NGO partner facilitators who were female; they decided to stay for the sessions but initially indicated that they would not be able to participate actively in them. As the sessions continued, however, they found themselves participating in the conversations and activities. When this was brought to our attention after the initial event, we discussed a number of possible ways forward. One of the facilitators suggested that we segregate the sexes in the future. Thorough discussions with our partner NGO ultimately resulted in minor adjustments to the entry strategies for the programme for the groups, and we agreed collectively to continue with the co-educational programme. Our own resolve in this regard, however, could be seen as both a by-product of our activism, and it could be argued that our discursive position may have led us as researchers all too quickly to disregard the cultural practices of some of the learners involved.[6]

The problem presented here raises a number of important ethical questions around power, participation, and engagement in the project. The question of how we ought to have handled the cultural challenges which arose is rooted in a basic question fundamental to engaged research about who should be thought of as representing 'the community' (Minkler, 2004). Should we have seen the men in the Life Skills programme who were initially opposed to mixed-sex dialogues about menstruation to have been representative of the community because of their assumed status within the community? Should we have seen our NGO partner facilitators as representative of the community in the light of their representational abilities from a community leadership perspective? Or should we have seen the women and girls facing challenges associated with menstruation as representative of 'the community', despite or in the light of their relatively less privileged position in the community? As we saw it, all these groups had an important role to play in representing 'the community', but the clashes which arose between the interests and aims of these groups meant that negotiation and compromise was necessary.

The men involved in the courses negotiated their own way forward in relation to their involvement in the programme, and this resulted in their participation in a process in which the aims and goals of mutual dialogue were achieved. This could be seen as a success in relation to the transformative and activist aims of the project, but was ultimately a success born of a compromise of the values initially laid down by the males who had been through initiation. As researchers we also made choices with respect to the programme, choices about whose values counted for more, whose interests should override others, and whose ends were more important. These choices were value laden, made from the perspective of activists and agents for social change. On the one hand, these choices had ethical implications for the marginalised participants who were given the opportunity to assume new roles in social spaces through research activities. On the other hand, these choices also had ethical implications for the participants who occupied privileged positions in these social spaces and who were forced to enter into negotiations about social structures, power, and the underlying cultural norms embedded in them. The ethical implications of these choices may be easier to weigh up and assess for detached researchers than for those researchers who are also activists working through their research to bring about social change. At each stage, with all stakeholders in the process, we attempted to promote transparency and communication around aims, risks, and benefits, but we recognise in retrospect that we did not take enough time during the process carefully to think through the ramifications of these issues, and this, we believe, was directly related to the urgency we felt at the time.

Concluding Remarks

Because of the relational interactions between researchers and research participants in engaged research projects, there exists huge potential for the democratisation not only of the social relations in the research process, but within the processes of knowledge creation and dissemination (Boser, 2006; Glass & Newman, 2015). The collaborative and participatory nature of the work allows for research practices in which community capacity, criticality, and equality can be fostered. The ethical complexities arising from the transformational nature of the work should also caution researchers against the conclusion that there is no need for deep and analytical ethical review to take place simply because the work aligns itself with the aims of social justice or community-driven goals (Boser, 2006; Minkler, 2004). The considerations outlined in this chapter lead us to agree with Sultana, who argues that 'ethical research is produced through negotiated spaces and practices of reflexivity that is critical about issues of positionality and power relations at multiple stages' (2007, p. 475). As a result, the ethical challenges that arise in the context of engaged research are likely to stand as unique for the particular research process as it is co-navigated by the researchers and participants within that process. Following this, the considerations of how these challenges should be addressed and resolved should be made explicit to all stakeholders, as far as this is possible, in order to allow for the freedom of participants to determine their own roles and choices (Boser, 2006). Researchers who enter into the process while also wearing the hat of an activist should take critical moments to pause and remove each hat in turn as they assess their relationships with their co-investigators and participants, as well as the ethical choices which they may face at each stage of the research process.

Writing this kind of reflective chapter is difficult because it highlights the ethical dilemmas one has faced and perhaps failed to think through as carefully and critically as one should when the need was most urgent. But doing so critically and reflexively is important, if not for our own future work, then certainly in terms of guiding others in terms of being critical when entering the engaged research space to think through the challenges and dilemmas in advance, as far as this may be possible, as both researchers and activists. Perhaps it is also important in relation to the epistemic virtue of intellectual humility to recognise that regardless of where we sit on the academic ladder we are able to learn and often in surprising ways.

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Notes

1. Ethical clearance for this work was obtained through Rhodes University's Research Ethics Review Committee (RPERC) in the Psychology Department on 21 May 2013 (PSY2013/12), from the Rhodes University Ethical Standards Committee on 1 December 2013 (2013Q3-5), and from the Department of Education on the 11 March 2014.
2. Our target, upon collaborating with our research partners, grew from our community to the province. This was as a result of deciding that the data would be used to put together policy briefs for the Departments of Basic Education and Health.
3. There is a significant amount of literature on the ethical impact of and dilemmas associated with power relations in participatory and collaborative research (e.g. Goldstein, 2000; Sultana, 2007).
4. There are interesting questions to explore relating to researchers as the agents of power, as the individual with the authority to 'give power' to the marginalised and voiceless.
5. Across the NGO and research team, we represented a broad spectrum of cultural and racial groups.
6. This, we believe, is a concern that pervades activism itself. There is a significant tension in feminist activism, for example, between listening to the lived experiences of girls and women, and telling girls and women about their lived experiences. In all cases, the 'telling' comes from a particular standpoint that is itself imbued with the values, norms, and beliefs that may contrast with or even contradict the values, norms, and beliefs of those who are being 'told to'. For more on the concerns surrounding positionality (and in particular 'Western' biases), see Farhana Sultana (2007) 'Reflexivity, Positionality and Participatory Ethics: Negotiating Fieldwork Dilemmas in International Research', *ACME: An International E-Journal for Critical Geographies* 6(3), 374–385.

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14

Living in a Rural Community and Researching HIV and AIDS: Positionality and Ethics

Jacqueline Akhurst, Mary van der Riet, and Dumisa Sofika

This chapter draws on a qualitative quasi-ethnographic approach to researching a sensitive topic. Exploring people's management of risk in sexual activity when HIV and AIDS are prevalent adds layers of complexity to the research process, foregrounding researcher positionality. As the researchers lived in a rural, resource-constrained context in a former homeland in South Africa, various ethical issues emerged. Living in this environment raised particular insider/outsider challenges for the researchers, adding relational and emotional dimensions. Below, we explore participant and researcher vulnerability, including dealing with the emotional intensity of research-related responsibilities and highlighting the need for enhanced and ongoing ethical awareness for both participants and researchers.

Research ethics committees focus on ensuring that no harm comes to participants (non-maleficence) and, if possible, that participants gain benefits from research involvement (Emanuel, Wendler, & Grady, 2008). A participant-centred human rights-based approach to ethics promotes the well-being of participants (Wassenaar & Mamotte, 2012), and stricter moral obligations are needed when working with vulnerable people and communities (e.g., Molyneux et al., 2009).

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A quasi-ethnographic approach requires living in the research site for long periods of time (though the researchers did not live on site for the type of sustained period required in full ethnography), leading to different forms of relationships being established and raising issues about boundaries between roles. Råheim et al. (2016) note that in a study setting, the meanings people ascribe to being an insider or outsider imply an ongoing negotiation of researcher status. Initially the researcher is an outsider, but over time the person engages in the social life of the context, potentially becoming more 'insider' than 'outsider', thus complicating the research role. In this chapter, we explore how such blurring of these and other boundaries interacts with ethical considerations in our quasi-ethnographic approach which was adopted for pragmatic reasons due to the prolonged engagement in the context (being field based, with data collected in the participants' setting). The strengths of this kind of contextualised research are that conversations become more like everyday social interactions, rather than the more alien tools of surveys and interviews.

'Living there' opens up possibilities not found in more conventional research, such as involvement in community events. Thus, being grounded in the daily realities of participants requires a different approach to ethical considerations than those posed in more fleeting research designs (Molyneux et al., 2009). Researchers need to be acutely aware of the 'complexity of social life' (Spradley, 1980, p. 55), judging when and how to be involved. Conducting research in a resource-constrained context raises additional tensions due to the direct and indirect benefits of research involvement, further blurring the researchers' roles.

Researching a Sensitive Topic

The focus of this research was people's responses to and management of HIV and AIDS. With prevalence levels of 7.1% among 15- to 24-year-olds and 25.2% among 25- to 49-year-olds (Shisana et al., 2014), young people in South Africa have a particularly high risk of HIV infection. The rate of HIV infection is disproportionate, with the incidence among females aged 15–24 being over four times higher than in males in that group. The predominant mode of HIV transmission is through heterosexual intercourse (Anderson, Beutel, & Maughan-Brown, 2007), a difficult-to-research, private, and personal activity. The particular forms of behaviour that drive HIV infections include unprotected sex, having multiple sexual partners, transactional, and intergenerational sex (Shisana et al., 2014); these are sensitive issues to discuss.

Combined with the social and cultural dynamics of gender inequality, labour migration, alcohol misuse, and intimate partner violence, all linked to increased incidence of HIV (Jewkes & Morrell, 2012), discussing HIV and AIDS risk in sexual relationships is not straightforward.

Living with or being affected by HIV and AIDS includes coping with the life-threatening nature of the illness when unmanaged, managing antiretroviral treatment (ART), and dealing with death and the grieving processes. In South Africa the diagnosis of HIV is also stigmatised and people are fearful of personal associations with the disease (Skinner & Mfecane, 2004). Conducting sensitive research 'necessitates (the) routine ethical practices of confidentiality, anonymity and worthiness' (Kidd & Finlayson, 2006, p. 423), researching topics related to illness, death, and stigmatisation places high relational and emotional demands on both participants and researchers (Cloete et al., 2010). Discussing these emotive issues generates a particular kind of relationship between researcher and participant in which people are invited to share personal aspects of their lives with the researcher, a relative stranger who then becomes a confidante. The emotional dimensions of such interactions affect both participants and researchers, and require careful management of researcher roles.

This issue of participant vulnerability requires 'enhanced ethical awareness' (Råheim et al., 2016, p.5) on the part of the researcher, for example, managing disclosure of status and emotional distress incurred during the process. Wassenaar and Mamotte (2012, p.272) comment that 'the intimacy of qualitative interviews carries far more potential to cause subjective distress … and this must be carefully addressed'. Kidd and Finlayson (2006, p. 423) note that ethical issues arise from 'emotional intensity and professional responsibility inherent' in research engagements. For example, in managing the emotional dimensions of interactions, research and therapeutic roles can become blurred. This raises questions about researchers' competence to manage such moral and ethical dilemmas. Although Råheim et al. (2016) argue that absorption in and empathy with participants' accounts enables understanding of their experiences that is ethically important, there are unintended consequences resulting from developing trust and emotional closeness in qualitative research (Hewitt, 2007). This does not necessarily impact on the methodological integrity of the research because deep absorption is important for ethically sound research.

A relatively ignored but related issue is that of researcher vulnerability through exposure to others' life experiences and struggles, which are personally felt and emotionally taxing (Mosavel, Ahmed, Daniels, & Simon, 2011). Researchers may experience anger, frustration, shock, and distress in response to data that has been collected. Such reactions may blur the boundary between the researcher as participant and as observer, leading to the researcher being unable to manage the demands of the interaction appropriately, as well as being him/herself unintentionally 'harmed' in the research process. Several authors comment on the omission of assessment of the emotional impact of demanding research on researchers in qualitative research designs and ethical review processes (Malacrida, 2007; Mosavel et al., 2011). This leads potentially to compassion stress (Rager, 2005) or feelings of guilt (Råheim et al., 2016). Addressing researcher vulnerability through developing self-care strategies, providing support through debriefing processes, counselling, and reflexive writing have been described (Malacrida, 2007; Rager, 2005). Emotional vulnerability needs to be recognised and managed, including during the training of social science researchers.

Below we describe the research site and research team, and explain what data were used for the reflections in this chapter. We then focus on the ways in which the relationship between researchers and participants become blurred, and how these interacted with critical ethical concerns such as fair selection, scientific validity, and non-maleficence. Finally we explore ways in which we coped with the issues, giving some recommendations for consideration.

The Research Context

The research site is in a rural former homeland in the Eastern Cape, South Africa, with which the principal investigator (PI) had long been involved. The research team comprised a PI (initiator of the research), two graduate students, and one external British advisor/researcher. Two other research assistants assisted in the organisation of field work, recruitment of participants, and some data collection. The data were collected in the first language of the participants, isiXhosa, in which the graduate students and research assistants were all fluent. Some local community members were key informants and assisted with recruitment.

The researchers lived in the research site for extended periods since their home institution was 1000 km away. A day's air and road travel was necessary, adding a further layer of practical arrangements to be managed. The research team spent up to 14 days at a time living in one of two homesteads that became a base from which they conducted the research. This enabled access to participants and also provided increasing insight into the everyday challenges and social arrangements of living in this rural area.

Homelands were geographic territories in the Apartheid era, set aside for black South Africans as a way of securing prime land for white people and to provide a source of labour for parts of the country; they still tend to be more impoverished than are other areas. The community comprises 14 villages spread over 20 kilometres, which fall under a traditional chieftaincy as well as a politically elected councillor. The residents are predominantly Christian but retain many traditional Xhosa practices (such as those related to the initiation of young men and marriage). The area has an electricity supply and cell phone reception; however, there is no waterborne sewage or piped water except that from communal taps. The untarred roads are generally poor, especially after rain. A single daily bus services the area and private taxis are mostly pick-up trucks. The clinic and the chief's dwelling are in the centre of the area, with the villages ranging up to ten kilometres away. Primary schools are located in six of the villages and one secondary school is in the central village. It is 25 kilometres to the nearest town, hospital, and police station. Many people rely on subsistence agriculture and government grants (pensions, disability, foster, and child care), with few opportunities for formal employment. Some families receive supplementary remittances from family members working in towns. The most recent census indicated that 23.6% of the population had no annual income, with 65% earning below $2616 per year; and only 28.9% of the residents had completed formal schooling (StatsSA, 2011). Many of the youth who finish school remain at home unemployed or leave the area to seek work. This history of the impacts and continued effects of apartheid and its structural consequences has a bearing on the research as it unfolded because it impacted on the limited levels of agency of participants and had ethical implications related to the relationships that were formed in the context.

After gaining ethical clearance for the study through the institutional research committee (HSS/0695/011), the research team negotiated access and the terms of the research with the chief. Each village also has a residents' association with an elected chairperson who manages the events and visitors in the village, so we negotiated access to potential participants in each village through these representatives.

Data reflecting on the research process were collected during field trips to the site and during subsequent research meetings and debriefings. The contributors were four team members (PI, external advisor, and two graduate students) who had lived and worked for varying periods of time in the community. Recordings were made of debriefing sessions between the PI and the two graduate students, as well as interviews (by the first author), including discussions on the journeys to and from the field as well as back in the office, some of which were recorded and transcribed by members of the research team.

The reflective process covered methodological and ethical issues to enhance rigour and generate data that were ‘accurate’ for the context. In the next section, we focus on the ethical issues, particularly those about relationships and boundaries, referring briefly to methodological issues where they interact with ethics to promote scientific validity (Wassenaar & Mamotte, 2012).

Reflections on Experiences of a Quasi-ethnographic Approach

Living in the same conditions as participants, the researchers were seen to be proving their commitment to the goal of the research (trying to understand the reality of being affected by HIV and AIDS in a rural context). This demonstrated commitment probably influenced the development of rapport and trust of participants, potentially enhancing the quality of data collected. Råheim et al. (2016, p. 5) caution that researchers’ expressions of interest and attentive listening lead to participants revealing ‘wells of sensitive information’. Thus, being close to and having established trust with community members facilitated the research process but also risked participants feeling the associated distress of articulating emotional issues linked to HIV and AIDS.

Living in the context and gathering the data *in situ* gave the researchers insight into the dynamics of everyday life and an acute awareness of its inherent complexities (Spradley, 1980). Methodologically, this contextual insight provided a framework for interpreting data and enabling a critical understanding of the contextually specific social dynamics related to sexual risk-taking (e.g., traditional customs such as payment of ‘lobola’, a bride price, or the building of outside rooms for young men). Situating the data strengthened the researchers’ interpretive capacities, potentially enhancing scientific validity.

Living There and Positionality

As the team built social relationships, role conflicts became apparent as the boundaries between being researcher and community participants blurred, thereby constructing very particular ethical challenges. Close proximity to participants personalised the research process (Fine, 1993) with researchers also becoming ‘confidante’ or ‘friends’. The researchers became ‘insiders’, experiencing the research context directly, but remained ‘outsiders’ because their stays were temporary. Emanuel et al. (2008) highlight the ethical principle of respect for potential and enrolled subjects, particularly through protecting confidentiality. The insider status of the researchers could thus compromise the confidentiality contracts. For example, at times the researchers learnt things about community members which the people concerned had not directly revealed (such as others’ HIV status without the individual having made a disclosure). The research team also at times became caught up in interpersonal dynamics, as illustrated by being called on to intervene in a conflict between two families, and this mediation complicated their roles as researchers.

The realities of strictly gendered roles and functions created particular expectations of male and female researchers, emphasising their participation in social processes (Spradley, 1980), whilst undertaking the research. In this context, women are expected to defer to the norm of male authority for decision-making. This made it difficult for female researchers to lead research processes, or to direct male community members and research assistants. In addition, some men made inappropriate and sexually loaded comments to a female researcher, including unwanted physical touching, which created safety considerations and constrained her movements. These gendered relational demands increased the level of strain for the researchers.

Living ‘on-site’ is thus demanding and may affect researchers’ emotional health due to loss of privacy and feeling under scrutiny. The 24-hour researcher role meant that team members could not easily socialise ‘normally’, for example, going for a drink at the tavern, since this might affect community members’ perceptions of their research. Positionality thus became a concern: it may be useful for researchers to be seen as ‘insiders’, participating in social life and perhaps young people would identify with their doing similar activities, increasing rapport. However, researchers being linked to activities frowned upon by others in the community (the tavern was identified as a site of sexual risk-taking) may compromise researching such behaviours and could lead to negative judgements about the researchers or constraining some participants’ talk about risk. The expectations that researchers should occupy the moral high ground, being those who epitomise ‘good health behaviours’ and not risking HIV infection, is not necessarily an ethical issue. The strains experienced, however, raise the issue of care for researchers, considering the balancing of time between personal life and researching: researcher vulnerability thus becomes an ethical issue.

Boundaries of Researchers' Roles

Building close relationships with participants through 'living there' made space for the discussion of sensitive issues such as positive diagnosis, illness, or HIV transmission in heterosexual activity. Emanuel et al. (2008) emphasise the importance of monitoring the welfare of research participants in clinical trials, providing them with appropriate treatment or support. In our research, exploring such topics was critical to the amelioration of potential harms in the research process of talking about HIV. The emotional issues of stigma, illness, and death could only be discussed within relationships of trust.

Knowledge and awareness of HIV among community members appeared very variable. This challenged the researchers' roles, creating dilemmas about intervention. When participants seemed to have inaccurate knowledge or misconceptions, these blurred the boundaries between researcher and health educationist. For example, in individual interviews participants asked questions about treatment (e.g., whether ART becomes ineffective over time and why certain side effects were experienced) or a HIV-positive participant reported engaging in sexual activity with a HIV-positive partner, unaware of the possibility of re-infection.

The researchers in the field raised these dilemmas in telephonic debriefings with the PI. They were aware, as Råheim et al. (2016, p.5) comment, of the 'balance at play between knowing and non-knowing positions … We (as researchers) are not equal, being empathic and caring conceals power, and this may be ethically questionable'. In situations such as these, the researchers decided that it was important to talk about potential risks and either to provide information or to refer participants to others with expertise, for example, at the local clinic. Here the researchers purposely blurred the boundary between researcher and 'expert' and discussed the potential risks. This speaks to the ethical principle of non-maleficence, when not providing participants with resources and information could lead to harm (Emanuel et al., 2008). Being there also meant that researchers were questioned about HIV and AIDS outside of the formal research interviews and focus groups. This potentially added to the beneficence of the research because of minimal other HIV and AIDS educational resources. On the other hand, the researchers were constrained by not being experts in HIV and AIDS issues and were not always sufficiently knowledgeable to provide appropriate information.

Serious concerns were also raised by participants about the behaviour of local clinic staff members. Inappropriate disclosure of people's HIV status as well as the poor quality of service for those with HIV and AIDS were spoken about by many. Wassenaar and Mamotte (2012, p.279) highlight the ethical debates about the 'nature and degree of obligation … to assist participants with other problems' of which researchers become aware. Here, the ethical dilemma was whether the researchers should take these issues of discrimination further as advocates for the community members. The team debated this several times, expressing concerns that intervention would compromise future interactions with the staff at the clinic. As it transpired, community members challenged the clinic and the individual mainly responsible for the breaches of confidentiality was transferred. In this situation the team chose to keep firm the boundary between researcher and interventionist roles.

Another challenge to role boundaries occurred when recruiting HIV-positive participants. The researchers' presence in the area was linked to HIV research and some people stated that they did not want to be associated with the research because they feared possible stigmatisation. Also, certain individuals might have disclosed to a few others, but were not open about their own HIV-positive status. Through indirect recruiting and by creating very firm protections around anonymity, the research team developed ways of involving people without their needing to reveal such sensitive information.

The participants' struggles with a positive diagnosis, living with HIV, and their experiences of prejudice were difficult for the researchers to hear. The researchers needed to keep calm and provide the space for the person to continue to talk, processing the material quickly to enable appropriate responses; they then needed to cope with the residues of their thoughts and reactions later. They thus had to process the emotional strains of hearing about the devastating impacts of HIV on individuals and families. One family drew the researchers into the room of their bedridden daughter and asked for help: a very stressful experience for the researchers who felt that they did not have the resources to assist.

Careful attention to the welfare of research participants through the provision of support, as argued for by Emanuel et al. (2008), is not easily done. In debriefings with the PI, the researchers discussed whether they should be providing counselling (which they were not trained to do) or whether they should be referring the participants for additional support. The challenge was that in this resource-constrained context (with no active non-governmental HIV and AIDS organisations), the clinic was the only local source of healthcare and HIV and AIDS support, but its reputation was tarnished by breaches of confidentiality. Ultimately, the research team organised an outside HIV-positive activist to meet with a group who had requested assistance.

The dilemmas mentioned above raised questions of whether the researchers had adequate levels of knowledge about some of the topics, of what their educative role might be, and whether they could or should intervene in certain situations. These all illustrate challenges to the boundaries of researcher roles, juxtaposed with having some knowledge and perhaps being in a position to advocate for others. In addition, these highlight the ethical importance of emotional support and care for researchers (Kidd & Finlayson, 2006), including the important roles played by debriefing, team reflections, and supervision (Wassenaar & Mamotte, 2012). Mosavel et al. (2011, p.1330) emphasise increased concerns for researcher well-being when working with people who have 'difficult life experience(s) or are in some way disadvantaged or marginalized'. The reflections of our research team suggest that this is even more necessary for researchers who actually live in the research context. The team members reported needing regular times to reflect on material with their peers, but this was difficult in the configuration of the homestead in which they stayed where they had little privacy. The PI played an important role in offering regular debriefing, by cell phone contact at various points, for example, for reassurance and to 'talk through' decisions that needed to be made.

Doing Research in a Resource-Constrained Context

Dealing with day-to-day-life in this setting, which is characterised by high unemployment, created difficult and unanticipated challenges. Whilst not implied during any briefings, it became clear that people hoped that the research would 'bring change' or 'employment', with the researchers constructed as providers because they seemed to have access to resources. Being associated with the research team also brought status and limited financial reward to some people when they were contracted to assist with logistics. Community members saw the research project as an opportunity to earn a little income, however small.

Nyambedha (2008) comments that through failure to address the raised expectations of communities involved in the research, researchers may cause harm. Having to address these expectations was not straightforward, however. After one event, the researchers were confronted by a number of people who expected to be paid even though they had not been directly contracted to assist with logistics: this required careful negotiation to resolve through clarifying what the agreements had been. In another instance some individuals unofficially 'recruited' people as participants and then expected payment for this assistance. These kinds of interactions made it difficult to re-visit particular villages without the expectation of researchers providing monetary rewards.

Compensation for consistent longer-term participants also became complicated. In this resource-constrained context the 'compensation' for time spent on research-related activities was an incentive, but over time it became a ‘demand’ from participants. When researching in developing contexts, Wassenaar and Mamotte (2012) note that participation implies expectations of some benefit in return. This speaks to the ethical principle of fair selection of participants. Molyneux et al. (2009) comment that the wider community’s perception of fairness must be considered in purposive participant selection so that some are not denied the benefits of participation. In our case, the demands for financial rewards set up difficult dynamics and in some areas it was not possible to continue recruitment. The researchers were clearly defined as providers, but this was a very uncomfortable position for us.

A further illustration of unintended confusion was evident when perceptions of our research activities were conflated with the work of another non-researching organisation, doing small-scale agricultural development in some villages. Our research team was inaccurately credited for bringing developments into the area, further raising expectations of material reward through involvement in our research. In another example, a political party councillor tried to align our project with his activities, seeking to obtain credit for the work of the team. In these situations the researchers had to explain the project very carefully and to define their roles as being different from other community projects or political parties’ activities.

Enhancing Ethical Awareness

There are multiple challenges in conducting embedded qualitative research on sensitive social issues in a resource-constrained context, particularly the blurring of boundaries between insider and outsider, and between researcher and other roles. It is clear that there is a need for enhanced ethical awareness on the part of researchers during in-depth qualitative research processes (Råheim et al., 2016), and the complexities of research relationships means it needs to be an ongoing concern (Hewitt, 2007). The findings of this research project illustrate the immense benefits of the rich data that emerged from the processes (e.g., Jama, 2016; Mqedlana, 2016).

In the ethics literature, much is written about the protection of participants (Emanuel et al., 2008; Wassenaar & Mamotte, 2012), but less has been written about managing the effects of research on the researcher. Our researcher reflections show that the effects of research may be under-reported and may emerge unexpectedly during a study. Thus there is a clear need for research ethics committees and ethical guidelines also to consider the potential for harm to researchers through integrating supportive and processing mechanisms such as regular debriefing and reflection sessions. The value of reflexivity (Molyneux et al., 2009) became clear to our research team and they spoke of developing the 'self as researcher'. The complex boundary issues, and the related ethical concerns, illustrated the need to be sensitive to ways that their own involvement and responses to relational and emotional demands influenced and impacted on the research process. It is therefore essential for ethics committees to require that researchers anticipate potential challenges in relation to interactions with participants, considering ways in which multiple roles might be negotiated and the measures that need to be put in place can enable reflexivity when boundaries and roles might become blurred.

Molyneux et al. (2009) note the moral rather than legal aspects of the critical roles of social relationships between researchers, field teams, and community members in producing high-quality data. Such elements may be rooted more in the insights and integrity of the researchers than in being amenable to checks by ethics committees. This suggests that the work of making research an ethical practice unfolds during the course of any project, with constant re-evaluation of how to manage boundaries, whether to keep them firm or to allow some blurring. Neither firm nor blurred boundaries can be fully decided on at the beginning. The research process therefore comprises an ongoing set of checks and balances (Wassenaar & Mamotte, 2012), negotiations, and cues for subtle issues that are nevertheless vital to the research project. The boundaries that the researcher has to navigate in the course of research are not always easily visible (Ellen, 1984), and this requires continuous attentiveness to ethical issues during a prolonged engagement in the field.

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Section 3

The Politics of Voice, Anonymity, and Confidentiality

15

Introduction: The Politics of Anonymity and Confidentiality

Catriona Ida Macleod and Phindezwa Mnyaka

It is a standard requirement of ethics committees that researchers address questions concerning anonymity and confidentiality. The conventional practice is to ensure that participants' names and identifying details are expunged from the public records of the research and that high levels of confidentiality of data be maintained in the research process. In this introduction, we outline how authors of chapters in this section ask questions concerning these imperatives, including circumstances in which participants actively want their identity revealed and their voice heard, or when anonymising might not be possible, or may further disadvantage marginalised populations.

Each chapter in this section draws on fieldwork research that required careful thought about participants' anonymity and confidentiality in relation to institutionally defined notions of harm. Naidu (2018, this section) reflects on negotiating anonymity in the process of publishing a clinical case study that included poetry written by the participant undergoing medical surgery, as well as a case of an HIV/AIDS home-based care volunteer group. Rice and Mykitiuk (2018, this section) consider the implications of working with non-normatively embodied and en-minded research participants who frequently experience remaining invisible. Similarly, Marx and Macleod (2018, this section) think through the

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tensions generated by the erasure that anonymity might enforce by providing an account of attempting to obtain approval for research proposals that involved female participants who had experienced intimate partner violence and queer-identifying participants in drag, respectively. Like Marx and Macleod, Ashdown et al. (2018, this section) situate their research in a critical framework by considering the implications of working in indigenous Māori communities for whom conventional notions of anonymity in research may contradict a larger political and cultural project of reclamation in a context marked by colonialism. In turn, Rucell (2018, this section) asks what the social implications are for concealing the identities of organisations that do harm to participants whom a researcher encounters and whether the commitment to anonymity and confidentiality in such cases may be considered equally unethical.

All the authors in this section recognise the importance of thinking carefully through questions of anonymity and confidentiality. They acknowledge that these standard measures are put in place in the name of protecting research participants, firstly, from potential harms that may accrue in having their identity revealed particularly if they disclose sensitive information and, secondly, in terms of their right to privacy. We begin, therefore, by outlining the purposes of anonymity and confidentiality as commonly seen in ethics protocols. We then explore the arguments made by authors that the automatic anonymising of data and the imposition of confidentiality can constrain ethical conduct. This coheres around two key observations: firstly, the virtual impossibility of completely concealing the identity of participants or organisations within particular kinds of research and, secondly, the dilemmas researchers face, particularly those engaged in critical and emancipatory research, when participants request that researchers reveal their identities. We then pose some of the questions that have arisen in relation to the assumption that researchers must maintain anonymity and confidentiality, including how and if this adds or detracts from the credibility of research, whose interests are served in the process, and how the harms from which anonymity and confidentiality are supposed to protect participants are conceptualised. We conclude with some ideas concerning navigating the way through anonymity and confidentiality in critical research upon which each chapter in this section then builds.

Purposes of Anonymity and Confidentiality

Novak (2014) points out that anonymity is a complex term. It can apply to the legal name of a person, as well as to the possibility of locating that person based on a number of indicators. Anonymity is applicable at the individual level but also in terms of geography and at the level of the collective, as in organisations, schools, villages, NGOs, government departments, and communities. *The Belmont Report* (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, Department of Health, Education and Welfare (DHEW), 1978), which is often considered a founding document on research involving human participants, sees anonymity, confidentiality, and privacy as the means by which researchers can maximise possible benefits and minimise possible harms. The harms, in this instance, include negative emotional outcomes, stigma, retribution by a third party, damage to reputation of individual or organisation, or withdrawal of support by organisations, funders, family members, or friends.

Anonymity is closely related to confidentiality in that anonymising data assists in confidentiality. The two are not identical, however. Confidentiality implies that researchers will not share identifiable personal information with others. It is important for researchers to understand the limits of confidentiality. For example, in most countries, if researchers learn of instances of child abuse they must report it. Likewise, if researchers encounter other illegal activities or crimes, they may be subpoenaed to reveal their sources (Haggerty, 2004). Researchers need to weigh these formal requirements against their sense of ethical duty in extreme cases. Ashdown et al. (2018, this section), for example, provide a rationale for preserving anonymity in a project in which illegal activity may well be described by participants (such illegal activity may have been previously reported or not, but either way ethical questions arise for researchers). Wiles, Crow, Heath, and Charles (2008) found that researchers reported feeling personally compelled to break confidentiality when participants were at risk of harm but not in cases of involvement in illegal activity.

All the authors in this section acknowledge the necessity of considering seriously the potential of harm upon participants in the process of gathering data and dissemination of research. However, they challenge researchers to expand the intertwined notions of harm and ethics by taking into consideration the limitations of promised anonymity and by seriously reflecting upon both the limitations and potential offered by allowing participants to share their identities when researchers are committed to a critical research agenda.

The Limits of Anonymity

A number of researchers (e.g., Saunders, Kitzinger, & Kitzinger, 2014; van den Hoonaard, 2003; Walford, 2005) argue that guaranteeing complete anonymity to participants can be an unachievable goal, particularly in qualitative and ethnographic research. At a basic level, researchers on the team, particularly those who conduct interviews or interact with the participants in some way, will usually know the identities of the participants in any case. This means that what Tolich (2004) calls internal confidentiality among those involved in the research is rarely possible.

The more pertinent measure of anonymity, however, is that which applies to persons other than the primary researchers. Once again, there are challenges. In their chapter, Marx and Macleod (2018, this section) draw attention to the use of pseudonyms as a conventional method of maintaining anonymity. After facing the challenges of getting institutional approval to allow women participants who had left violent relationships to reveal their identity should they wish, they (the researchers) opted, in a new study of queer performances, to use each participant's stage name instead. This decision entailed a degree of possible identification within the queer community of that city. Naidu (2018, this section) reflects on engaging community groups and NGOs that may be easily identifiable. Similarly, in one case study, Ashdown et al. (2018, this section) work with participants drawn from a residential therapeutic community for men with a history of criminal offending. In both cases, people who live in the communities in which the research was conducted may be able to recognise the participants and the sites of the study. Moreover, the growth of internet technologies has meant that protecting the identity of participants is an even bigger challenge than it has been previously (Novak, 2014), an issue reflected on by Naidu (2018, this section) in discussing the inclusion of a participant's published poetry.

The requirement in qualitative research, in particular critical research, to provide significant contextual information so that the findings may be read in context means that readers may be able to locate the study simply from descriptions of the site, even if pseudonyms are in place for both the individuals and the organisations featured in the research (Tilley & Woodthorpe, 2011). This is exacerbated by the fact that academics tend to use research sites that are geographically convenient, so readers may guess the location of the study and also individuals who are part of the study (Walford, 2005).

Finally, there is a growing emphasis on the need to report to funders which raises questions regarding the anonymity and confidentiality of participants, especially if the funders are also the organisations in which the study took place. In contrast to this, Rucell (2018, this section) suggests the need to rethink one's commitment to confidentiality and anonymity when researchers encounter incidents that harm participants in a given organisation. Drawing from examples in which there may be unreported incidents of violence, she asks whether blanket anonymisation makes research data 'impotent', which in turn may weaken researchers' contribution to public interest. In such cases, the individual focus of harm prevention may be at odds with public transparency.

Some researchers have gone so far as to suggest that anonymity is a nearly impossible ideal. Van den Hoonaard (2003) maintains that anonymity is only really maintained through 'the natural accretions of daily life, the underuse of data, and the remoteness of place and time between the gathering-data stage and the eventual publications of findings' (p. 141). Stein (2010) reaches the same conclusion, questioning whose interests are served in the quest of anonymity.

Identifying Participants

A number of chapters in this section reflect on the challenges that occur to anonymity requirements when participants themselves insist on not using pseudonyms. Naidu (2018, this section) relates how in a therapeutic case study the participant wanted her name associated with the poetry that she produced in the sessions. Similarly, Rice and Mykitiuk (2018, this section) grapple with the question of the intellectual property rights of participants who produce art and performances as part of their research study.

Both cases highlight the importance of voice when thinking about anonymity. Voice, ownership of data, and intellectual property are key components for consideration in anonymising data. Voice refers to the possibility of people who, through a range of power relations that serve to marginalise them in society, are silenced in particular spaces. Rice and Mykitiuk (2018, this section) suggest that anonymity may shore up the distinctions between researcher and those who are researched in terms of voice.

Concerns over data ownership emerge particularly in in-depth (auto)biographical life story, oral history, and narrative work (Tilley & Woodthorpe, 2011). As people delve into their own or their community's histories, the question emerges of who owns these data and who determines how they are used. This applies not only to contemporary accounts, however, but also to archives in which records of people's lives are held. Wright and Saucier (2012), for example, ask, 'Is the concern over confidentiality giving way to a new emphasis on returning names (and agency) to vulnerable groups in the past [who have passed away]?' (p. 65). Assigning a name to a participant may, in part, be a form of assigning partial authorship. At the same time, researchers need to remain critical of how the processes of 'giving voice' and 'returning' are inscribed with power relations that may reinforce the status quo of particular power relations.

This is particularly significant in contexts wherein researchers engage with communities marked by colonialism. Indeed, Ashdown et al. (2018, this section) suggest that individualised notions of concealing identities reveal cultural bias. In their engagement with Māori participants, they point out that naming individuals is relevant to indigenous peoples due to shared goals of self-determination. In such a context, naming the individual is tied to a larger social and political project in a site where communities have experienced dispossession. For the authors, concern with non-maleficence may in turn lead to a failure to recognise the contribution of participants.

Similarly, Marx and Macleod (2018, this section) point to the complexities of concealing the identities of queer participants and women who have experienced intimate partner violence. Both groups of participants often contend with invisibility and masking their identities may equate to a form of 'going back to the closet' in cases in which participants may have had little opportunity to speak. Remaining cognisant of the complications of affording spaces for voice, the authors point out the need to reflect on how masking identities can both promote and undermine ethical practice from feminist and queer perspectives. For Rice and Mykitiuk (2018, this section), negotiating visibility is critical when adopting a disability justice perspective. In their chapter, they draw on cases that make use of art-based mediums that in turn transgress the boundaries of anonymity and privacy. They reflect on how non-normatively abled participants contend with the entwined legacies of being put on display or being hidden away both in academic research and beyond, as well as the manner in which participants are often reduced to parts of their bodies and minds. Assigning authorship to creative output, which entails revealing identities, speaks to such forms of representation.

Difficult Questions Regarding Anonymity and Confidentiality

In the light of the issues discussed in this section, researchers increasingly question the stock ethics committee requirement that researchers should outline *what* measures are put in place to ensure anonymity and confidentiality. Further questions that should be posed are: firstly, *whether*, and under what circumstances, measures need to be put in place and, secondly, whether a case can be made for participants to refuse anonymity and confidentiality. Giordano, O'Reilly, Taylor, and Dogra (2007), in their analysis of the ethical guidelines of the World Medical Association, British Psychological Society, British Association for Counselling and Psychotherapy, and the American Anthropology Association, indicate that these bodies do not *impose* the requirement that researchers should protect the identity of their research participants. In the light of this position, it is imperative that critical researchers engage in reflection on the various issues that attend to identity management in research. In the following, we speak to a number of these issues, including credibility of the research, whose interests are served, and conceptualisations of harms.

Lincoln and Guba (1985) established credibility, the confidence one can have in the 'truth' of the findings or the equivalent of internal validity, as an important component of qualitative research. The question of whether anonymity adds to or subtracts from credibility has received some attention. Giordano et al. (2007) argue that anonymity assists credibility. On the one hand, participants may be more honest in expressing themselves, especially about sensitive personal matters, if they know that what they say cannot be traced to themselves. On the other hand, making participants' identities known may encourage accountability for the information shared. As Lelkes, Krosnick, Marx, Judd, and Park (2012) indicate, however, this accountability may be accompanied by a motivation to distort reports in socially desirable directions.

Anonymity is supposed to protect participants from potential harms associated with being part of the research. A number of researchers have, however, questioned whose interests are really served in anonymising participants. In this section, Rucell (2018) indicates how anonymity provisions may be put in place to protect the institution from legal action. Similarly, Walford (2005) suggests that the promise of anonymity forms part of researchers' access strategy, particularly in institutions where there is much external scrutiny and evaluation. Novak (2014) indicates that anonymity can act as a licence for researchers to interpret the data in ways that 'free(s) them from the responsibilities of truth telling and accuracy' (p. 69). Moreover, in cases in which participants have produced artistic work as part of the research, such as in Rice's and Mykitiuk's research (2018, this section), by not crediting the participants' work, only researchers' CVs are enhanced. The same argument can be applied to any intellectual output of research on which the researchers are authors whilst the participants go unacknowledged when anonymity is imposed.

In terms of the usability of the findings, Walford (2005) argues that failing to name sites of research gives the results a spurious sheen of generalisability. While Rucell (2018, this section) is concerned with negative effects when individuals and organisations are not transparent, Tilley and Woodthorpe (2011) believe that where organisations are doing innovative work, and may provide examples of good practice to others, anonymising the sites decreases the usability of these good practices. Consequently, these are not beneficial to the sector within which the research was conducted either for the reputation and prestige of the specific organisation or for the sector in general.

For the most part, researchers and institutional ethics committees define questions of harms, non-maleficence, and beneficence prior to entry into the field. Seldom considered is how participants may understand potential harms and the measures needed to protect them from these harms. For Marx and Macleod (2018, this section) working within a feminist and queer perspective means being attendant to how such procedures may limit participants' involvement in setting a research agenda.

How harms are conceptualised, however, is also a matter of contention. As Rucell (2018, this section) points out, harms are generally forecast based on the imaginations of reviewers and researchers rather than on sound evidence bases. Sikweyiya and Jewkes' (2011) work is pertinent in this regard. They pose the question: does research on gender-based violence (GBV) pose greater than minimal risk of harm to researchers and participants? This is an important question in the light of the fact that ethics committees frequently assume there are high risks (e.g., secondary trauma and/or increased violence against the victim) associated with conducting GBV research. Their conclusion, after interviewing 12 experienced GBV researchers from various countries as well as a desk review, is that the idea that GBV studies carry more than minimal risks of harm when precautions are followed is speculative rather than evidence-based. Furthermore, harms, as highlighted by Ashdown et al. (2018, this section), are generally considered at an individual level. When researchers view harms at a collective level, a different picture may emerge in relation to the harms enacted upon communities that are rendered either known or anonymised.

What Are the Issues that Need to Be Considered?

If an automatic assumption of the provision of anonymity and confidentiality is removed, what are the issues that researchers need to consider in order to act in an ethical fashion? In the following, we discuss how the epistemological and methodological stances of the research make a difference. We speak to the key question of 'vulnerability' and what that means for thinking through levels of anonymisation.

The authors featured in this section do not see research as a neutral process of knowledge production but rather as an intervention in the world. It is precisely this point that underpins these authors' uneasiness about the standard requirements of anonymity and confidentiality. Working from disability justice, feminist, queer, indigenist, and social justice perspectives, these authors foreground the power relations that render particular people (often called 'vulnerable') invisible and silent or, alternatively, exotic and other. Their critical approach to research renders it impossible for them to ignore the implications reflecting on the implications of their research for their participants' agency and voice.

Particular methodological approaches also pose challenges to anonymity. Oral history, Le Roux (2015) indicates, 'sets out to contribute to historical understanding, validate respondents' lives, contribute to democracy and facilitate socio-political transformation' (p. 552). Enforcing anonymity denigrates respondents in this case. Longitudinal studies, which involve extended timeframes and intensive research relationships, pose challenges to the possibility of anonymity (Taylor, 2015). Action research, participatory research, and research collaborations also test the boundaries of anonymity and confidentiality. As pointed out by Reid and Brief (2009), in community-based research, confidentiality means that participants have no assurance that their involvement may lead to social change.

The notion of 'vulnerability' is key in the application of anonymity and questions of participation, in research. Vulnerability can be thought of in terms of reduced autonomy, such as in the case of children and prisoners or in terms of susceptibility to emotional, physical, or social harm. Researchers who study 'vulnerable' populations are generally asked for significant detail in their ethics protocols regarding how they will manage the risk of harm, including through the measures of anonymity and confidentiality. The logic in this instance is that 'vulnerable' populations are in need of more 'protection' than otherwise would be the case and that greater care needs to be taken to ensure that their rights to privacy and the principle of non-maleficence are maintained.

Marx and Macleod (2018, this section) point out, however, that the notion of 'vulnerability' is a contested one. Under which circumstances and to what extent a person, group of people, or community are considered 'vulnerable' is a matter of historical and locational variation. The notion of 'vulnerability', in addition, homogenises the identity of the people spoken about and leaves aside questions of agency, resilience, alternative identities, and actions. It focuses attention on the person who is 'vulnerable', rather than on the social circumstances that construct and maintain that position. In addition, people who otherwise would not be considered vulnerable may experience vulnerable times, such as bereavement, birth in the family, and retrenchment (Tolich, 2004).

Processes

If anonymity and confidentiality are not considered standard responses at the outset of a research project, if researchers are not obliged to fight for exceptions concerning anonymity, and if researchers are not expected to deal with the fall-out from unrealistic promises of anonymity, what processes need to be put in place to ensure ethical research conduct? In the following, we provide some tentative suggestions. As with most ethical principles and processes, however, these are generally refined through the test of application and time.

Various scenarios are possible in thinking through the questions of anonymity and confidentiality in research: (1) researchers set out at the beginning to allow participants to manage their own identity in the research process and outputs; this is included up front in the research proposal and ethics protocol; (2) researchers, with motivations based on vulnerability and potential harm, decide which participants/groups of participants should be enabled to manage their own identity in the research; (3) researchers retain the standard options of anonymity and confidentiality, but, during the process, participants insist on not remaining anonymous. In addition, there are various levels of anonymity in each of these scenarios (as indicated earlier) that require thought. In the following, we deal specifically with option (1) in terms of consent processes.

Researchers are tasked with obtaining informed consent from participants prior to collecting data. If identity management forms part of this process, as indicated in option (1), this opens up the question of how to navigate this terrain. Providing potential participants with the choice of how to be named is not a simple one. Consideration of what information participants would need to empower them to make informed choices is essential (Giordano et al., 2007). Researchers would need to think through the possible consequences for participants, organisations, and locations that are named, of potentially both positive and negative consequences. Most of these potential consequences will be specific to the particular research. It is essential, however, to consider how one named person's disclosure might impinge on the autonomy of others and on their right to confidentiality.

In terms of the information supplied to potential participants, this again will depend on the study. It would be useful to consider a few generic pointers:

- If participants are not co-researchers, or are not provided with the possibility of vetoing particular ways of writing about them, then they need to understand that how their views, opinions, and/or relevant data are presented in final form might not be what they had anticipated. They need to know that the autonomy of the researcher means that s/he has some discretionary space for interpretation of data based on the epistemological approach taken.
- Once the participants' identity appears in print or online, it cannot be retracted.
- While researchers may target particular audiences in publishing their work, there is no guarantee of who will read the work or in what context.
- Not all contributions will feature in the final report. This does not diminish the importance of their participation as all the material that was collected will have contributed to the patterns that are discerned.

It is also important to consider how this information is presented to participants and how options are negotiated. Our suggestions are:

- Researchers need to enter into careful dialogue concerning any potential positive or negative consequences (some of which only the participants would know), which is then later recorded (e.g., on a signed form or other written confirmation).
- Researchers could consider ongoing consent options. This allows for participants to change his/her/their anonymity/confidentiality status without changing his/her/their participation in research and/or services offered if the research is about services.
- Researchers may also pilot consent forms to iron out any difficulties that might arise.

When critical epistemologies and methodologies are novel to ethics committees, the standard protocols may be enforced more than is usual and the risk of rejection may be high as is evidenced by Rice and Mykitiuk (2018, this section) as well as by Marx and Macleod (2018, this section). Authors in this section suggest a range of ways in which critical research ethics protocols may improve upon traction, in particular regarding questions of anonymity, confidentiality, and safety. Rice and Mykitiuk (2018, this section) contend that it is contingent upon researchers to introduce critical theory into the writing of ethics protocols. In other words, researchers need to do the work of convincing reviewers through theoretical argumentation. While this is certainly a productive avenue, teachers of critical theory know that a single reading is seldom sufficient to induct readers into the complexities of critical theory or ethics. Placing the burden on critical researchers of convincing ethics committees of the merits of critical research is inequitable given the ease with which non-critical methods, particularly experimentation, are readily accepted and perpetuated. Marx and Macleod (2018, this section) go further, suggesting that ethics committees should include reviewers who are au fait with critical theory and are, hence, able to engage with the nuances required of thinking through the ethical complications that may arise.

Conclusion

Students are often introduced to the histories of unethical research studies that involved harmful participation. Guidelines such as the Belmont Report emerged in the context of such legacies in human research. As a result, ethics protocols require that researchers indicate an awareness of potential harm prior to undertaking fieldwork. Protecting the identities of participants is one of the key requirements in standard protocols. This section presents a number of cases in which researchers outline the limits imposed by automatic anonymisation of participants and question the effects of confidentiality. While a few cases draw attention to the difficulties in ensuring complete anonymity, a number of authors also consider what happens when identification may be desired or welcomed. For researchers working from indigenist, feminist, queer, and dis-ableist perspectives, visibility presents both challenges and opportunities when participants have experienced historically, and continue to experience, a silencing of narratives. The chapters in this section, therefore, point to the necessity of continually re-thinking and revising how researchers construe ethical practices around anonymity and confidentiality within institutions that set parameters as well as for researchers who are actively engaged in fieldwork.

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16

To Be or Not to Be…Revealing Questions of Anonymity and Confidentiality

Thirusha Naidu

Identity and acknowledgment are intrinsic to self-esteem, self-concept, and recognition as a person in society. The concept of anonymity in social and health research is closely linked to those of identity, confidentiality, privacy, and protection (Novak, 2014).

Remarkably, anonymity and confidentiality are rarely contested in ethics in qualitative research (Baez, 2002; Kaiser, 2009; Saunders, Kitzinger, & Kitzinger, 2015; Tilley & Woodthorpe, 2011). A well-established convention is for researchers to pre-emptively assure participants of anonymity by concealing their identities, and to guarantee confidentiality by keeping the information secret that they share in the course of the research process (Svalstog & Erikkson, 2010; Walford, 2005). This practice is so entrenched that it is referred to as the 'convention of confidentiality' and is maintained primarily as a method to protect research participants from harm (Baez, 2002, p 35; Kaiser, 2009).

As research practices change in response to contexts, emerging methodologies produce challenges, and therefore traditional ethical conventions must be revisited. This may be driven by the realisation that current ethical norms regarding confidentiality and anonymity in research are significantly influenced by biomedical ethics and may not be transferable to qualitative research (Taylor, 2015; Tilley & Woodthorpe, 2011; Van Den Hoonaard, 2003). This chapter considers issues pertinent to the separate but related ethical elements of anonymity and confidentiality in social and health research. In these

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discussions, I draw on my experience of three separate studies: one clinical case study and two community group research projects.

Delineating Anonymity and Confidentiality in Critical Social and Health Research

Confidentiality refers to information and anonymity refers to identity. Confidential information is secret information which is entrusted on the understanding that it will not be divulged to a third party (Cain, 1998; Giordano, O'Reilly, Taylor, & Dogra, 2007). Anonymity refers to personal identifying details of research participants and groups. In quantitative studies as well as qualitative studies conducted with groups, anonymity is often paired with confidentiality. It is rare for participants to question how researchers plan to keep information confidential or what elements of the information provided will be kept confidential. What researchers are really promising participants is that the information will be published but will not be linked to them personally and therefore cannot cause personal harm. This works especially well in survey research wherein participants are not required to provide any personal identifying information (Lelkes, Krosnick, Marx, Judd, & Park, 2012). In fact, the researcher or author of the publication may never have any personal contact with the participant if fieldworkers conduct the survey or if it is conducted online.

The issue is more complicated when there is a single research participant, organisation, or group that is the subject of study. Traditional or external confidentiality, in which the information and identity of participants are not identifiable to the research community or an external audience, is unlikely to be breached and thus result in harm. However, ethics committees do not reasonably address the potential breaches that may result when participants are recognised via data presented to their own group or community through deductive disclosure. This is particularly relevant when participants have experienced unusual life events or are members of small communities, marginalised communities, or closed groups. In such instances, study participants may be recognised or even misidentified as a result of certain specific types of information or the way in which information is presented and organised in the published work (Helbok, 2003; Kaiser, 2009; Le Roux, 2015).

As participants become informed of their rights in the research arena, they are inclined to question and disrupt long-held standards of their roles, voices, and identities as they transform from participants to potential collaborators and even co-researchers. The latter refers to the practice of co-operative inquiry when all those involved in the research are viewed as co-researchers, participating, shaping, and contributing to the activity that is being researched (Reason, 2002). This chapter considers these issues in the light of three fieldwork examples. In the first, a clinical case study, the participant requested that her real name be used in the paper (Naidu & Shabangu, 2015). The second and third examples comprised two related case studies of community-based groups in which significant questions of anonymity and group identity emerged.

Do No Harm, or, Respect for Persons? Ethics in Clinical Case Study Research

In this section, I discuss how the dilemma of harm versus respect for persons may be encountered in clinical case study research. I present the case of Buhle (pseudonym) who requested that her name be used in the write-up of her therapy. I discuss the issues of anonymity and confidentiality in relation to case studies in general, as well as the ethical principles that apply in thinking through these issues in relation to case studies.

Buhle 'Please Use My Real Name'[1]

Buhle was 18 years old when she was referred to the clinical psychology clinic by her orthopaedic surgeon. She was diagnosed with a condition that required spinal surgery. However, when attempts were made to sedate her in preparation for surgery she became extremely anxious. Despite her condition being potentially disabling in the long term and, at the time, extremely restricting for her in daily life, she was resistant to surgery. Part of the reason for this was that her family was concerned that the surgery was so dangerous that she would not survive it. Buhle's reticence was intensified by her adolescence and her collective cultural values (Tan, Passerini, & Stewart, 2007). Buhle's family had significant influence over her decisions. Her collectivist cultural norms implied that decisions about her health would need to be made through family consultation as they would impact on the spiritual well-being of the entire family through the connection and communication the family had with the ancestors. The ancestors collectively have influence over and protect all their descendants of which Buhle was one. Mkhize, Mathe, and Buthelezi (2014) note that current ethical conventions in clinical practice are dominated by Western paradigms. The latter place individual wishes and personal autonomy over in-group or kinship consultation which is different from Southern- and Eastern-influenced epistemological paradigms which tend to have more collectivist leanings (Jonas, 1996; Mkhize et al., 2014).

Buhle was referred to the psychology clinic for therapy and was seen first by an intern clinical psychologist and then by the author, a registered clinical psychologist and supervisor. During the initial stages of therapy, we realised that Buhle wrote poetry. This was incorporated into the therapy process and her poetry was used to track her progress in therapy. She was asked to write poetry to express her thoughts, feelings, and experiences regarding her health. Her poems were used as a basis for her therapy. The therapy was successful in reducing her anxiety to the extent that Buhle underwent surgery and made a good recovery. The method of using poetry in therapy in health psychology was fairly unusual as was the quality of Buhle's poetry so we decided to publish an account of the case as a clinical case study (Naidu & Shabangu, 2015). Informed consent was obtained and Buhle was assured of her anonymity and the confidentiality of her story. We ensured that Buhle was kept abreast of the entire process leading to publication. This included Buhle's approval of her pseudonym, and she read and approved final drafts of the manuscript.

Buhle was pleased with the final manuscript but questioned the use of a pseudonym and expressed the wish that her real name be used in the publication. This is consistent with recommendations for case study research where consent is genuinely informed by reviewing it at different stages of the project (McCleod, 2010). Buhle wanted the opportunity to have her poetry published and to be known for her work. I explained that using her own name would allow her to take credit for her poetry, but this would also mean that other information about her medical and psychological condition would become known. Although waiving anonymity seemed to be a good idea at the time, she might regret it later. She was considering a career in the corporate sector and the fact that she received psychological treatment for anxiety would be freely accessible to future employers and colleagues in the age of digital communication and social media. Psychological diagnoses and treatment continue to be stigmatised in general and particularly in corporate environments. I was not convinced myself because it seemed unfair and exploitative that I was using her poetic works but not allowing her the credit by my assuming that she would be harmed by it. Anonymising the participant though she wants her identity revealed is effectively denying her recognition for her story (Kelly, 2009).

As a researcher, I felt disempowered by the fact that if I conceded to Buhle's request I would have to explain to the ethics committees (at the university and the provincial Department of Health) why I chose to create conditions that could potentially harm the participant. Considering recent increases in malpractice litigation in South Africa, it is possible that these restrictions have more to do with protecting the institution from possible litigation than protecting the client or participant from harm (Seggie, 2013). Nevertheless, denying her request to forego anonymity deprived Buhle of the opportunity of gaining credit for her work and suppressed her autonomy and voice, both of which raise other important ethical issues. In an attempt to alleviate this, I suggested to Buhle that it was entirely up to her to publish her poetry under her own name at some time in the future. This again posed the problem that cross-referencing her poetry in an internet search would yield the paper published about her treatment and thus associate her with her personal and medical information. Inherent to the concern that Buhle's identity would be revealed is the assumption that her identity being discovered or inadvertently revealed could result in potential harm to her. The reality is that this could just as easily benefit Buhle, and by concealing her identity, we were denying her the possibility of being recognised and admired for her poetry. Finally, we decided to publish the chapter using a pseudonym and would leave it to Buhle to publish the poetry if she wished. This would at least acknowledge her agency in accepting whatever the outcome would be.

Neither Buhle nor I had the power to decide whether her real name should be used because institutional ethics committees mandated the application of anonymity and confidentiality when using clinical material in research. The standard exemplar for the informed consent document issued by the University Ethics Committee guaranteed anonymity and confidentiality. Ethical clearance was also obtained from the Department of Health which similarly mandated anonymity in the publication of clinical case material. Ethical clearance to publish the case material would not be granted if anonymity was not assured. Ethics committees tend to make the assumption that there will be an assurance of blanket anonymity and confidentiality as the limits of confidentiality are rarely explored in research documents or in discussion (Cain, 1998; Guillemin & Gillam, 2004; Lelkes, Krosnick, Marx, Judd, & Park, 2012). As indicated earlier, blanket anonymity, which is the policy of never publishing names, may be delusory and perhaps more damaging than negotiated or contested anonymity (Clark, 2006; Gerver, 2013; Moore, 2012).

Researchers in the field favour a nuanced view of anonymity and confidentiality, arguing that in practice ethical issues might realistically be described as processes rather than as events. Guillemin and Gillam (2004) distinguish between 'procedural ethics', presented to ethics committees before research is conducted and 'ethics in practice' which are negotiated in situations that are 'difficult, subtle, and unpredictable'. They assert that researchers' competence of 'ethics in practice' is tested in performance through a willingness to recognise and acknowledge ethical dimensions in the 'micro-ethical' (Guillemin & Gillam, 2004, p. 262).

Anonymity and Confidentiality in Clinical Case Study Research

In case study research, the researcher often establishes a more personal connection with participants than in survey research as participants often share deeply personal and generally private issues with the researcher (Yin, 2014). Data in case study research pertain to a specific person, group, or organisation usually selected for its uniqueness. These issues of depth and specificity make the tasks of anonymity and confidentiality increasingly challenging for the researcher as readers may be able to identify the person, group, or organisation. While careful anonymisation processes may make it possible for the participant/s to remain anonymous in case study research (Clark, 2006), the very nature of this kind of research means that in some instances it is not possible for information to be kept confidential. The key question in this regard is: does the researcher, by revealing confidential information, inadvertently forego anonymity despite promising this to the participant? For example, the researchers' contact with Buhle resulted from the uniqueness of the course and content of a therapeutic intervention. Researchers had a wealth of specific and in-depth data about her which had to be carefully considered to maintain confidentiality whilst giving an authentic account of the case.

Case studies provide invaluable teaching and research opportunities for clinicians and remain a mainstay of the apprentice-based model of practical clinical training (Pies & Kantrowitz, 2011). Clinical case studies have been used for a long time to inform and teach clinicians about the detail, subtleties, nuances, and contextual issues (personal, social, cultural, religious, etc.) that emerge in clinical case studies and yet these remain elusive in theoretical papers and other research formats. When a case study begins as a clinical case and is then written up for publication by the treating clinician, a double bind emerges, presenting clinicians with multiple challenges (Blake, 2011; Osipov, 2011; Pies & Kantrowitz, 2011). In clinical case studies, clinician-researchers must weigh up the additional ethical, legal, and moral obligations of being a clinician against those of being a researcher (Blake, 2011; McCurdy & Fichett, 2014; Miola, 2008). For example, we had a contractual relationship with Buhle which ensured confidentiality in the therapeutic relationship. In taking the decision to use the case in a publication, the confidentiality of the relationship had to be renegotiated with Buhle. Her personal information would be available to others to read. We had to consider carefully how to ensure that she remained anonymous, whilst concurrently telling her very personal and unique story.

Where the clinical case study involves a participant with mental health issues, considerations pertaining to emotional vulnerability, potential stigma, and exploitation become relevant. The clinician, as researcher, may require the client to provide informed consent to participate in a study, yet this is often the very person who is called upon to make assessments of the client's competence or judgement in order to consent. In providing informed consent for case material to be used in publications by their therapists/clinicians, clients who then become participants have to consider possible stigma, the obligation to comply, and the implications of a continuing relationship with the clinician. As much as stigma should not exist, psychologists and psychiatrists have to acknowledge the reality that stigma against mental illness does persist. Buhle was a young woman who had a corporate career planned. We could not predict what level of stigma she might encounter in a corporate environment and how revealing her identity and personal information might stigmatise her.

Anonymity is a well-established principle that has, for the most part, gone unquestioned. When confidentiality is added to the equation, complexity arises. How may a researcher include relevant information without inadvertently revealing the client's identity, and thereby breaching confidentiality? As indicated earlier, case studies typically contain unique information, thus creating the possibility that the subjects of the case study may be identified when that information is presented (Osipov, 2011). It is not uncommon for researchers to modify the content of case material to avert this risk (Baez, 2002; Blechner, 2012). This practice, however, may be seen to be tantamount to falsification of data and has the potential to create further ethical transgressions of the principle of autonomy by making the client feel as if she/he has been misrepresented by causing offence or by altering or destroying the original meaning of the data (Blechner, 2012; Kaiser, 2009). McCleod (2010) recommends routinely changing identifying information relevant to the case and provides ten explicit recommendations to guide ethical process in clinical case study research. Here, I present how I considered these guidelines in relation to the case of Buhle:

1. The ethical codes of the professional group (clinical psychologists) of the authors were adhered to.
2. Ethical procedures were transparent, were made clear to Buhle, and details were provided in the publication.

3. Institutional ethical clearance was obtained.
4. Ethical clearance was not obtained at the commencement of therapy because the therapists did not plan to publish the case until after it became evident that the content and process were unique.
5. The alternative consent procedure to obtain consent after the commencement of therapy was approved by the ethics committee.
6. Informed consent *was* possible so independent expert consultation to audit all aspects of the inquiry process was not required.
7. Buhle had the opportunity to read and comment on successive drafts of the manuscript.
8. Buhle was offered ongoing support from the researcher/therapist and independent parties following the publication of the study.
9. The therapist *was* the author of Buhle's case study and therefore did not have to undergo a similar informed consent process as did Buhle.
10. The authors as therapists engaged in ongoing supervision with two colleagues to examine personal factors associated with the case study.

A sensitive balance between preserving the richness of the data while also protecting participants must be maintained in qualitative research. This might involve elaborate anonymisation and confidentiality strategies that are contextually contingent. This involves considering anonymisation in six different categories: people's names, places, religious or cultural background, occupation, family relationships, and other potentially identifying information. Idiosyncratic details that could identify the participants also might be altered to preserve anonymity (Saunders et al., 2015; Ummel & Achille, 2016).

Ethical Principles Applied to Case Study Research

In the case of Buhle, the main question that arose was whether her identity could or should remain confidential in the light of her request for her identity to be revealed. As a result, several related and intertwined ethical questions emerged. Who decides on whether a research participant's identity should remain concealed? What does this suggest about the power dynamics between researchers and participants? Reflecting on the underlying principles of ethics viz., beneficence, non-maleficence, autonomy, and social justice, it is evident that the prescription of anonymity and confidentiality in research with human subjects is based largely on the principle of non-maleficence. The principles of autonomy, beneficence, and social justice are cited less often in relation to anonymity (King, 2006). This supports the idea that ethical principles are not always balanced appropriately. In Buhle's case, I questioned whether concealing her identity in fact impeded her autonomy. Here, the principle of non-maleficence needed to be weighed against autonomy. Where participants exercise agency in choosing to reveal their identity, the ethical principle of autonomy might be particularly relevant. Autonomy is related to agency and based on liberal-humanist views of self-determinism. There are instances when visibility might be ethical (Gibson & Brown, 2009), such as in the case of Buhle who could gain credit for her poetry and her own role in her recovery if her identity were revealed.

Another ethical convention that places the principles of non-maleficence and autonomy in conflict is that the researcher is charged with actively predicting and preventing harm which may result from participation in the research. The tacit assumption is that the researcher has the requisite knowledge that could potentially result in harm, not only of her own research study but of the participants' context and conditions (Vainio, 2012). While it is often cited that these precautions should be reasonable, the assumption is that the reasonable party is the researcher and not the participant (Mondada, 2014; Moore, 2012; Svalstog & Erikkson, 2010). The dominant assumption in academia is that in waiving their right to confidentiality and anonymity without being fully aware of how they will be represented, participants take the risk of exposing themselves to a multitude of harms ranging from shame and embarrassment to stigma, being ostracised, and even legal action. In favouring anonymity and confidentiality in research, the corresponding assumption is that researchers will represent participants' voices and stories honourably (Mondada, 2014; Moore, 2012; Novak, 2014; Woodhouse, 2012). The assumption is that human subjects possess a unique rational consciousness enabling them to make independently logical and informed decisions. What then of social discourse, ideology, and heterogenous forms of power that impact on and shape this rational consciousness?

There seems no ethical way to investigate a clinical case without patient approval (Cheit, 2014). However, it has been suggested that if sufficient time has passed between treatment and reporting, the clinician may report case material without express permission from the client, provided that no identifying material is used in the publication. In this case, it may be left to the discretion of relevant institutional ethical review boards to grant proxy permission. Here, the ethical principles of beneficence and social justice may be applied where unique or important clinical information, if published, could benefit others and would be for the greater good. Obviously, there is great potential for exploitation with sensitive case material and, in the case of mental health research or clinical mental health practice, the risk of ensuing social, psychological, and emotional harm to patients. Nevertheless, this must be weighed against the acknowledgement that mental health research owes much of its foundation to case study research, especially in disciplines such as psychology and neuropsychology. In the case of Buhle, the novelty of the treatment method could justify publication if the principle of beneficence is applied, in that others could benefit from using and experiencing the approach. The persistence of issues of anonymity and confidentiality in the literature alludes to the gravity with which researcher/clinicians hold the issue of writing about their patients. Conditions and contexts of case study research fluctuate. Therefore, researchers must constantly re-evaluate ethical challenges in collaboration with participants during the research process.

Research Ethics As a Social Practice or Biomedical Convention?

Revealing the names of groups can also be complicated as group members' identities or information about individual members of the group may emerge. Nevertheless, there is less likelihood of this than there would be by revealing the identity of a single case study participant. This section examines how I considered anonymisation in relation to two different groups.

I Am Them and They Are Me: Anonymity and Group Identification

In the first community-based fieldwork example, I conducted a narrative study exploring caregiver identity in a group of community-based HIV and AIDS caregivers.[2] The group chose a distinctive name that was linked to the group identity. Part of the interview process included exploring individual caregivers' ideas about what the meaning and implications of the group's name was as well as how they related to this identification as individuals.

I spent some time in the writing up of the research by considering the implications of revealing the name of the organisation. The name was intrinsically related to the group's identity, practices, and motivations (Naidu, Sliep, & Dageid, 2012; Naidu & Sliep, 2011). The group members gave no indication that they wanted the group's name concealed. In this case, to offer group members anonymity was relatively unproblematic as none requested that their individual identity be known, and so the issue was related to group, rather than individual, identity.

One of the issues that the group faced at the time was that they were not being consistently paid for their work. Revealing the group's name and highlighting the importance of their work could result in their lobbying local government for remuneration; even so, individuals would retain their anonymity. This is consistent with what Mkhize (2006) describes as a communal approach, whereby knowledge is not imposed but is constructed socially and communally through negotiation. Giving the community the chance to recognise its role offered the opportunity to maintain social equilibrium (Mkhize, 2006). Revealing the group's name could provide the advantage of the group being recognised over other similar groups in the community and could increase the likelihood of acknowledgement and remuneration. I eventually proceeded by revealing the group's name on the basis that it was intrinsically linked to its work and identity (Naidu et al., 2012).

In another study I undertook with community-based caregivers who were part of a non-governmental organisation (NGO) that relied on private fundraising and international volunteers to develop its resources and skills, the situation was quite different.[3] Here, the dilemma was that my co-researcher and I were specifically asked to make the name of the organisation known. The organisations' members chose to do this, firstly, because they took great pride in its work in making the organisation's structures, processes, and activities transparent. Secondly, the profile-raising consequence of being the subject of academic research could favour attracting potential funders. During the research process, as we visited to observe and participate in activities and collect data, we were featured in and asked to write articles for the NGO's online newsletter which was being sent to current and potential funders, patrons, volunteers, and visitors. As part of the research output, we produced two videos to describe the work that was done and to explain the research processes that were used. We shared these videos with the NGO that then posted them on its website. Music on the videos included choral music from a CD that was produced and sold by the organisation as part of a funding initiative. We assured the members of the NGO that we would use their name at all presentations and events at which we presented the work conducted on their organisation. It was disconcerting at first as I felt as if we were exposing the group to the world. However, this highlighted for me the inequity and absurdity in using blanket or default anonymity and how even I as a researcher had allowed myself to be persuaded into believing that this was a gold standard in ethical positioning (Svalstog & Erikkson, 2010). The university ethics committee was not consulted on this issue out of deference to the members of the group. The researchers took the position that to consult the ethics committee to grant permission to allow the participants to reveal their identity would dishonour the participants' spontaneous and explicit choice for their identity to be revealed. There have been no repercussions from this thus far.

Resolving Reflections

Anonymity and confidentiality as influenced by the Western hegemonic ideal of privacy may be seen as having protective value. This view makes several sweeping assumptions which might be questionable in contexts in which collectivist practices predominate or even in specific groups in individualist contexts. In the research studies in this chapter, I discovered that, in some instances, community-based groups seemed less concerned about having their identity revealed than they were about the benefits they potentially receive from being known. In a frame dominated by Western ideas of privacy, the researcher is expected to offer the assurance that she will not reveal the participants' or groups' identities or any information that was shared in the research process that might cause harm to the participants. This assurance must be offered despite the researcher having limited control over others (community members, relatives, etc.) in the social contexts in which the research occurs. Moreover, it is based on the assumption that the group or participants will want to remain unknown and will not insist upon an opportunity to be heard. Indeed, it is interesting to consider whether anonymous participants feel heard or not despite having had the opportunity to speak. In fact, my asking about anonymity was irrelevant; despite my assumption as a researcher that anonymity is desirable, the participants, having their own goals and wanting to be heard, could have found my offer counterproductive.

Ethical processes abstracted from corresponding social settings shoulder the mantle of 'empty ethics' (Corrigan, 2003, p. 768). Preserving the richness of data and protecting participants is the eternal challenge in qualitative research (Corrigan, 2003; Saunders et al., 2015). I had to wonder as a researcher whether I was protecting the participants in my studies from real or imagined dangers with which, apparently, they were not concerned at the expense of their gaining from the research what was really important to them. Certainly, this is an instance wherein blanket anonymity would not apply, and I needed to respond in a contextually contingent manner (Gerver, 2013; Saunders et al., 2015).

It is increasingly evident that anonymity and confidentiality need to be closely re-examined for their application in critical social- and health-related qualitative research. Traditional expectations of default or blanket anonymity and confidentiality rapidly unravel in the face of qualitative research practices in social and health contexts. I came to realise through engaging with Buhle that my integrity as a researcher was not based on blindly following conventions but by listening carefully to the patient as participant and on a consideration of her expectations of the research process. Through working with the community caregiver groups, I was reminded of the importance of considering the context in which anonymity is offered and whether this serves or disregards the participants' needs and intentions (Naidu & Sliep, 2011). It might be that offering anonymity and confidentiality in case study and small community research is unethical as this proffered anonymity and confidentiality is largely unattainable. The nature of researcher-participant relationships, forms of information being exchanged, the contexts, conditions, and practices under which the research is conducted preclude guarantees of secrecy. Nevertheless, internal review boards (IRBs) and institutional ethics committees continue to promote anonymity and confidentiality practices.

Critical engagement is called for in deciding whether, how, and when anonymity and confidentiality are applied in qualitative research. Anonymity and confidentiality should not be negotiated only with research participants. As in the case of Buhle, it should be done iteratively and then constantly renegotiated with consistent reference to multiple dimensions of context throughout the research process (McCleod, 2010). Participants too have elevated their voices, claiming recognition, acknowledgement, validation, and authentic rather than nominal participation in research practices and publications (McCleod, 2010; Reason, 2002). Whilst this critical engagement and the ensuing transformative practices may seem overwhelming, untenable, and even unethical to traditionalists, it might be that this destabilising of the researcher as patriarchal gatekeeper speaks to a levelling of unquestioned tacit power differences between researchers and their subjects. Rather than offering only default yet ephemeral anonymity and confidentiality under the rubric of informed consent, it would be more realistic for researchers to negotiate boundaries for revealing identity and information under the rubric of informed disclosure.

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Notes

1. Ethical clearance from University of KwaZulu-Natal Biomedical Ethics Research Committee BE122/14.
2. Ethical clearance from University of KwaZulu-Natal Humanities and Social Sciences Ethics Committee HSS/0504/090.
3. Ethical clearance from University of KwaZulu-Natal Humanities and Social Sciences Ethics Committee HSS/0186/014.

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17

Cripping the Ethics of Disability Arts Research

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Negotiating artistic research within university strictures reveals a number of tensions: tensions around what we reveal and what we conceal, who we are as researchers and human beings, and tensions related to offering anonymity and confidentiality while giving due credit. As feminist academics committed to social justice, we struggle to negotiate these tensions in a way that prioritises the needs and desires of participants. We also recognise that institutions require researchers to conduct our research in particular ways. Rules and regulations about ethical conduct developed out of a desire to protect participants and researchers (Gray, Cooke, & Tannenbaum, 1978); in practice, however, they often leave us wondering about whose interests they serve and how they shore up boundaries between who is researcher and who is participant in research contexts.

In this chapter, we engage with tensions that arise between following university ethics protocols and co-producing research with participants, in particular, artists with disabilities (including mobility, sensory, psychiatric, cognitive, learning, illness related, and more). We offer two case examples to illustrate complexities of voice, anonymity, and confidentiality. In these examples, we explore: (a) occasions when standard Research Ethics Board (REB)

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protocols regarding anonymity and confidentiality contravene participants' desire for recognition as artists; (b) processes of consent, including the possibility of conceptualising consent as continuous and in flux; and (c) issues of voice, representation, and aesthetics in the production of arts-based research. These case studies emerge from our work at Re•Vision, an art and social justice research centre at the University of Guelph in Canada, in which we conduct multimedia storytelling workshops and have co-created a research-based drama, *Small Acts of Saying*, with non-normatively embodied and enminded research participants.

Our work is necessarily embedded in institutional histories in which disabled body-minds have been put on display or hidden away (Rice, Chandler, Harrison, Liddiard, & Ferrari, 2015); we found that in this context, participants may not always desire anonymity and confidentiality and may prefer contingent and continuous processes of consent in which they co-determine the time frame, space, and audience for their art. We do not offer definitive or universal solutions to those ethical conundrums we have encountered, in fact, we hesitate to provide prescriptive instruction for fear of inscribing fixity for necessarily fluid processes. Instead, we discuss how to move beyond 'tick-box' approaches to working ethically with disability communities. We adopt a disability justice perspective which we understand to mean being led by people with disabilities, pushing against ableist practices/representations/systems in our work processes/outputs, and 'cripping' or attending to and embracing the difference that disability makes to ethical decision-making in artistic research (Chandler cited in Reid, 2015, para 7). Cripping ethics, as we understand it, involves orienting to disabilities, not as differences that delimit or confound ethical processes but as complex embodiments, including visible and invisible mind-body attributes, which, through challenging normative standards of the human undergirding conventional ethical frameworks, expand possibilities for ethical conduct by opening the field of decision-making in research. In this way, our discussion provides a jumping-off point for further exploration of the meaning and implementation of 'cripping' ethical principles in and beyond academia.

Re•Vision

Re•Vision, an assemblage of arts-based research projects led by Dr Carla Rice, is an initiative funded by the Canadian Institutes for Health Research (CIHR) and is designed to speak back to dominant representations of disability using arts-based methods, including multimedia storytelling and research-based drama.[1] Throughout the CIHR project, people with disabilities and healthcare providers (not mutually exclusive groups) created over hundred 2–5 minute films about their experiences. Participants made films at workshops in which we worked together to generate stories that centred on the makers' voices. We adapted our workshop structure from StoryCenter's method of bringing people together to tell their stories using a digital format (Lambert, 2013). Additionally, Re•Vision incorporated facilitator trainings, wherein disability-identified individuals were trained in workshop facilitation; these facilitators then led subsequent workshops, including healthcare providers as participants. By making their own self-reflexive films, researchers themselves became research participants; some also identified as members of Disability Arts communities beyond Re•Vision.

As Re•Vision's work progressed, an emphasis on Disability Arts and on incubating the Disability Arts community emerged (Chandler et al., under review; Rice, Chandler, Liddiard, Rinaldi, & Harrison, 2016). Filmmakers and facilitators often came from, went to, or created Disability Arts communities before, during, and/or after their engagement with Re•Vision. Disability Arts communities comprise self-identified D/deaf, Mad,[2] and disabled people creating art, often but not always about the experience of disability; these communities move beyond a social model of disability, and they advocate primarily for the removal of barriers by advancing the participation of people with disabilities as producers, creators, audience members, and participants in artistic work, and in the creation of a disability culture (Chandler et al., under review). Project films have been screened for audiences ranging from healthcare providers to film festival attendees at arts festivals and in community theatres, in classrooms, and at conferences.

Thematically, the films challenge dominant medical models and representations of body-mind difference, including the troubling legacy of the spectacalisation of disabled bodies in reference textbooks and as cases for experimentation and medical fascination (Garland-Thomson, 2007). They engage with storytellers' preferred perspectives on and representations of their lives. Healthcare provider stories similarly challenge dominant narratives, due in large part to disabled people's leadership, facilitation, and encouragement of providers to explore the role that mind-body difference plays in their own lives (Rice et al., 2015).

Re•Vision also developed a research-based drama *Small Acts of Saying*. The play was an ensemble performance designed to challenge accepted notions of disability that create healthcare barriers. Based on the devised theatre method (Milling & Heddon, 2005), the play was developed collaboratively by a disability-identified director and disability/difference identifying Re•Vision participant-performers. Performed for several audiences in the Northern hemisphere during the Fall of 2014, the play treated themes of embodied knowledge and reimagined 'accessibility' in the healthcare context.

Arts-Based Research

Broadly, arts-based research incorporates methods that integrate artistic expression into the building of the understanding of phenomena. Arts-based methods are often conducted in a community-facing, participatory manner, in which artists and participants either train in research processes or otherwise work in close proximity with researchers to enact research (Rice & Mundel, forthcoming). In our case, we also troubled the boundaries between researchers and researched, inviting researchers to become implicated in the creation of art and engage in self-reflexive artistic practices. Participatory arts-based methods, like other community-based/participatory research methods, have in common a commitment to re-envisioning 'expertise' and challenging researchers to work *with*, rather than *on* or *for*, participants (Israel et al., 2003). They do so by conceptualising research processes as being equally as important as research outcomes; creativity and flexibility are valued in these methods (Boydell, Gladstone, Volpe, Allemang, & Stasiulis, 2012). Arts-based research has the possibility of creating social change in and beyond the groups that conduct this research; the processes and products are commonly emotionally evocative and act as creative explorations of what it means to live in the world and in a body in a particular way (Finley, 2014). Doing research in this way allows us to explore spaces in between how participants have been imagined by others and how they would prefer to imagine themselves (Rice, Chandler, & Changfoot, 2016).

Multimedia storytelling is an arts-based method that has been used in educational contexts and research spaces (LaMarre & Rice, 2016; Rinaldi et al., 2016). It invites participants to tell their stories in a flexible multimodal medium; participants give voice to their stories, while simultaneously visually imagining them. The method opens up space for stories without words, stories that operate on multiple sensory registers, and stories that leave us wondering. They invite participants to 'speak from the flesh, to create and represent through the flesh and to construct and interpret their identities in mind and body' (Benmayor, 2008, p. 200). Participants do not make stories in a space devoid of social meaning; however, stories are created for an audience in a time and place. Accordingly, just as these stories carry with them individual and social histories, so too do they carry the spaces that surround their creation. Tensions of voice and purpose in storytelling have surfaced in our prior explorations of the impacts of the method on participants and audiences alike (e.g., Mykitiuk, Chaplick, & Rice, 2015).

Case Study 1: Ethics of Confidentiality, Anonymity, and Acknowledgement

Many, though not all, of the workshops conducted through Re•Vision included participants who self-identified as artists either before or after the workshops. Some participants are self-identified artists and/or curators of disability arts; they bring works of art from where they are created to where they are viewed, moving from the (relatively) private sphere of artistic production to the public sphere of artistic viewing. Curation involves 'bring[ing] different cultural spheres into contact' (Obrist, 2014, p. 24). In so doing, curators disrupt the gaze as it has been traditionally imposed upon people with disabilities who have been seen as spectacles or as examples in medical contexts and elsewhere (Rice et al., 2017).

The importance of the curatorial tradition within the disability context cannot be overstated, in terms of both the ability to select and to portray certain aspects of self and to choose which aspects of bodily self to display (and to whom). Even, or particularly, when disabilities are not visible, the display/portrayal of complex embodiments and enmindments is an act of curation and is often socially governed by someone other than the person with the disability. A biomedical brush paints disabilities as: abnormalities, conditions requiring intervention and cure, and aberrances caused by defective biology. In medical textbooks, people with disabilities have been used as examples of 'rare' or 'abnormal' conditions; as 'befores' on the way to 'fixed' or 'cured' body-minds; or as examples of the incurable, the tragic, or the diseased (Garland-Thomson, 2012). Disabled bodies were (and still are) displayed in parts: faces covered with black boxes, identities concealed under the auspice of ethical conduct. This dehumanised representation of disability in which people are reduced to the parts of their body-minds deemed defective, resembles the spectacalisation of disability beyond the clinic or medical text, in historical 'freak shows' and contemporary mass media alike (Sandell, Dodd, & Garland-Thompson, 2010), a representation that people with disabilities, including artists, have actively challenged. As Gay, with Fraser (2008), writes: 'Disabled people throughout the world are engaged with a long and complicated struggle with the way we are portrayed and the meanings attached to these portrayals that include disability as stigma, as a sign of a damaged soul, as being less than human, as dependent, weak, sexless, valueless' (p. 21).

Many participants were troubled by the idea that to be included in Re•Vision's work they needed to adopt a pseudonym or have their identities concealed. This is not surprising, given the entwined legacies of being put on display or hidden away in institutions and homes with which disabled people have had to contend (Rice, 2014). Often, creators preferred to use their real names and to own the artwork produced. Particularly when films were screened at film festivals or art shows, participating artists asserted their unquestionable right to be recognised for their work and some took up leadership roles in curation in more than a conceptual sense.

Revealing storyteller identity is 'a central aspect of making a political statement about a group', an especially salient task when those making the art are from misrepresented communities (Mykitiuk et al., 2015, p. 379). This is also an important part of reconfiguring roles in research encounters or at least attenuating asymmetrical power relations between researcher and researched. The job of defining boundaries between researcher and researched and establishing the overall direction and meaning of the project traditionally falls to the researcher (Scantlebury, 2005). Researchers working from feminist/critical perspectives commonly attend to power dynamics in research relationships by working to facilitate participant comfort with data collection protocols and by working relationally (Blodgett, Boyer, & Turk, 2005). Researchers oriented towards community-based methods often work actively to share power, inviting participants to help decide on research directions, questions, and analysis (Banks et al., 2013). In Re•Vision, participants and researchers were not mutually exclusive categories: researchers became participants and participants became researchers at various stages of the research processes. Still, we were conscious of the multiple roles we brought into the space; power distribution remained unequal despite our 'cripping' of the roles of researcher and researched.

Arts-based research carries its own set of ethics considerations, including authorship, ownership, interpretation, and aesthetics, as well as more standard ethical considerations like informed consent, anonymity, and confidentiality, and the emotion that might emerge from the conduct of research (Boydell et al., 2012). The issue of artistic ownership and acknowledgement is particularly relevant to Re•Vision artist-participants and has surfaced in and after our workshops. Lafrenière, Cox, Belliveau, and Lea (2013) question the ultimate ownership of artistic research: is a piece produced by an artist in the cadre of a research project an artistic product or a research output, or both? Who might be credited, and whose CV and career does the production enable? Boydell, Volpe, et al. (2012) offer a solution wherein the artist owns creative research pieces once they have engaged with it; however, this is not an easy stance for all researchers to adopt as some argue that 'protecting' research participants entails minimising artist 'ownership' of 'products' (Lafrenière et al., 2013). These examples, however, apply to arts-based research projects wherein artists engage in knowledge translation/dissemination of previously conducted research, or when the artist is not himself or herself a participant in the research process. In our multimedia storytelling workshops and in the research-based drama, participants were themselves the artists, though the identity of artist itself carries particular complexities, and not all participants conceptualised themselves in that way.

Playing an active role in framing their work was particularly important to those who identified as artists beyond the storytelling space. Filmmakers were eager to add the films to their CVs and to share their work in order to contribute to the growing Disability Arts movement in Canada (Chandler et al., under review). A major part of being seen as more than a spectacle but as a human being with desires, preferences, and occupation, involves being more than a research participant. Given the problematic legacy of conducting research *on* people with disabilities, some artists agreed to participate in the research only because of its artistic components; many brought critical awareness of the ableism typically embedded in research practices and the need to 'crip' decision-making processes. It makes sense, then, that creators, as a condition of participation, would seek to control not only the content of the representations (and the conditions under which they were made) but also their screening and wider dissemination.

Despite our embrace of the disability justice principal that artist-participants have the right to self-identify as artists/creators, research ethics protocols frequently made enacting this commitment challenging. At the beginning of the project, this kind of research was novel for the REB with whom we were working. We went through many rounds of revisions with the REB in finalising our ethics protocols. We were initially asked to do things that were in conflict with our commitments to enact truly cripped ways of doing research. For instance, we were asked to obscure the identities of all people in the multimedia stories, pixelating faces and rendering voices unrecognisable. This REB was using standard ethical guidelines to justify their need to maintain participant anonymity in order to protect against disclosures of participants' experiences to those who might be in a position to impact on their lives in negative ways. Here, the expectation that anonymity would be preserved eerily echoed the legacy that would reduce people with disabilities to 'abnormal' or pathologised body-minds.

Another request that reproduced ableist logics, or re-inscribed the power of the non-disabled researcher and conflicted with disabled participants' control of their representations, was the expectation that researchers would not get to know or develop friendships with participants beyond the workshop space and would not re-contact participants after the project's end. These expectations foreclose the research relationship to the research encounter, conflicting with a deeply held disability justice-grounded commitment to a continual, processual, and dynamic perspective on ethics that is based on relationships, reciprocity, and trust. Because of the problematic legacy of using the stories and bodies of people with disabilities to prop up the careers of researchers and uphold deeply ableist notions of normative humanity, there is a particular need to build reciprocity and trust in research relationships with disability communities. Being unable to re-contact participants subsequently minimises the possibility for building the Disability Arts community and puts the power of decision-making around screening the stories and framing the art into the hands of researchers.

Terminating contact with participants further presumes that participants' stories are fixed and static rather than fluctuating and changing with subjectivities. It minimises the possibility of envisioning consent as an ongoing dynamic process that may change as participants change. While informed consent has been a cornerstone of research ethics, its adoption in conventional research protocols positions the process of obtaining consent as something that is done prior to research contact and closed after a signature has been obtained. When consent is described as a process, this generally extends only to the length of the study; in projects such as ours in which outputs may be screened or performed long after the research has 'closed', we question the need to close consent with study closure. After all, the stories participants tell at one moment may not fit in the future. When this individual is a disability-identified artist practising on ableist terrain, they may assert the need for greater control over which versions of their selves they present through art into the future.

We learnt the rubs between procedural and processual ethics through experimentation and failure. Even with our knowledge of the harms done to those with disabilities in research and our commitment to cripping the process, we did not fully account for the inaccessibility of the ways in which research ethics can be inscribed onto research process. We think it is important to acknowledge how our awareness of the limitations of procedural ethics came partly through our inability to anticipate all possible ethical conundrums that arise in this kind of research. Standard ethics procedures have their place, especially in preventing the more overt or generally acknowledged violations of participants (such as in the now infamous Tuskegee Syphilis Experiment, when researchers withheld critical life-threatening/-saving information from participants). These procedures were designed to avoid *repeating* ethical misconduct and are updated to reflect the ever-changing nature of ethical conduct. Acknowledging the dynamic, ever-changing nature of ethics would be a helpful step towards envisioning a more accommodating ethics process.

Every time participants alerted us to the discomfort they felt with participating in research as prescribed, we learnt new ways of approaching the ethics process that would be open to disability and enable a radical processual ethics. For instance, through failing to account for the need to be able to re-contact participants before screening their work, we learnt that we needed to state explicitly in our ethics protocols that we would offer participants the opportunity to revisit their consent throughout and beyond the project. Through the REB request for pixilation, we discovered that we needed to introduce some critical theory into our research ethics requests, highlighting the history of the representation of disability as an assembly of abnormalised parts rather than a self-represented whole. We continue to grapple with tensions that emerge between participants' preferred self-identification as artists and curators of their experiences rather than as research participants. This unresolved tension leads us to wonder, each time we distribute consent forms to participants, about the process of agreeing to participate in research and what that means for creators in terms of personal risk and perceived safety in research.

Case Study 2: Voice and Staging in *Small Acts of Saying*

Our research-based drama, *Small Acts of Saying*, similarly brought up ethical tensions with which we continue to grapple. Mykitiuk et al. (2015) detail how disabled artists reclaim the stare through talking back to the spectacularisation of disabled bodies and minds in *Small Acts of Saying*; the play explores audience reactions to arts-based research in which artists intentionally put disability on display. In this case study, we reflect on curation in the process of choosing which stories to tell in the context of the play, noting again the performer awareness of audiences and possible readings of their performances. A review by Boydell, Volpe, et al. (2012) offers us a starting point for interrogating the ethical tensions of voice and representation but largely assumes that the creator(s) of the artistic piece and the research participants are different people. Both dynamics operated for us because we had research participants who were performers, as well as a disability-identified director who had directorial discretion in determining the overall aesthetic presentation of the play.

In *Small Acts of Saying,* we wondered about the selection of the stories to be told which were, necessarily, a fraction of the sum total of participants' lives and embodied realities, as well as about potential conflicts between the aesthetic and representational visions of the director and between various storytellers. The play was grounded in the expectation that all people involved would have a role in determining its devising and direction, following the tradition of devised theatre (Milling & Heddon, 2005). And yet, within the tradition of theatre, where the director's job is to lead, some voices are inevitably more dominant than others and aesthetic decisions sometimes conflicted with political positions and research aims.

Here, we see how accessibility requirements might conflict when negotiating voice/vision in the context of research-based drama as well as how aesthetics, research purposes, and researcher/performer politics can arouse tension. For example, the director conceptualised large boxes to signify performers' medical files as a major part of the denouement of the dramatic action. Storytellers moved through space to engage with these boxes. Though the director envisioned the file box as an important part of the play's action, the devise paradoxically imposed normative ways of moving onto some cast members who struggled to carry their boxes. One cast member tripped and fell during a rehearsal. Despite this challenge to normative ways of moving, the director felt strongly about the presence of the boxes for the play's aesthetic integrity and elected not to alter the aesthetic.

We do not present this tension as either a breach of ethics or as a power struggle but as an illustration of how multiple visions and accessibility requirements simultaneously operate in disability arts research. Using the framework of accountability in emancipatory disability research, Barnes argues that 'to be accountable to the entire disabled population would be impossible' (2003, p. 7). Access needs will necessarily come into conflict as we navigate artistic and research spaces in collectivity. Participants came into the space as people who had lived experience of being pathologised, controlled, and monitored in many contexts, as did the director, a disability artist who took up a position not previously open to individuals with disabilities. Boydell (2011) comments on how performers may experience the emotional ramifications of engaging with challenging subject matter; in this case, however, rather than those without lived experience, performers with situated realities and lived experiences were re-exploring their own experiences and emotions. Reconciling various accessibility requirements is complicated by conflicting research, aesthetic, and political aims. At times, the commitment to present an aesthetically sophisticated piece contravened the bodily realities of performers. These tensions also take shape through constraints imposed by the (neoliberalised) research apparatus itself, which necessitates the production of a polished art piece within the prescribed period, thereby imposing pressures on performers to attend all rehearsals, to be on (normative) time, and to tell stories in a certain amount of time, and so on. (Rice & Mundel, forthcoming). From a disability justice perspective, these constraints emerge as ethically problematic and reveal the limits of attempting to crip the arts through arts-based research.

For performers, telling stories is not necessarily enough to ensure that all voices are heard in the way that they all want them to be heard. As with multimedia stories, the play is delivered to audiences who have their own preconceived notions of performers' lived realities, perceptions that necessarily impact on their listening (Dion, 2009). The words are not delivered into an empty space of understanding but are filtered through ideas about what performers might be saying. For example, one of the performers crafted a narrative designed to be humorous commentary rather than responding to the humour in the piece; however, audiences read the story as inspirational. This response was possibly tethered to a preconceived understanding of people with disabilities as tragic victims or heroic survivors. Audiences, particularly medical audiences, are largely unused to hearing stories directly from people with disabilities that may actually have little to do with their pathologised 'condition', stories that may just be funny. Particularly in a play like *Small Acts of Saying* in which stories ranged from funny to angry to sad, audiences may not have been prepared to shift their reading beyond the conventionally told stories of disability.

Elsewhere, we have considered the 'problematic of audiences', in terms of both how vulnerable stories might do harm to audiences and how audience responses may do harm to storytellers (Mykitiuk et al., 2015). Storytellers might fear that their stories will become 'psychologised' or be misunderstood; this is particularly true for individuals whose stories have been repeatedly psychologised. An REB response to this concern might be to encourage anonymisation of performers, or else have those without lived experience represent or dramatise the work. From a disability justice perspective, this re-inscribes ableist logics underpinning most disability representations (which position disabled people as research participants or allow for disability's humanisation only when portrayed by non-disabled actors) rather than embracing crip logics which work to ensure that people who embody difference are recognised as performers, artists, and researchers. Audiences may not be ready to hear stories just as performers with disabilities wish, however. The performer whose funny story was misread described how in the past they made what they now consider 'bad art' in order to get people to listen; they told a story that would make audiences feel included. In *Small Acts of Saying*, they delivered a different kind of story and that was mis-read. This leaves the disability-identified artist in the uncomfortable position of being, as they put it, a pedagogical commodity for the telling of disability in a capitalist, artistic twenty-first century, rather than an artist.

Conclusion

Research ethics protocols were built out of necessity to help researchers avoid doing harm to those with reduced power in the research encounter. Without being open to difference, however, REBs lack, at times, the improvisational stance required when working differently with body-mind difference. Particularly in arts-based research, we have engaged in continual negotiations with REBs in order to do our work in a way that crips ethics. In enacting disability justice-oriented arts research, we have attempted to invite new ways of conceptualising the researcher-participant relationship and the role itself of the 'participant'. We entered into this work with our own ideas about what might be involved in conducting ethical disability arts research. As we have moved in these spaces, we have inevitably failed. Through failure, we have reimagined how to do this work in a way that corresponds with a cripped ethic, welcoming a plurality of experiences and ways of being.

Negotiating issues of voice, anonymity, and confidentiality is made complex by research 'as usual'. Particularly when participants have a history of being slotted into boxes or dis-assembled into component parts, further imposing checkboxes, black boxes, and aesthetic boxes can have negative impacts on experiences of research. Through the cases of multimedia storytelling and research-based drama, we have offered critical examples of times during which participants challenged the given standard ethics protocols. In both cases, we grappled with issues of anonymity and confidentiality against a burgeoning Disability Arts community in Canada. Many participant-artists engaged with the project under the condition of being identified as artist. Pixelating faces, assigning pseudonyms, and showing multimedia stories in the contexts of researchers' choosing contravene the expectation that artist-participants actively collaborate in the research from start to finish, and as such has the potential to recolonise disabled people's stories as research products.

In the context of research-based drama, the development, staging, and performance of *Small Acts of Saying* raised issues of voice and audience interpretation. It also alerted us to the impossibility, under ablest neoliberal logics, of completely resolving conflicting accessibility requirements and conflicts between aesthetic, research, and political aims when ensemble casts, researchers, and directors work together to speak to audiences. This is held in tension against participant-performer desires for representation on their own terms in ways that acknowledge their unique artistic contributions to the ensemble. Here, we witness how rehearsed responses to ethical conundrums cannot acknowledge the complexity of disability and other arts research. A 'quick fix' for the potential for emotional harm on the part of the performer would be to have others perform their words, thereby abstracting them from the audience and protecting their identities. Doing so, however, would require us not to acknowledge artists' contributions.

Finally, arts-based research means creating a product that is more fixed and final than subjectivities and experiences. The stories that participants tell are not representative of the entirety of their experience which are in continual flux. In presuming that one-time consent can stand for the duration of the screening or performing of stories neglects to acknowledge the contextual, process-based nature of consent. Offering the opportunity to revisit consent and opening multiple options for levels of consent have acted as provisional ways of engaging with artist-participants to work towards a fuller acknowledgement of how circumstances and orientation to creative pieces can and do change and shift as time goes on.

We consider a process-based orientation to ethical engagement with participants to be preferable to one that fixes ethics to a set of forms and procedures set out at the beginning and closed at the 'end' of a research project. This has meant, for us, ongoing negotiations with both REBs and participant communities. It has meant a contextualised consideration of ethics including the ethical harms done to groups in the past in the name of 'protection'. We underscore the imperfection of this work and the unfinished nature of the engagement with ethics itself. As we continue to conduct this research, we will inevitably stumble upon ways in which we could more closely attend to the ever-changing needs, conditions, and understanding of participant communities.

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Notes

1. This project received ethics approval from the Research Ethics Board at the University of Guelph in 2012 (certificate number 12AP010).
2. We use the terminology 'Mad' to refer to art produced by and related to the experiences of users or former users of mental health services and other people with non-normative ways of thinking and feeling. An evolving interdisciplinary field, Mad Studies offers critical inquiry into mental health and madness in ways that foreground the oppression, agency, and perspectives of Mad people, past and present, as well as in diverse cultural contexts, to challenge dominant understandings of 'mental illness'.

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18

The Ethics of Allowing Participants to Be Named in Critical Research with Indigenous Peoples in Colonised Settings: Examples from Health Research with Māori

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The aim of this chapter is to question the default to enforced anonymity in qualitative research. Ogden (2008c, p. 693) notes that 'Many research participants do not wish to be anonymous. They participate in research because they

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anticipate a benefit, such as the hope that their contributions are valuable enough to make a difference and that they will be recognized for it.' So why are participants typically rendered anonymous when qualitative research is published in research outputs such as theses, articles, and books? And what is the particular relevance of naming participants in research involving indigenous participants in colonised settings? We explore these questions by drawing on two example studies with indigenous participants in Aotearoa/New Zealand that illustrate some of the possibilities and some of the challenges of naming participants in comparison to enforcing anonymity. In one of these studies, all pre-teen participants chose to be named (Pidduck, 2016); in the other study, we did not offer participants with a history of criminal offending the option of being named (Ashdown, 2016). This chapter focuses on the relevance of autonomy and self-determination to highlight how enabling indigenous peoples to have control over research in which they are involved is important for indigenous development. At the end of the chapter we present a model of degrees of anonymity that we developed based on our research and on the literature. This model clarifies the nature of anonymity and offers a framework for researchers who are considering naming participants in research outputs.

Anonymity as a Research Norm

Providing research participants with anonymity has become a norm in social science research because of the assumption that being named may lead to harm (Nespor, 2000; Scarth, 2016; Walford, 2005; van den Hoonaard, 2003). In qualitative methodologies, anonymity is so normalised that 'the practice of giving a false name to a research site and to the people within it has become almost unquestioned' (Walford, 2005, p. 85). Anonymity involves removing all potential identifying details with the aim of ensuring that quotes are not traceable to individual participants. It is questionable whether anonymity will guarantee that participants in qualitative research are untraceable (Guenther, 2009; Nespor, 2000; Scarth, 2016; Tilley & Woodthorpe, 2011; van den Hoonaard, 2003; Walford, 2005). Confidentiality certainly cannot be offered in qualitative research if confidentiality means that all comments are made in complete confidence. In this chapter we question the norm of 'enforced' participant anonymity (Giordano, O'Reilly, Taylor, & Dogra, 2007, p. 270).

We take up Ogden's (2008a) argument that researchers 'sometimes forget that participants might not share the same privacy concerns and would like to be acknowledged for their contributions' (p. 17). We argue that the question of naming or anonymising participants is particularly pertinent in research with indigenous peoples because of the problematic history of research speaking about the indigenous other (Smith, 2012). In developing this argument we draw on scholarship about indigenous research methods, worldviews, self-determination, and ethics (Hudson & Russell, 2009; Hudson, Milne, Reynolds, Russell, & Smith, 2010; Delany, Ratima, & Morgaine, 2015; Kovach, 2010; Smith, 2012). With some notable exceptions there has been surprisingly little academic work that substantively discusses or challenges the norm of participant anonymity (Guenther, 2009; Nespor, 2000; Scarth, 2016; Tilley & Woodthorpe, 2011; Walford, 2005). This chapter outlines our journey into the issues around enforcing anonymity or offering indigenous participants the opportunity of being named. The start of our journey was a fortuitously timed exposure to two instances of research by Māori researchers naming Māori participants. In the first instance, some of us attended a talk describing research with children and *whānau* (extended families[1]) from a Māori immersion early childhood education centre called Te Kōpae Piripono (Tamati, Hond-Flavell, Korewha, & the *whānau* of Te Kōpae Piripono, 2008). This centre delivers its programme in full Māori language immersion (i.e., 100% Māori language use) and is a *kaupapa Māori* initiative in that it operates from within a Māori worldview and actively expresses this worldview (Tamati et al., 2008). Participants appeared in videos shown during the talk and were named in the report by Tamati et al. (2008). In the second instance, we became aware of research into alcohol consumption by O'Carroll (2013) in which Māori participants were allowed to be named. Despite these two examples, there is a lack of discussion and guidance on how to work through the issue of naming participants in indigenous research. Our aim is to provide a detailed consideration of what eventuated in our two studies and a guide for researchers who are considering offering indigenous participants the opportunity of being named.

The two postgraduate student researchers who led the two studies described in this chapter (Jacob and Paris) are Māori and are actively involved in their communities. One of their supervisors (Tia) is Māori and provided cultural research supervision on both projects. The other authors do not have Māori *whakapapa* (ancestry) but regularly support Māori students and service users. Smith (2012) advocates for non-indigenous researchers acting as mentors of early career indigenous researchers when needed. This mentorship is not without challenges in the managing of one's identity and privilege as non-indigenous supervisors of indigenous research. For example, non-indigenous researchers cannot provide cultural advice from an insider perspective and may have difficulty in comprehending the indigenous worldviews that are likely to feature in indigenous research. Smith (2012) proposes an ongoing need for decolonising methodologies to counter the perpetuation of colonialism through research because otherwise 'the cycle of colonialism is just that, a cycle with no end point, no emancipation' (pp. 203–204). Smith (2012) outlines a range of indigenous methodologies and methods that have a common goal of self-determination. Kovach (2010) argues that indigenous methodologies stem from tribal knowledge and are distinct from Western methodologies although they still share similar attributes with Western qualitative research approaches. Hudson and Russell (2009) note that 'The main concerns for many indigenous peoples in research revolve around respect for their indigenous rights, control over research processes and reciprocity within research relationships to ensure that equitable benefits are realised within indigenous groups' (p. 61). Some indigenous researchers refer to their approach as indigenism and indigenist, modelled on the terminology and critical underpinnings of feminism and feminist approaches to research (Smith, 2012). *Kaupapa Māori* Research (KMR) can be considered an indigenist approach to research that grew out of the work of many Māori researchers (Hudson et al., 2010; Smith, 2012). *Kaupapa Māori* refers to ways of working that embody a Māori worldview. There is no single version of KMR nor guidelines that specify an ordered series of steps, but KMR is guided by a range of principles that are in close alignment with principles of critical research, particularly emancipatory social justice research and participatory community action research. One core principle of KMR is *tino rangatiratanga* (Smith, 2012) which translates to absolute sovereignty, chieftainship, authority, and self-determination (Delaney et al., 2015; Orange, 2011). *Tino rangatiratanga* is an historically and politically loaded term because of its central role in *Te Tiriti o Waitangi* (The Treaty of Waitangi), which promised *tino rangatiratanga* over resources to Māori (Orange, 2011). This treaty between Māori and the British Crown is the founding document of the nation of New Zealand (Orange, 2011). Treaty settlement claims are ongoing for some *iwi* (tribes) because terms of the Treaty were not adhered to by the Crown, resulting in monumental disadvantage for Māori in terms of loss of autonomy, culture, land, and lives (Smith, 2012). *Mātauranga Māori* (Māori knowledge) continues to be undervalued or defined in non-Māori terms (Smith, 2012). Moreover, Māori who have participated in research often feel used: this is in part because negative depictions of Māori predominate even when the aim is to reveal and reduce disparities (Smith, 2012). KMR can be seen as a response to these concerns and was developed in order to 'claim research as a space within which Māori can also operate' (Smith, 2012, p. 202). Put more simply, KMR is research 'for, by and with Māori' (Smith, 2012, p. 185).

The two studies presented in this chapter both applied principles of KMR. The first study was led by Paris for her master's degree in psychology. Paris was supervised by Gareth and Elizabeth, and received cultural research supervision from Tia. Paris conducted her study in Ōtaki, where she grew up. Her *whānau* continue to live there, which provided an important connection to the community. Paris used a photo-elicitation interview method to explore how *tamariki Māori* (Māori children) living in Ōtaki understood the concept of *hauora* (health and well-being). The eight *tamariki* who participated acted as co-researchers by taking photographs for a week and seeking signed informed consent from other people who appeared in any of their photographs. The *tamariki* were offered the opportunity of being named in outputs, particularly Paris' master's thesis (Pidduck, 2016), and all *tamariki* agreed to being named.

The second study was led by Jacob, also for his master's degree in psychology. And, like Paris, he was supervised by Gareth and received cultural research advice from Tia. In addition, Jacob received workplace supervision as well as research advice from Claire and Brian. Claire is the programme director of *Te Whare Moana* (Moana House), a community-based residential therapeutic community for men with a history of criminal offending. The majority of residents identify as Māori, and Moana House has a *kaupapa Māori* foundation. Brian is a registered clinical psychologist and provides supervision to staff of Moana House. Jacob's experience of working at Moana House led him to develop his study of exploring the experiences and aspirations of residents by using individual interviews. In the process, participants of Jacob's study were not offered the opportunity of being named. On the other hand, permission to name Moana House was sought as part of the ongoing collaboration between Jacob, Claire, Brian, Tia, and Gareth. This permission was not mandated in the ethics approval, but other aspects of the two studies relating to anonymising or naming individual participants were shaped by local ethics review and ethical principles

Ethical Principles and Naming of Participants

Ogden (2008a) emphasises the role of ethics codes in maintaining the norm of participant anonymity: 'A consequence of such codes is that researchers often assume anonymity must always be protected' (p. 17). Many writers have concluded that even if the names of participants and study sites such as schools, organisations, or towns are removed in an attempt to ensure anonymity, sites and participants might be identifiable, and therefore, confidentiality cannot be guaranteed (Nespor, 2000; Tilley & Woodthorpe, 2011; Walford, 2005). People from the site of a study are likely to be able to recognise participants unless so little material is quoted that even the participants would be unable to identify their own data in a research output, which can result in decontextualised findings that make a questionable contribution to knowledge (Walford, 2005). Non-maleficence is the ethical principle that research should do no harm, or, more precisely, that researchers have 'a duty to avoid, prevent, or limit harm to others' (Ogden, 2008b, p. 379). It is possible, however, for participants to experience harm if their contribution to research is *not* recognised when they desire this. Beneficence is the ethical principle that research should do good. Smith (2012) highlights how KMR should aim to benefit Māori in being *for* and *by* Māori and not just *about* or *with* Māori. Beneficence does not mean that personal benefit can be promised to individual participants. Moreover, conceptualising benefit solely at the individual level contradicts Māori philosophies of the collective self, organised through *iwi, hapū* (subtribes), *whānau*, and other Māori groups. In indigenist research, self-determination acts as a guiding objective with the proviso that benefit cannot always be expected to be 'immediate or direct' from one piece of research (Smith, 2012, p. 193). But at the same time, Smith (2012) emphasises that it is important to ask of each piece of research: 'What knowledge will the community gain from this study? […] To whom is the researcher accountable?' (pp. 175–176). Naming participants can be seen as one component of researchers' accountability along with a wider accountability to communities.

Within many current systems of ethical approval, researchers are expected to obtain signed informed consent from all cognitively competent adult participants before they become involved in research. Local ethics committees often provide templates for information sheets and consent forms, and where these templates enforce anonymising of participants, it is hard for researchers to challenge this. The template information sheet and consent form in the University of Otago's human research ethics application form allows researchers to develop a way of offering participants the option of being named in research outputs. In the guidance for the information sheet, the following is noted:

> Some research projects may offer a choice to participants regarding their anonymity. If so the Information Sheet and Consent Form should reflect this with the Information Sheet including a statement such as: On the Consent Form you will be given options regarding your anonymity. Please be aware that should you wish we will make every attempt to preserve your anonymity. However, with

> your consent, there are some cases where it would be preferable to attribute contributions made to individual participants. It is absolutely up to you which of these options you prefer. (University of Otago, n.d., p. 11)

Similarly, the template for the consent form states: '[If participants will be given a choice to remain anonymous or be identified, use the following]: I, as the participant: a) agree to being named in the research, OR; b) would rather remain anonymous' (University of Otago, n.d., p. 11). These example templates may be useful to researchers whose local ethics committees do not provide such options in templates or guidance; they enabled us to develop a process of offering participants the option of being named in one of the two studies that we describe in more detail in the following section.

Reflections on Naming Participants from the Two Core Studies

Paris' Study (in Paris' Voice)

Four ethical processes were considered prior to recruitment for my study with *tamariki*. Throughout each of these interactions, the intention of offering participants the option of being named was raised. Firstly, the Ngāi Tahu Research Consultation Committee was consulted as required by the Memorandum of Understanding between the University of Otago and the local *iwi*, Ngāi Tahu.[2] Secondly, a *kuia* (female elder) from Ōtaki was consulted about the proposed research. Thirdly, ethical approval was sought and gained from the University of Otago Human Ethics Committee (reference 13/273). And lastly, principals of local schools were consulted about supporting the recruitment process.

During the recruitment phase I met with each *tamaiti* (child) and their *whānau*. These *hui* (meetings) took place at either their *whare* (house) or one of the schools. As part of the consent process, *tamariki* were given the option to be named in the research. *Whānau* were reassured that this decision would be re-considered throughout the research process and prior to the submission of the thesis. All eight *tamariki* and their *whānau* indicated that they would like to be named and signed forms to record this initial decision.

In the next phase of the study, the interview transcripts were sent via email to *whānau* before a group *hui* with the *tamariki* and their *whānau*. Five of the eight *tamariki* were present at the *hui*. The remaining three *tamariki* (and *whānau*) were contacted at a later date. The intention of this *hui* was to allow *tamariki* to comment on the transcript of their interview (e.g., whether the information included was correct and whether or not they wanted changes to be made). I provided a summary of initial findings to the *tamariki*. This summary included themes and photographs that had been identified in their interview. The *tamariki* agreed with the summary. Once my thesis was in its final draft I contacted the *tamariki* and their *whānau* again. With seven of the eight *tamariki*, I was able to have face-to-face contact, and I contacted the eighth participant by telephone. *Tamariki* and *whānau* were asked to check that the information included in the participants' section was correct and were shown the quotes and photographs they had contributed. They were then asked if they would still like to be named in the thesis. All eight *tamariki* again agreed to being named, and they and a parent/caregiver signed another form recording this decision.

It was important to highlight to the *tamariki* and their *whānau* that once they had agreed to be named and the thesis was printed, this would be irreversible. Understandably, some of the *tamariki* were *whakamā* (embarrassed, shy) about having quotes and photographs included in the thesis. Parents/caregivers were often proactive in highlighting that this was a positive aspect and often noted that the *tamariki* would be helping me complete my university studies. However, they did not pressure the *tamariki* to be named. The eight *tamariki* all agreed to be named in the final thesis, and they and their *whānau* were happy (and proud) to share their narratives.

Jacob's Study (in Jacob's Voice)

Participants in my research were residents of Moana House recruited through a series of *hui*. These *hui* informed residents and staff of the purposes of the research and of what would be required of each participant; it was made clear that they understood that the research project was distinct from my role as a staff member of Moana House. Names were drawn from a hat in the presence of all residents and staff in a way that avoided any potential impression of favouritism. All participants were then asked to speak to their key worker about their participation in the project before signing the consent form. Residents at Moana House work alongside a key worker who oversees the resident and collaborates with him to develop an appropriate recovery plan. Each participant, the key worker, and the researcher went through the information sheet together so that any questions could be answered. The resident and the key worker were both required to agree to the resident participating in the project. Prior to each interview, the resident was asked to call a house meeting within the programme's schedule in order to be transparent about when and where each interview was being held. This protocol was approved by the University of Otago Human Ethics Committee (reference 14/019).

The interviews commenced with my introducing myself with my *pepeha* (tribal saying) in *Te Reo* (the Māori language) then inviting the participant to do the same. All residents of Moana House regardless of ancestry are schooled in their *pepeha* but were encouraged to introduce themselves in whatever way they pleased. I asked participants a series of open-ended questions for the semi-structured interview. None of the participants raised any concerns about their interview experience. Each participant was also given the option of calling another house meeting to describe his interview experience to other residents for the sake of transparency. Once the transcripts were analysed and the themes identified, participants were given a summary of the research results. All participants agreed that the summary accurately captured the experiences that they aimed to communicate.

There were several issues around anonymity that arose in this study and reinforced the decision not to offer participants the opportunity of being named in research outputs. During a *hui* about the research, one of the residents asked if the information from the interviews would be used as a part of his rehabilitation programme. He was worried that if he disclosed information about rule breaking, this information could result in some form of punishment or his being removed from the programme and recalled to prison. Following their interview, participants were given the option of attending a debriefing session with their key worker. During this session, the resident was invited to discuss his interview experience and any concerns that may have arisen, which then were addressed in a way that reinforced the clear distinction between the research and the delivery of the programme.

One of the main reasons participants were not offered the opportunity of being named was to reduce potential harm to others. If the participants were to be named in the research, those who have experienced harm in the past due to the actions of any one participant may be at risk of further emotional damage if they became aware of the research. Allowing the participant to share his story could be perceived as glorifying anti-social aspects of the past. Additionally, hearing or seeing a participant's name could trigger harmful memories and have an adverse emotional impact on an individual who may have been harmed by the participant in the past.

Another potential consequence of naming participants is retaliation from gangs for breaking the 'code of silence.' Participants who have been in gangs or who have chosen to discuss gang-related issues could be at an increased risk of harm. Therefore, maintaining participant confidentiality is crucial to ensuring the safety of participants. Naming participants could also have negative consequences for their ability to gain employment or enrol in courses in the future. There were a number of participants in my study who had been either previously or currently enrolled in courses, while other participants expressed interest in enrolling in courses in the future. Being identified as an individual with a history of incarceration could have negative implications for participants' ability to participate in education or employment without being judged or asked inappropriate questions about their offence.

Recommendations for Researchers Considering Offering Participants the Opportunity to Be Named

The two studies presented in this chapter raise a range of important considerations about offering participants the opportunity to be named. Age is one of the points of variation between our two studies but was not the deciding factor in the decision of whether to offer participants the opportunity to be named in either study. The participants in Paris' study were in their pre-teens when they took part and thus their parents/guardians gave proxy consent in addition to signed assent being provided by the children. Other researchers have named participants who are children (e.g., Hohneck, 2013; Roth, Tobin, Elmesky, Carambo, McKnight, & Beers, 2004). Roth et al. (2004) included one school student participant as a co-author because of their contribution to the writing. We cannot be sure about how well Paris' pre-teen participants understood the implications of being named, but the same question applies to adult participants named in any research. Longitudinal research with children and adults of varying ages could help develop our understanding of a minimum age or stage of development at which the opportunity of being named might be appropriate.

The vulnerability of Jacob's adult participants to potential negative consequences discussed above was more important to consider than their age or understanding of informed consent. It is, however, an example of paternalistic decision-making by us as researchers that Jacob's participants were not offered the opportunity of being named. People with a history of criminal offending have been named in previous research. Four of the five co-authors of Bosworth, Campbell, Demby, Ferranti, and Santos (2005) were prisoners at the time of the research, and they provided an insider perspective on being involved in research in prison. Similarly, Stan Coster is a co-author of the article by Andrae, McIntosh, and Coster (2016) which focuses on Coster's *whakapapa* and life experiences including imprisonment in Aotearoa/New Zealand. These two examples highlight how the issue of naming raises questions about the boundaries between participants and co-authors, particularly in participatory research.

Both Paris and Jacob have insider status as Māori and as insiders within their research sites, Paris being from Ōtaki and Jacob being involved with Moana House. Much of the research in which participants have been named has involved insider researchers (Hohneck, 2013; Mahuika, 2011; McLellan, 2013; O'Carroll, 2013; Olson, 2013; Tamati et al., 2008). Insider status is relevant for the decision to name participants as it increases the likelihood of ongoing relationships between researchers and participants, which is crucial for continued consultation with participants regarding their decision to be named or anonymised. The seeking of consent moves beyond signing a form on only one occasion if participants are being offered the opportunity of being named because confirmation of ongoing consent from participants is essential after the results have been drafted. Consent is underpinned by the participants trusting the researcher, particularly in research with indigenous peoples (Smith, 2012). Insider status can facilitate trust and the process of community consultation, which merges with the seeking of consent from individuals in indigenist research (Smith, 2012). At the same time, researchers can benefit from reflecting critically on the doors opened by their insider status in order to avoid taking advantage of pre-established trust.

The anticipated form of dissemination of the research output is also important in the decision about whether to name participants. Jacob's participants were not involved in any formal dissemination of the findings but did engage in informal feedback during house meetings. In Paris' study we anticipated that participants would be involved in public dissemination in the local community from the outset; thus, it would have been contradictory to then anonymise them in the thesis. The availability of some or all of these reports on the internet can make it possible for the identity of anonymised participants and research sites to be inferred. To mitigate this, for example, Michie (2011) raised a crucial point in stipulating that future researchers citing his thesis should not list the names of any of his participants who agreed to be named in the thesis as their permission to be named did not extend to future publications over which they would have no control. Similarly, Paris' thesis is not available online in order to limit the possibility of the photographs or quotes being re-used without permission from participants.

Another consideration is who is responsible for the decision about whether the opportunity of being named is offered, which again relates to the self-determination of indigenous participants and the power relations between researchers and participants. In both our studies, we made the decision about whether the opportunity to be named was offered. It has been argued by van den Hoonaard (2003) that the decision should come from participants themselves. This occurred for Scarth (2016), who was asked by some participants to include their names and the names of their deceased relatives. The local ethics committee granted permission and about half of the 16 participants chose to be named. In some instances, researchers may be pressured by ethics committees, supervisors, collaborators, gatekeepers, or community members to enforce anonymity or to offer participants the opportunity of being named.

Based on our research and past research involving naming of participants or discussing reasons for anonymising participants we have developed a model of five degrees of anonymising or naming of participants:

1. 'True' anonym*ity* occurs only when informants are never asked their names (e.g., Hohneck, 2013; see also van den Hoonaard, 2003, 2011). This means that researchers are very unlikely to be able to breach informants' confidentiality in research outputs or in court. When applying this approach, the researcher has limited ability to re-contact participants and must plan to collect data and permissions during the first contact.
2. 'Full' anonym*ising* occurs when participants' names are known to researchers (e.g., on consent forms) but all identifying details are masked in research outputs including details of the research site (e.g., Waikari, 2011, masked school names). Whether this form of anonymising guarantees the untraceability of participants in qualitative research is questionable (see Guenther, 2009; Nespor, 2000; Scarth, 2016; Tilley & Woodthorpe, 2011; van den Hoonaard, 2003; Walford, 2005). Jacob's study applied this form of anonymising. When applying this approach, the researcher has to be mindful of information communicated in quotes that may reveal the identity of a participant, other person, and/or research site.
3. 'Soft' naming occurs when limited details of the participants' names are provided such that identification is possible by the participants themselves but more difficult for others depending on their familiarity with the research site (e.g., only first names were used by McLellan, 2013; O'Carroll, 2013; Scarth, 2016; Tamati et al., 2008). When applying this approach, the researcher has to check that participants would be willing to be named in this way once the research output has been completed, and whether other people can be identified from quotes must also be considered.

4. 'Full' naming occurs when the research site and full names of participants are provided such that identification is clear to all readers to the extent they could potentially locate the participants (e.g., Hohneck, 2013; Mahuika, 2011; Michie, 2011; Pidduck, 2016). Paris' study applied this form of naming. When applying this approach, the researcher has to check that participants are willing to be identified once the research output has been completed and be mindful of whether other people and organisations can be identified by any details accessible from participants' quotes.
5. Co-authorship occurs when the participant is recognised as a co-researcher (e.g., Andrae et al., 2016; Bosworth et al., 2005; Roth et al., 2004). An opaque form of co-authorship may occur at the same time as 'full' anonymising by 'soft' naming if individuals act as both participants and researchers without any clear distinction (see also Wilkinson & Kitzinger, 2013). When applying this approach, the boundary between researcher and participant blurs, but the instigating researcher ideally should be working equitably with the co-author(s) and would consider the ethics of revealing or suppressing information about input in the research.

This model provides a way of thinking about the appropriate level of naming or anonymising for a particular study and can serve as a resource for discussions with regulatory bodies and community groups. The model is not specific to research with indigenous people but pertinent to indigenist research, given the centrality of self-determination when considering whether indigenous participants are to be offered the opportunity of being named.

In conclusion, our discussion of the possibility of offering participants the option of being named raises important questions about the ethics of anonymity and non-maleficence. The answer to our challenge to the norm of enforced participant anonymity is not to swing to enforced naming of participants or a presumption that all participants should be encouraged to become co-authors, though that is a worthy endeavour where achieved. Guenther (2009) notes that the debate around anonymity of participants can result in researchers being 'uncomfortable with either option of naming or not naming' participants (p. 414). In turn, this state of discomfort for researchers is productive in that it keeps the ethics of naming or anonymising on the agenda as a process that always requires attention and innovation. Additional research into the practices of naming or anonymising participants and ongoing reflection through academic discussions and community discussions is required to develop these initial guidelines and reflections from our two studies.

We end on a note of optimism that critical research, particularly emancipatory social justice research and participatory community action research, is leading to benefits for marginalised groups. The issue of naming participants is very relevant in research with indigenous peoples who have been subjected through research to historical injustices; discussion of the considerations around naming or anonymising participants adds to critical debate on the best ways of achieving greater autonomy for communities involved in research that is about, with, and truly for them.

Authors' Note Jacob and Paris led the two projects that form the basis of this chapter. Jacob carried out background research on the studies that have addressed naming of participants and wrote several sections of the chapter. Paris carried out background research on *kaupapa Māori* research and wrote several sections of the chapter. Tia, Elizabeth, Claire, and Brian all contributed to the research described in the chapter and to its conception and editing. Gareth oversaw the two projects, carried out background research on the studies that have addressed naming of participants, and wrote several sections of the chapter. We thank Mihi Ratima and two reviewers for their feedback on the chapter. We also thank participants and their whānau for their involvement in our research. Jacob's research was supported by a Henry Rongomau Bennett Foundation scholarship. Paris' research was supported by a Health Research Council Master's scholarship.

Glossary of Terms

Aotearoa	the land of the long white cloud; New Zealand
Hapū	subtribe(s)
Hui	meeting(s)
Iwi	tribe(s)
Kaupapa	approach, principles
Kuia	female elder(s)
Māori	the indigenous peoples of Aotearoa/New Zealand
Mātauranga	knowledge, wisdom
Pākehā	non-Māori (commonly specific to European New Zealanders)
Pepeha	tribal saying describing the person's whakapapa
Rohe	tribal boundaries
Tamaiti	child
Tamariki	children
Te Reo Māori	the Māori language
Te Tiriti o Waitangi	The Treaty of Waitangi
Tino rangatiratanga	absolute sovereignty, chieftainship, authority, self-determination
Whakamā	embarrassed, shy
Whakapapa	ancestry or genealogy, commonly recounted in a pepeha
Whānau	extended family/families
Whare	house(s)

Notes

1. We provide translations of words in Te Reo Māori (the Māori language) when they are first used; a glossary is provided at the end of the chapter.
2. The University of Otago's main campus in Dunedin is located within the rohe (tribal boundaries) of Ngāi Tahu.

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19

Ethics Review and the Social Powerlessness of Data: Reflecting on a Study of Violence in South Africa's Health System

Jessica Rucell

> Last week I had a meeting with the entire night nurse staff…because the Maternity Obstetric Unit wasn't taking some patients. In one week, we had three cases of stillbirth. That's why we had to meet. [Secondary hospital] alerted me. …We don't have accountability in the system. This has been happening all along. The CEO [Chief Executive Officer] didn't meet with the Unit for the first five years on the job. That meeting you attended, that was the first meeting [the CEO] ever had about maternity things. …She's [Unit Manager] also not monitoring. If you don't pick it up personally, you won't find out. Dr. Tlou Lekgoathi, Senior Family Physician, Public Day Hospital, Cape Metro[1]

Scholarship widely acknowledges that violence against women and gender-based violence in South Africa have reached epidemic proportions (Coovadia, Jewkes, Barron, Sanders, & McIntyre, 2009; Gqola, 2015; Moffett, 2006). Recently, the range of adverse treatment pregnant women receive when seeking healthcare and particularly in maternity wards during childbirth has been labeled as violent (Chadwick, 2017; Jewkes & Penn-Kekana, 2015; Pickles, 2015). This includes slapping, sexual assault, humiliation, the denial of health services, coercive medical procedures that are either unnecessary and/or performed without consent including long-acting and permanent contraception (e.g., sterilisation), refusal of pain medication, denial of admission to health facilities, and the detention of women and newborns after childbirth for lack

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of payment (World Health Organisation, 2015). This ubiquitous problem has been described as 'obstetric violence' and has become punishable by law in some countries (D'Gregorio, 2010). While this problem is found in both public and private health systems, my research focused on the public sector which is directly managed by public servants.

The excerpt above, from an interview for my doctoral research, shows an example of the systemically poor management that is adversely impacting on public services, and on pregnant women and their families. This narrative shows how the poor performance of health managers can create patterns of risk for those seeking maternal healthcare. To contextualise the urgency of the public health system's problems of oversight, it is useful to reflect on the task fulfilled by Maternity Obstetric Units (MOU) in the Cape Town Metro. Everyday, between four and eight women deliver in a primary care MOU. In other words, the creation of new life for six to eight families per day depends on care from these Units. Addressing patterns of violence and inadequate accountability where and when they occur to pregnant women is, thus, urgent, not only for the pregnant woman and her foetus or newborn but also for her and her partner's families, and the communities from which they come.

Ensuring social benefit is especially important when research concerns public goods, for example, health system functioning or corruption in schools because such data and analysis is able to directly contribute to social benefit. Developing systems to monitor public goods is important for any polity and especially for states going through societal transition in which there is an attempt to replace former structures of inequity.

South Africa provides an example of such transition, as it has been shifting from centuries of colonial and apartheid regimes based on White-supremacist rule to a majoritarian democracy since 1994. During the early period of this political shift, the Truth and Reconciliation Commission's (TRC) investigation found health services to be a perpetrator and enabler of mass violence (TRC, 2003, p. 31). Recent research has suggested that Black pregnant women continue to face violence from the public health system (Farrell & Pattison, 2004; Kruger & Schoombee, 2010; Essack & Strode, 2012; Chadwick, 2017).[2] My research investigates why and how obstetric violence is caused and spread in South Africa's public health system. By applying qualitative methods and a historical approach, I examine the socio-political drivers of this violence and what sustains abuses of power by public servants (health professionals, administrators, and policymakers) who are responsible for providing health services in the public interest. The majority of participants in my study are public servants, and includes those with limited visibility and power, for instance, Nurses and those with significant visibility and power, for instance, Chief Directors.

It is commonly argued that, given the potentially vulnerable position of participants, and the sensitivity of a research topic and its locations, conforming to informed consent, confidentiality, and anonymity requirements is essential (Garrard & Dawson, 2005). In addition, academic research in the social sciences is increasingly controlled by processes of ethics review which aim to certify compliance to these and other required methods (Haggerty, 2004). Certain of these requirements, however, can impose limitations on obtaining and using data, especially on topics of public interest. In this chapter I question the potential for the social benefit of academic research to be limited by bureaucratic barriers, conflicts of interest, and requirements of the blanket anonymisation of data.

This chapter primarily draws on the regulation of my research by Ethics Committees, EC and the ways in which this has limited the contribution to social benefit that my dataset can make.[3] Firstly, my experience of gaining ethical approval illustrates the regulation of research through the imposition of bureaucratic barriers which have the overt objective of preventing unethical academic conduct. Secondly, institutions may have to negotiate several interests in fulfilling the responsibility of reviewing applications for ethical clearance. I highlight the potential for conflicts of interest in the Ethics Review model and how this may inhibit the potential for social benefit from research. Thirdly, ECs routinely require the methodological strategy of anonymisation for research involving people. By considering research concerning a public good, I analyse how anonymisation strategies necessitating the suppression of socially valuable information can produce what I call ‘powerless datasets’. In this way, the chapter questions the underlining reasoning of regulatory bodies who consider that informed consent and anonymity of research locations and participants is the best method of achieving utmost ethical conduct. To conclude, I raise several approaches to remedy these problems.

Background to This Public Interest Research

The presence of violence in maternity health services is not unique to South Africa. Pregnant women who are discriminated against because of their race, economic, and/or disease statuses, among other characteristics, are commonly subject to obstetric violence throughout the world (see Bowser & Hill, 2010; Pires, d’Oliveira, Diniz, & Schraiber, 2002 for literature reviews on this problem).

My research in South Africa has shown that the poor accountability and answerability, referred to in this chapter's initial quote, enables obstetric violence. By way of example, in early 2010 a series of meetings to discuss obstetric violence was convened by a medical school professor with hospital CEOs and senior midwives from primary to tertiary levels of care. The result of these meetings was that 'reports of abuse [by medical students] were reduced'.[4] However, the professor reported that by November of the same year, 'every one of the twenty-four students… interviewed' who had interned in maternity wards throughout the Cape Metro 'reported a range of very distressing abuses committed against patients in labour'.[5] As a result, similar meetings were initiated over the following two years, which then included Directors of the Provincial Department of Health.[6] A year later, a senior physician described an example of how the absence of internal answerability sustains obstetric violence.

> Two months ago there was a nurse who pulled a pregnant woman by the ear from the floor. I think she might have fallen because of pains…, she cried out to the nurse for help. The nurse went there already annoyed and pulled her by the ear… Do you know they delivered with the woman on the floor? They [nurses] made her deliver on the floor… I think she was a foreigner. …It was criminal. …They [medical students] took it up the channels but I won't be surprised if it won't just die. When I had to pull out the files I realised that they [midwives] didn't even report that she gave birth on the floor. … I never see the results [of reports], that's my issue with it. In the end there is no accountability.[7]

As of 2017, medical students in Cape Town continue to report observing obstetric violence, especially in the form of 'psychological and verbal abuse [which] is routine', including the victimisation of especially discriminated against groups, for example, 'HIV positive mothers'.[8] This summary of my findings demonstrates how, in the absence of functioning internal and external systems of accountability, major consultations, for example, those initiated by the Professor, are not sufficient to ensure the Provincial Department's stated 'zero tolerance' for obstetric violence (Honikman, Fawcus, & Meintjes, 2015). My study demonstrates that the recent policy designed to curb obstetric violence in South Africa, referred to in Honikman et al. (2015) has been poorly developed and implemented. Moreover, the potential social value of research into obstetric violence, emerging from at least some reporting of major malpractice, appears to be dependent on the willingness of a university to agitate for accountability from administrators. This potential is lost, however, through EC barriers, conflicts of interest, and routine anonymisation, which I discuss in the following section.

The Loss of Social Benefits Due to Bureaucratic Barriers

In this section I analyse the increasing surveillance of research through ECs, specifically the constraints of the potential to design, implement, and apply public interest research. Applying for EC approval is an intensely bureaucratic process. Compounding bureaucratic barriers is that some research requires multiple institutional approvals. Regulators of academic research may represent governmental, non-profit institutions, as well as for-profit companies. For instance, my research required approvals from the University of Leeds (No. AREA 12-013) and the University of Cape Town UCT (No. HREC 290/2013) as well as additional approval from the Western Cape Department of Health (No. RP093/2013). These approvals allowed me to present my final requests for access to the Chief Executive Officers and clinic managers at the various hospitals in the Cape Town Metro selected for the study. This summary of my multi-institutional ethics review process demonstrates the intense regulation of academic research.

Ethics Committees place little emphasis on evaluating and enabling the social benefit of research. In line with a bureaucratic process, applications entail completing forms which require extensive descriptions of the prospective research topic and methodological design, including questions concerning the safety of research participants. While these requirements result in increased scientific rigour, value, and justification for initiating research, they do not allow for consideration of the broader social contribution of research. For instance, not one question in my review process specifically enquired about the potential *social* benefit that would result from the research. The closest to this type of question came from my University of Leeds Application form under the heading ‘Risks of the Study’ which focused on the potential benefits and risks to research participants from engaging in the study (University of Leeds Research Ethics Committee Application Form, updated 17 January 2012).

These Ethics Committees’ lack of enquiry into the broader social implications of research indicates that public interest is not a priority for them in determining sound ethical practice. My experience of ethical review is not unique. Some scholars find the consideration of social impact to be a common limitation of the EC model (Garrard & Dawson, 2005). Rather than assessing the potential social benefit and harm of research, in practice, ECs are primarily concerned with mitigating within a narrow view of individual harm. The Economic and Social Research Council, United Kingdom, for instance, defines harm as ‘substantive harm to participants (and others affected by the proposed research)' (Economic and Social Research Council, 2016). Haggerty (2004), who is an EC board member at the University of Alberta, Canada, finds that ECs consider potentially harmful research to be that which may cause 'damage' to participants' 'reputation, finances, or relationships, [or that may] offend' or subject participants to 'trauma' (p. 400).

Rather than agreeing with the EC's narrow interpretation that the social responsibility of research is to limit harm to participants, my position is closer to Buchanan's and Miller's (2006). They argue that institutions and researchers have a moral responsibility to develop methodological designs aimed to distribute fairly 'the benefits and burdens' arising from research across society (Buchanan & Miller, 2006, p. 729). As has been indicated, however, established EC procedures do not prioritise the potential to contribute social value in the public interest. The intensifying regulation of research combined with the lack of consideration for, and interest in, bolstering the social value of research may contribute to altering and/or preventing public interest research as early as the proposal/protocol stage.

Conflicts of Interest

In this section, I raise questions pertaining to conflicts of interest that may arise from applying for, or overseeing an EC process. Conflicts of interest arise when institutions or a person has incompatible interests with more than one party, for example, relationships through employment, consultative, or board membership. As a researcher, I was required to follow the EC processes which requested disclosure of any conflicts of interest. I posit here that there may be a greater chance of conflicts of interest for those overseeing ethics review processes when research proposals require multiple approvals, as described earlier. In addition, research concerning public interest, and studies relating to health systems in which institutions of higher education have a stake in those health systems, may entail greater risks of conflicts of interest.

These proposals, requiring multiple ECs approval which are located in interlocking systems, demand additional reviewers, but it is also likely for these systems to have overlapping interests and members, such as in, my case, those of health and higher education. The academic staff of universities' health sciences often provide clinical oversight and management of public hospitals. In South Africa, these responsibilities are fulfilled through joint professional posts between universities and a provincial Department of Health. These responsibilities create dual institutional allegiances when academic institutions have vested interests in protecting the health facilities they manage clinically and use as resources for their teaching and for interning students. Moreover, such academic staff, who receive remuneration from both institutions, are likely to teach in public hospitals and regularly may advise government on policy and administrative matters. Such staff often administer and manage academic and health system resources, sometimes overseeing significant aspects of research grants and public health systems.

Conflicts of interest may arise when university health sciences academic staff have a seat on ECs. As was just outlined, these academic staff, their colleagues, and supervisors are commonly formally connected to public health systems. Thus, university departments who determine the initial approval and design of research proposals are likely to have vested interests in the public image of these important sites of research inquiry. Given the interests that follow these formal partnerships and joint responsibilities, determining approval of, for instance, proposals concerned with governance, corruption, management, or routine malpractice of public health resources may cause such conflicts.

Generally, once academic departmental approval is gained, researchers can apply for a necessary nationally accredited EC clearance. In South Africa, this can be obtained either through a university-based EC or an independent for-profit EC (Pharma-Ethics, 2017).[9] As noted in the previous section, studies involving participation at the facility level of services in South Africa require a secondary layer of official approval from a provincial Department of Health. Importantly, in South Africa, this required clearance is not framed as an ethics approval but rather an official 'approval for health research'. Nonetheless, the institution whose services and/or management and governance may be under scrutiny is required to provide further approval of research proposals thereby demonstrating a clear conflict of interest.

Another challenge to public interest research can be to obtain the generally required informed consent of local heads of public and private facilities that are locations of study. These administrators have the discretion to deny access to research studies even when all other approvals have been gained. This occurred in my experience. One of the seven institutions I approached for research declined access to me. Informally I was told my study was denied access out of the Executive's interest to protect the institution from an examination of such a controversial topic. In another instance, I was afforded partial access, whereby the clinic manager agreed and encouraged the study, but the CEO refused to consider the request for informed consent and did not respond to my repeated inquiries; the clinic manager was told in a meeting that they would not approve the request. After the majority of fieldwork had taken place, this obstacle was overcome as a result of changes in management. Lastly, an acknowledged conflict of interest, similar to those discussed earlier, resulted in limiting my access to two of the remaining five facilities I had gained full approval to study.

My study of the governance and management of reproductive healthcare clearly tested the boundaries of conflict of interest. Although my critical protocol did achieve necessary approvals to conduct the research in the majority of the hospitals to which I had applied, I suspect this was not a result of the absence of conflict of interest or a genuine openness and commitment to public interest research on the part of my Universities, the Department of Health, or the facilities where I did gain access. Rather, relevant to my gaining and maintaining what one health sciences Professor called 'unprecedented access', especially for someone foreign to the health system, was the institutional and political connections I developed and nurtured early on in the application process.[10] Without the support of key academics and policymakers of influence, my research protocol may have been amended at the stage of applying for academic departmental approval in South Africa. Research that involves issues of public interest such as malpractice and corruption make negotiating conflict of interest more difficult for both researchers and those overseeing ECs.

The Ethical Problems With Anonymising

When academic research involves people as participants, the study design is generally required to include the methodological strategy of blanket anonymity. Anonymisation is understood as 'not disclosing the identity of a research participant, or the author of a particular view or opinion' (Clark, 2006, p. 4) with a view to reducing potential harm.

In this section, I argue that requiring anonymisation to reduce harm equates to constraining the intended, and unintended, benefits of research. I question the reasoning underlying the consensus of regulatory bodies that blanket anonymity equates with ethical conduct. I ask whether, in fact, lack of public transparency—particularly when research concerns public goods—enables the least risk of harm when this is applied more broadly than to individual participants.

Instead of a singular interest in protecting individual participants and research locations from stigma or personal harms, I posit another foundation that may be involved in the current regulatory consensus to anonymise, thereby gaining access to research sites. Requiring researchers automatically to apply a methodological strategy of anonymisation involves a trade-off: on the one hand, to obtain access to locations and participants of interest, and, on the other hand, the ability of researchers to produce the greatest social benefits from their research. In order to facilitate the former, the latter is forfeited or it is greatly reduced. Through an analysis of two studies that have produced 'less-powerful' evidence of obstetric violence (my own, and a Human Sciences Research Council, HSRC study (Cloete, Simbayi, Zuma, Jooste, & Wabiri, 2015), I argue that this requirement can threaten the power of academic research to best contribute to public interest. In other words, requiring blanket anonymity can render a dataset powerless. While the initial EC regulating my application did not foreclose the proposal of an ethical strategy of disclosure of biographical participant and site details, this approach is legally restricted in the United Kingdom where the standard of anonymisation of captured data is routine.[11] Therefore, this ethical clearance (as well as the additional approvals I was later required to obtain) meant that my research design significantly encouraged my 'complicity' in incorporating 'blanket anonymisation' (Clark, 2006, p. 5). Methodologically for my study, this included anonymising research locations and ensuring confidentiality for all informants. Although confidentiality and anonymisation are different, their processes are connected in that confidentiality entails 'not disclosing to other parties opinions or information gathered in the research process' (Clark, 2006, p. 4). My experience corroborates findings that the EC model has expanded, and through this expansion provides little exception for the disclosure of participants' identities and research locations (Clark, 2006; Haggerty, 2004).

By providing important evidence, academic research has the potential to contribute to the public interest of addressing gender-based violence, which, as was noted earlier, is understood to have an epidemic scope in South Africa (Coovadia et al., 2009; Gqola, 2015; Moffett, 2006). The routine application of anonymity strategies may cause datasets with evidence of violence to be powerless with regard to specific evidence in the public's interest. For example, a nationwide 'Stigma Index Survey' conducted by the Human Sciences Research Council of South Africa (HSRC) revealed evidence of the forced sterilisation of women. The 2014 HSRC study assessed experiences of the stigma of people living with HIV. The study found that 498, that is 7.4% of respondents, 'reported forced sterilization', among other coercive reproductive health practices by the public health system (Cloete et al., 2015, p. 16). The HSRC could not, however, follow up on these serious findings. Professor Khangelani Zuma, Co-Principal investigator for the study, explained to the public the powerlessness of the research team when journalists pressed the issue: 'all respondents to the survey were anonymous and cannot be traced, so action could not be taken against the Department of Health or hospitals at which sterilisations took place' (Child, 2015, June 12, Non paginated). The Department of Health spokesperson, Popo Maja, stated similarly, '[i]t is extremely difficult to investigate the four hundred and ninety-eight cases because the survey was anonymous' (Child, 2015, June 12, Non paginated). In this case the EC requirement of anonymising the research locations and participants deprived a nationally commissioned survey of the information necessary to act on a significant finding of egregious obstetric violence. This example bolsters Haggerty's (2004) argument that academic research, which is constrained by agreements of anonymity, unlike journalistic investigations, can become void of 'political weight' and 'critical' contributions (p. 409).

Clark (2006) rightly asserts that the manner in which anonymisation is applied influences the degree of limitation for the data to be utilised for the public good. Characteristics often deemed relevant only for the background context may in fact be 'crucial for analysis' (Clark, 2006, p. 6). For example, the HSRC survey anonymised the names of hospitals and clinics but not of gender. After their results were made public, it became clear that both markers (hospital and clinic names) were critical for analysis, further research, and the dissemination to relevant institutions obliged to ensure the protection of those seeking healthcare services.

Similar to the weaknesses of the HSRC survey, the requirement of anonymisation for my study resulted in an inability to name the hospitals and professionals perpetrating direct obstetric violence, thereby allowing for the evasion of accountability. I have been unable to document and use specific information for a range of problems relating to obstetric violence and accountability, including routine neglect of services in terms of stock-outs of goods and equipment (e.g., the long-term, of over two years, stock outs of essential sterile equipment); several accusations and observations of likely corruption; numerous accounts of dysfunctional accountability mechanisms including sub-district Directors seemingly not following up on several reports of obstetric violence, including reports leading to foetal/neonatal mortalities; the disclosure of facilities where forms of direct obstetric violence have been observed routinely; and of public servants who have been identified by respondents to have repeatedly abused women during childbirth in primary and secondary facilities. A few examples of the forms of obstetric violence I am unable to report on with specifying information include: *routine* denial of pain medication during active labour; the administration of progesterone-only Depo-Provera contraceptives with lack of informed consent, and at times coercively;[12] egregious abuse of women during childbirth (e.g., unnecessary, and un-anesthetised episiotomies,[13] and those administered without sterile surgical sutures;[14] unnecessary repeated manual vaginal dilation during the second phase of labour, reported as 'almost like sexually assaulting the patient').[15] These practices during childbirth cause additional pain, restrict the power of women, and contribute to risks of maternal and neonatal health. Had blanket anonymity not been required, my study may have offered considerable data about where obstetric violence is taking place. Additionally, it could report to the various regulatory authorities about multiple levels of management responsible for the failure of oversight which, relates to the perpetuation of this particular for of gender-based violence.

Conclusion and Suggestions

This chapter concerns the limitations posed by Ethics Committees' narrow interpretation of ethical conduct. Ethics Review regulations reason that by suppressing or restricting the specific details of a study, the protection of participants and the achievement of the greatest ethical conduct is achieved. To question this thinking, and especially the lack of attention to the social value of research, I have drawn on the regulation of my research into the functioning of a public good, that is South Africa's public health system.

The chapter draws on my experience of applying for, and gaining, the multi-institutional ethics and official approvals required for my study. I found the potential for research to contribute social value in the public interest is not a priority of the Ethics Review model. This, coupled with the expansion of bureaucratic barriers imposed by EC requirements, may contribute to altering the methodological design, and/or preventing public interest research as early as the protocol/proposal stage. Moreover, I found that when research concerns certain public goods, there may be significant opportunities for conflicting interests throughout the review process. I argued that this can lead to avoidable and/or biased decisions which can impact on the social benefits of research. Specifically, I highlighted that in health sciences, academics often have joint posts with public health systems and that this may raise incompatible interests both for members of ECs and within academic institutions. Importantly, while conflict of interests were found during the implementation of my study, my experience illustrates, at times these can be negotiated productively by researchers: by repeatedly providing strong evidence-based justifications for their research, taking an active role in their engagement with EC authorities, and revisiting access to sites that were initially made inaccessible by approvals.

Through an analysis of two studies that found evidence of obstetric violence, I argue that the standard Ethics Review requirement of anonymising identifying characteristics of participants and locations can weaken the contribution of academic research by producing what I call 'powerless datasets'. I found that research can be made powerless through two processes. Firstly, conflicts of interest may limit the scope and intended benefit of a research project by constraining research design, for example, when authorities of a site of research refuse to consider applications for access. Secondly, required anonymity can constrain both intended, and unintended, research outcomes. By constraint, I mean the limiting of a dataset's usefulness to further investigations, and an inability to report specific evidence to vested authorities, for example, to institutions who are legally bound to respond to corruption or violence against women.

Through this analysis I problematise the underlining reasoning that blanket anonymity equates to the strongest approach to ethical conduct. I conclude that perhaps the expansion of the Ethics Review model, and its routine anonymisation requirement, translates to a trade-off, thereby gaining access to locations and participants of interest through the forfeiture of greatest social benefit. And in this way there is often a minimised role academic research can have in the oversight of public goods. I argue this is a weakness as for example, while there are several regulatory bodies vested with the power to scrutinise South Africa's health system, they have been ineffective. This is clear from the consensus that the system is in crisis due to poor governance and oversight (National Planning Commission, 2011; TAC, 19 February, 2015). I argue that academic research can play a critical role if given the chance by institutions and regulatory bodies to prioritise the public interest of research. This is particularly important in contexts, such as South Africa's, where corruption, poor management capacity, and violence are endemic, for instance, in public institutions (von Hodlt & Webster, 2005). If research investments continue to produce powerless datasets, social benefits will continue to be weakened. Instead academic research needs to be acknowledged and used as the major public asset that it is.

While I am critical of the narrow form and application of the Ethics Review model, it is important to mention the reasons that I am grateful for its expansion to the social sciences and its global influence. Firstly, universities possess the power of enforcement to ensure the disclosure and ethical regulation of research. Additionally, the requirement of an Ethics Review process ensures a platform for all researchers to consider the ethical aspects and consequences of the social value of their work. Importantly, the imposition of a regulatory necessity presents an opportunity for the broad consideration of which approaches to ethical conduct best ensure the most commonly held benefit leading to the least individual and social harm. Academic research has brought about considerable critiques of its unethical conduct. This has established a plurality of operational models to which academic institutions and researchers adhere (for instance, see Smith Tuhiwai, 2012). It is telling that the institutionalisation of this variety of epistemic models has been developed by Indigenous and African peoples who have been subject to notoriously unethical research. This shows that the current globalising Ethics Review model, based on Eurocentric bureaucratic regulatory codes, has been found inadequate and in several cases has been replaced.

Given these findings, I recommend the following be considered to address the constraints raised by the current Ethics Review model. Firstly, further evaluation of the performance of the model in relation to intended and unintended outcomes of social benefit is needed. Secondly, the investigation of potential conflict of interest at the differing levels of ethics and officially required clearance should be instituted with each application.

I recommend that these steps are taken by universities and their communities to give broad consideration to which epistemic, cultural, and operational model is best suited to ensure the greatest ethical conduct in their locality. Interestingly, the University of Cape Town has taken steps towards such an approach. Their EC includes 'social value' as an 'ethical requirement' of research (Human Research Ethics Committee, 2013, p. 1). This is described as research '…worth doing. It must be relevant *to broad health and development needs of South Africa* and to the *individual needs of those who suffer* from the conditions under study. Ideally, the findings should translate into mechanisms for improving the health status of South Africans' (Human Research Ethics Committee, 2013, p. 1, emphasis added). The plurality of epistemic models to consider ethical conduct provides a rich starting point for any researcher and EC to better enable their work to powerfully contribute the greatest social benefit.

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Notes

1. Personal interview, 27 October 2013. All names used for persons informing the study are pseudonyms that retain participants' ethnicities.
2. *Black* refers to all of those discriminated against under colonialism and apartheid, namely, South Africans categorised as coloured, Indian, and black African. *African* is used as an inclusive term referring to the people of South Africa or the continent.
3. For ease of reading, I use 'Ethics Committee' and 'EC' to refer to the committees to which I applied for ethical review, which used different names. University of Leeds uses Research Ethics Committee, REC; the University of Cape Town uses Internal Review Board, IRB, and ethics committee for shorthand.
4. Personal communication, Academic Head of Department, Professor Eleanor Grant to a Chief Director, WC Provincial Department of Health, David Claassen 23 November 2010.

5. Ibid.
6. Archive, Academic Head of Department, Professor Eleanor Grant 'Aide Memoir of Meeting with [MOU] Staff' and Hospital Administration 1 July 2011; Meeting Agenda, Attendees Senior Administrative and Professional Directors and Staff, 3 August 2012.
7. Personal interview, Senior Family Physician, Public Day Hospital, Tlou Lekgoathi 27 October 2013.
8. Interview, Academic Head of Department, Professor Eleanor Grant, 3 May 2017.
9. Pharma-Ethics is an independent corporate EC operating in South Africa. It provides reviews of research proposals for fees ranging from 20,200 ZAR (1,500 USD) for clinical trials to 3,000 ZAR (230 USD) for student proposals.
10. Personal communication, Professor Sophie Bunting, Health Sciences, 18 July 2013.
11. In the UK, the Data Protection Act (1998) legally regulates the obligation of researchers and all other capturers of personal data specifically to anonymise data to ensure protection of personal information and participants' identities (Clark, 2006, p. 4). While the Act encourages case-by-case discretion for the granting of exemptions, it does provide for 'personal data that is processed only for research, statistical or historical purposes' to be disclosed (Information Commissioners Office. Retrieved at https://ico.org.uk/for-organisations/guide-to-data-protection/exemptions/).
12. Adding to concern about the coercive administration of contraception is that since at least 1991 scholars have argued that for a variety of reasons progesterone-only injectable contraceptives are risky (Sathyamala, 2000). Increasingly scientific evidence suggests that especially the three-month progestogen-only injectable contraception, commonly known as Depo-Provera, puts women at increased risk of being infected with HIV (Polis et al., 2014, 2016; Hapgood et al., 2018). For example, the results of a meta-analysis shows that women using Depo-Provera have a 40% higher risk of HIV infection compared to women not using a hormonal method of contraception (Polis et al., 2016). Though this scientific point is still under contestation, validation of the strength of these recent conclusions can be evidenced by the World Health Organisation's (2017) shifting of progestogen-only methods to a 'category two' level of risk, which requires health professionals to advise women seeking these contraceptive methods of the potential for an increased risk of contracting HIV (p. 6). An open-label multi-year randomised control trial running predominantly in South Africa, the 'ECHO study' aims to determine conclusively the risk of progesterone-only injectable contraception, and will disclose the findings in 2019. For details, see http://echo-consortium.com.
13. Personal interview, MOU Unit Manager, Midwife, Asanda Mlandu, 26 October 2016 conducted with the participation of the Operations Manager.
14. Observation notes, MOU, 30 September, 7, 14 October 2013.
15. Personal interview, medical student, secondary hospital internship, Thomas Russell, 30 November 2013.

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20

Erasure: A Challenge to Feminist and Queer Research

Jacqueline Marx and Catriona Ida Macleod

Ideological commitments can be difficult to sustain in the messiness of real world research. In this chapter we discuss the development of ethics protocols for two projects taking a feminist and queer perspective, respectively. We show how our feminist and queer commitments were tested during our experience of the ethics review process, and how the path we had to navigate took unexpected turns. Concerns about ethics and the recommendations of research ethics committees can significantly impact on both the nature of a study and the way in which it proceeds. For this reason, it is important to examine critically the conventions upon which research ethics committees' determinations are based. In this chapter we interrogate if, and how, conventions around anonymity and confidentiality can align with the progressive intentions of feminist and queer theory.

Anonymity and confidentiality are intended to protect participants from the risks associated with being identified (Oakes, 2002). We recognise the importance of these protections but argue that it is equally important to be cognisant of their limitations. Our story shows how the imperative to mask participants' identities and the individually identifying characteristics of their lives can both promote and undermine what it means to do ethical research, particularly from feminist and queer perspectives. We argue that the requirement for identity masking cannot be enforced without taking into account historicity and the sociopolitical contexts and power relations in which a

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study and its participants are located. We conclude the chapter by giving some consideration to the potential of a situated ethics approach in critical research and the implications for ethics review processes.

The Story of Two PhD Proposals

Our story begins in June 2006 when I[1] registered to read for a PhD under the supervision of Catriona Macleod. I have a theoretical interest in identity, agency, and resistance and when I registered for the degree I wanted to ground this interest in a study with women who had extricated themselves from relationships in which they had experienced intimate partner violence. The feminist literature that I was reading made me aware of the imperative to observe the processes through which knowledge is produced, and my part in that. I understood that doing feminist research could not be limited to a choice of research topic or a theoretical framework or to methodological decisions regarding techniques for sampling and analysis. Doing feminist research means attending to the ways in which power shapes every aspect of the research process, including conventional ethical procedures.

Developing the ethics protocol for the research was tricky. One question on the ethics protocol template used in our University asks: 'Is provision made to protect subjects' rights to privacy and anonymity and to preserve confidentiality with respect to data?' The question is posed in a way that suggests that such provision is not negotiable: '*Is* provision made?' not '*Should* provision be made?' The expectation was clearly that I should detail how I was going to change or omit any potentially individually identifying information. This is in line with standard ethics requirements, in which, as van den Hoonaard (2003) argues, the imbrication of research ethics in biomedical and quantitative research makes the provision of anonymity appear non-negotiable and the easiest of ethical requirements to apply.

We were, however, bothered by the possible implications of this requirement for doing feminist research. We reasoned that in feminist research that is concerned with women's agency and resistance, the participants themselves should be able to make decisions regarding how individually identifying information would be managed. We agreed that it was problematic to assume that we should make these decisions on behalf of the women, as this could further undermine the agency of women who, by virtue of having been in violent relationships, have experienced challenges to their physical and personal integrity. So we developed an ethics protocol that asked participants to decide how they wanted to manage personally identifying information. In order to assist participants to make these decisions, we drafted a participant information letter and a consent form that described some of the conventional strategies researchers use to mask identity. Suggestions included the use of pseudonyms and the omission of other potentially individually identifying information, such as where they lived and worked. Although we assumed that the women participating in the study were likely to choose to employ some degree of identity masking, leaving the decision in their hands did mean a participant could choose to reveal her identity by opting not to employ an identity masking strategy.

Conducting research with individuals from vulnerable populations requires that special consideration be given to protective strategies such as identity masking because vulnerable participants are generally understood to be particularly susceptible to harm with a limited ability to protect themselves (Larkin, 2009). The term 'vulnerable' is generally used to describe individuals who are considered to have diminished decisional capacity, but it is increasingly being applied more broadly to include individuals in subordinate or dependent relationships (e.g. Council for International Organizations of Medical Science, 2016). This broader application of the notion of vulnerability means that a precise definition is elusive and varies in relation to the context in which it is used (Larkin, 2009). In the context of research with women who had experienced intimate partner violence, we were primarily concerned with the potential to arouse the emotional and psychological harm that the women had experienced. Intimate partner violence can lead to depression and anxiety (Kendall-Tackett & Campbell, 2005) and the negative effects of abuse can persist for some time after the abuse itself has stopped (Ackard, Eisenberg, & Neumark-Sztainer, 2007).

To manage the risks associated with participating in our research, we indicated that only women who had already extricated themselves from the relationships in which they had experienced intimate partner violence would be considered for participation in the study. For the purposes of this research, 'extricated' was defined as having ended the relationship at least six months prior to enrolling in the study. Furthermore, because evidence suggests that the impact over time of different types of abuse and multiple incidents of abuse is cumulative (Bonomi, Anderson, Rivara, & Thompson, 2007), it was indicated that I would request information in brief regarding the intensity and duration of the violence experienced by potential participants prior to enrolling them in the study, and that women who indicated that they experienced excessive violence in their intimate relationships would not be invited to participate. We also argued that if a participant returned to an abusive relationship, either by returning to a previous partner or by entering into a new abusive relationship during the research, I would immediately negotiate the termination of the research relationship. Terminating the research relationship would involve sensitive discussions with the women and possible referral for psychological counselling. This is in line with the recommendations of the World Health Organization (2001) for research on domestic violence against women.

The ethics protocol was first reviewed by a department research ethics committee. Some of the feedback that we received from this committee was useful and was incorporated into a revised ethics protocol. For example, we were advised to give participants an opportunity to indicate that certain sections of the material should not appear in the write-up and public dissemination of the research. Another useful piece of advice was that participant consent should be obtained again at the end of the study so that participants could review their decisions regarding the management of their personal information and the nature of the information they had disclosed in the light of their experience of participating in the research. Although the department ethics committee appreciated our efforts to incorporate their recommendations into a revised ethics protocol, the committee concluded that the revised ethics protocol should be submitted to the University ethics committee for a final determination regarding approval. We viewed this decision as stemming primarily from a concern about potential legal liability rather than the well-being of the research participants, as evidenced in the following point made in their feedback:

> Ms Marx should seek advice from the Department of Journalism, the Law Department and the Dean of Research concerning the manner of write-up so as to reduce the risk of legal action against the researcher, the supervisor and the University by a third party (specifically the alleged abusive partner) in cases where the participant does not opt for anonymity.

Furedi (2002) has argued that research ethics committees are sometimes more concerned with averting litigation than in ensuring that researchers act in the participants' best interests, and this certainly seemed to be the case in this recommendation.

The legal advice we obtained was that there is scope within the parameters of the South African law to have proceeded with the proposed research without exposing the participants, the University, or ourselves to serious risk of litigation. In collecting women's accounts of intimate partner violence our focus centred on narratives pertaining to identity, agency, and resistance. While we expected that these narratives would be constructed in relation to their experiences of intimate partner violence, it was not the details of the violence itself that were of concern to us. Our research was also not about the male partners who had perpetrated the abuse. Unless the male partners came forward and identified themselves as the perpetrators implicated in the women's narratives, it is highly unlikely that they would have been identified as a result of this research. A statement to this effect was inserted into the revised ethics protocol before it was submitted to the University ethics committee for review.

In December 2007 we were informed that the University ethics committee did not approve the study. The University ethics committee reiterated the concerns raised in the department review but also contended that the women who would be participating in this research could not fully understand the implications of the risks associated with being identified and, consequently, that this decision could not be left up to them. We were taken aback by this claim because we had assumed that no one was better positioned to make a decision regarding the potential risks of being identified than the women who had experienced the violence first hand. I was also disappointed that, in the 18 months during which the protocol had been reviewed, no one had addressed an ethical concern that was foremost in my mind: that the women participating in this research were never going to speak for themselves; I was the one who would be representing their stories and, consequently, the one who ultimately would decide what was and what was not revealed. There is considerable debate on the problem of speaking of and for others and, in this debate, key concerns arise regarding the politics of location and representation (Alcoff, 1991; Clifford, 1983; Mohanty, 1995; Rich, 2003), but concern for the way in which these issues would be navigated did not feature in any of the feedback we received.

The University ethics committee never explained the basis of their assumption that the women who I intended to interview were incapable of understanding the risks associated with their participation in research on agency and resistance in the context of intimate partner violence. Respect for autonomy is a fundamental research ethics principle and it is an obligation to respect the decision-making capacities of individuals (Israel & Hay, 2006). This principle is the basis of the imperative to obtain informed consent, but also to recognise and to respond to those instances in which an individual's capacity to provide informed consent is diminished (Israel & Hay, 2006). In the research ethics literature, particular groups of people are identified as being less likely, either temporarily or permanently, to have the decisional capacity to provide informed consent. Examples of some of these groups of people are young children (Allen, 2002; Bruzzese & Fisher, 2003), people who are very ill (Casarett, 2005), people who are intellectually disabled (Iacono, 2006), and people with mental disorders such as schizophrenia (Carpenter et al., 2000) and dementia (Hellström, Nolan, Nordenfelt, & Lundh, 2007). In this literature it is acknowledged that central to the question of decisional capacity is an individual's ability to understand the information provided to them about the research and, in relation to that, to be able to evaluate properly the implications of being involved in it. As the women who had experienced intimate partner violence were not impaired, too sick, too young, or too frail to consent to participate in our research, the University ethics committee's failure to respect their autonomy appears to have been inappropriate.

Edwards, Kirchin, and Huxtable (2004) critique what they refer to as the paternalistic tendency of research ethics committees to negate individual autonomy when the risks associated with participating in research are deemed to be more than minimal. Their position is that if individuals have the decisional capacity, are fully informed about the risks, and have the autonomy necessary to make a decision regarding consent, then they should be allowed to do so and this should not be undermined by a paternalistic ethics review committee. Indeed, no matter how well intentioned in a protectionist discourse, the University ethics committee's decision regarding our protocol for the study on intimate partner violence infantilised prospective participants in assuming a lack of understanding of the implications of participating in the research.

All I had to show after nearly two years of being registered for PhD study was a hefty student fee account and the knowledge that choosing to do something out of the ordinary in terms of established research ethics conventions had been a bad decision. Also I had to decide whether to deregister or to start over on a new research project. At a particularly low point, a good friend took me on a night out to a local gay bar that was staging a drag show. While watching the show, I found myself thinking that drag was precisely the example that Judith Butler had used in her seminal text *Gender Trouble* (1990), which had developed so much of the debate on agency and resistance. The performances that my friend and I were watching, however, did not just employ gender parody. Representations of race and class played a role in determining their range of connotative meaning, shaped as they were by the specificities of the South African sociopolitical context. In these performances I saw an opportunity to start over, retaining my theoretical interest in agency and resistance, and locating the enquiry in practices of dressing-up, cross-dressing, and drag—in spectacles that historically have been used to make gay men and lesbian women visible.

Having learned a lesson about keeping within the parameters of research ethics conventions, we developed a conservative ethics protocol that put us firmly in charge of protecting participants' rights to privacy and anonymity. Although we still felt uneasy about undermining participants' agency with regard to the management of identity masking, there was an aspect specific to this new setting that helped to justify acquiescing in the demands of the ethics committees. Early on in my engagement with the drag performers, I observed that most were better known by their stage names. This gave us the idea, in preparing the new ethics protocol, to suggest that participants could choose their own pseudonym and that the pseudonym could be their stage name. In this way participants were able to manage their identities to some degree. For some participants choosing to be identified by their stage name meant being identifiable to others in their community. Having found a new location in which to ground the research inquiry and with a new conservative ethics protocol in place (at least on the surface of things), we received ethics approval for the study in a matter of weeks.[2]

The Role of Anonymity and Confidentiality in Silence and Erasure

While the research project on drag concluded some years ago (Marx, 2011), our concern remains about the imperative automatically to change or erase research participants' names and the distinctive individually identifying aspects of their lives. In a recent communication with the editor of a collection of queer African scholarship, I had to explain that I could not disclose the name of the town in which the bar where the drag performances were staged is located because this would be contrary to provisions in the approved ethics protocol. The editor's response was that this requirement had 'forced a whole lot of people in your research back in the closet'. Her remark is poignant because in the process of collecting data for the research on drag performance, I became aware that for some of the older participants, some of whom were in their eighties, participating in the research was an opportunity to talk about their lives—and the events shaping their lives—that had been subject to the violence of public erasure. This public erasure was particularly pertinent in South Africa during apartheid, when the state prohibition of same-sex intimacies was intensified through the enactment of a variety of laws that sought not only to regulate same-sex relationships but to render the lives of gay men and lesbian women invisible. The criminalisation of drag under the Prohibition of Disguises Act (Republic of South Africa, 1969) is an example of the latter.

Similarly, although we did not conduct the research with women who had extricated themselves from relationships in which they had experienced intimate partner violence, research in South Africa shows how intimate partner violence is experienced by women through a lens of power and control, with men enforcing women's adherence to the narrow role of 'wife' (Boonzaier, 2008). This miniaturisation of women's lives through violence erases their agency not just publicly, but in the domestic realm too. And, in line with the sentiments of the abovementioned editor, we argue that refusing women the right to an informed voice through research participation contributes to the erasure of their agency. Furthermore, as one of the reviewers of this chapter observed, by disallowing our research on women's experiences of intimate partner violence, the University ethics committee contributed to the invisibility of domestic violence.

Nelson (2000) argues that the examination of the social processes through which issues are constructed as ethical concerns is a valuable contribution from the social sciences in the debate on ethics. In research with women who have experienced intimate partner violence, and in research on drag and the fashioning of queer visibilities, it is interesting to consider the conditions under which these particular groups of people are assumed to constitute vulnerable populations requiring special protection, and the ethical limitations of conventions such as identity masking.

A standard account of the history of the development of research ethics invariably begins with reference to the Nuremberg trials and details of Nazi medical experiment abuses, as well as other problematic medical studies prompting the development of research ethics guidelines such as The Nuremburg Code (1949), The Belmont Report (Department of Health, Education and Welfare, 1978), the Declaration of Helsinki (World Medical Association, 1964), and the Council for International Organizations of Medical Science (2016). It is in these guidelines that anonymity and confidentiality are conceptualised as strategies to protect participants from the risks associated with participating in research, and the rights to this protection solidified in the principle of autonomy and respect for persons. While emphasis on the rights of participants to anonymity and confidentiality needs to be viewed in the context of the potential for research to exploit participants, the question of autonomy must, equally, include the right of participants with full information and decisional capacity to forego anonymity and confidentiality.

In recent years, researchers in a range of research areas, but particularly in the context of participatory research and research with historically marginalised groups, have begun to challenge unqualified assumptions about anonymity as being in the participants' best interests (e.g. Dube, Mhlongo, & Ngulube, 2014; Evans, 2004; Le Roux, 2015). In some cultural contexts being shielded by a pseudonym is seen as cowardly (Tilley & Gormley, 2007), and the uncritical acceptance of anonymity generates concerns about representation, voice, and authorship in research which involves historically marginalised groups (Berkhout, 2013; Martin-Hill, 2008; Svalastog & Eriksson, 2010). Among these researchers it is argued that undermining participants' self-determination is not only paternalistic, but also reminiscent of colonial rule (Dube et al., 2014). In the light of this, it is important to ask why, as seen in our case, anonymity and confidentiality are constituted as special ethical concerns in research on intimate partner violence and queer visibilities.

Arguably, in the context of the proposed research projects, cisgendered heterosexual women and queer people are presumed to constitute vulnerable populations because of a history of violence. At the root of this violence is their presumed threat to heteropatriarchy. This is certainly a common theme emerging in much of the research on intimate partner and homophobic violence in South Africa where violence is constructed as a method of correction: a way of remedying what is perceived as the transgression of their place in society by women and sexual minorities (e.g. Jewkes, Penn-Kekana, & Rose-Junius, 2005; Moffett, 2006). This is why, in South Africa, the rape of lesbian women is colloquially termed 'corrective' rape (Nel & Judge, 2008, p. 24). This violence works vicariously to silence or closet the will for a more liveable life. In this context, the decision to speak out about one's experiences can be read as a sort of 'coming out'; and pushing back against power relations that operate through mechanisms of silence and erasure makes this coming out interpretable as a form of resistance. Looking at the issue of identity masking from this perspective, the imperative for anonymity and confidentiality can be seen as perpetuating the silencing and closeting of people whose lives have historically been subject to erasure, as well as undermining their attempts to challenge the regulatory frame that justifies their subjugation. Under these circumstances it is difficult to see how anonymity and confidentiality are *necessarily* in the participants' best interests. Thus, we argue that while commitments regarding anonymity and confidentiality are intended to protect participants from the risks associated with being identified, the strategies by which such commitments are achieved have different implications for different social groups and can even undermine what it means to be ethically responsive.

This does not mean that we view visibility vis-à-vis revealing one's identity in research as a panacea for the violence of erasure. We know that visibility, in the Foucauldian sense, is also a mechanism for surveillance and control (Foucault, 1977). In South Africa in the past two decades, legislative changes and debate on gay and lesbian families have been instrumental in affirming queer rights. The growing affirmation of queer rights and visibilities, however, has been undermined by a parallel growth in violent homophobia and transphobia (Nel & Judge, 2008). What we are suggesting is that those whose lives are on the line should be recognised as being best placed to make decisions regarding the risks associated with visibility, as well as concealment. This, we believe, is best dealt with through a situated ethics approach.

A Situated Ethics Approach

Substantial feminist, post-colonial, and queer scholarship (e.g. Butler, 1990; Haraway, 1988; Spivak, 1988) has problematised universals. The argument in this scholarship is that knowledge is situated and perspectival can be applied to ethics too. Situated ethics is an approach to ethics that places deliberations on ethics in the specific and complex contexts in which research practices are located. While a situated ethics implies opposition to universalism, Simons and Usher (2000, pp. 1–2) argue that taking a situated ethics approach does not necessitate a complete rejection of 'universal statements or principles of a general nature', but demands that we acknowledge that these are 'mediated within different research practices' in local and specific contexts and will thus take on 'different significances in relation to those practices' and contexts. Taking a situated ethics approach means understanding that the inevitable 'weighing up [of] often conflicting considerations and dilemmas' that research occasions cannot be resolved easily by appealing to 'unambiguous and univalent principles and codes' (Simons & Usher, 2000, p. 2). While principles and codes provide guidance on ethical decision-making, Piper and Simons (2005, p. 58) note that '[e]thical practice depends on how principles are interpreted and enacted in the precise social-political context of the research'. In the context of feminist and queer research, a situated ethics approach allows critical researchers to examine relations of power without assuming that subordination exists, or how it exists, or what form it takes, or what it necessarily enables or constrains. This is not to argue for a relativist position on ethics, but rather for a view of ethics as a practice in which we critical researchers negotiate our relationship with the requirements and restrictions of competing ethical imperatives.

It has been argued that the development of ethics protocols and the ethics review process would be easier to navigate if research ethics principles were less ambiguous and more clearly defined than at present, and there have been some notable attempts in this regard (e.g. Emanuel, Wendler, & Grady, 2000; Emanuel, Wendler, Killen, & Grady, 2004). The problem, however, is that although practical guidelines around issues such as anonymity and confidentiality can be quite useful, they can also narrow down what is considered permissible. Arguably, as a set of universal commitments, research ethics principles are necessarily broad and it should be the responsibility of the researcher to translate these requirements in relation to the specificities of the proposed research. In doing so, we critical researchers demonstrate our competence to recognise and engage with the ethical issues arising in the context in which our research is located.

A situated ethics approach to anonymity and confidentiality would require speaking to dilemmas in such a way as to locate them within the power relations operational in the specific context. Figueroa (2000, p. 98), for example, asks ‘Does respecting anonymity and confidentiality override antiracism?’ The answer to this question is complex, and depends on the situation. In the first instance, there is the question of the limits of confidentiality, and the circumstances (e.g. a direct threat of harm to self or others) that justify or require researchers to break confidentiality. So, researchers may be justified in breaking confidentiality when this promises to prevent a racist attack or one motivated by sexism or homophobia. In the second instance, how racism, or sexism, or homophobia plays out may be subtle and the harms less overtly visible, but no less insidious. Does the harm caused by racism, sexism, or homophobia uncovered in research outweigh the harm caused by breaking confidentiality? Third, and most pertinently in terms of our research proposals, is it possible for ethics review committees to adopt a situated ethics approach which allows for nuance regarding the initial requirements of conventional considerations such as anonymity and confidentiality?

Implications for Ethics Review

As our story of the two PhD proposals illustrates, our interpretation and application of ethics principles must convince research ethics committees that we are planning to do ethically responsible research. Unfortunately, research ethics committees are not always able to recognise our efforts in this regard. In some instances medical experts are over-represented on university research ethics committees (de Vries & Forsberg, 2002; Moodley & Myer, 2007) and, even when this is not the case, committee members still tend to be unfamiliar with the aims and methods of social science research and are thus inclined to apply ethics principles inappropriately to critical research (Gallant & Bliss, 2006; Louw & Delport, 2006).

Concern about diverse disciplinary skills and knowledge is gradually being translated into revised guidelines for the composition of research ethics committees. These guidelines generally acknowledge that research ethics committees require a broad range of expertise in order to evaluate properly the various aims and methods of research proposals and to reconcile these with the various ethical implications that such research occasions (Eckstein, 2003). Unfortunately, while diversity in disciplinary expertise is important, it does not eliminate the potential for various social biases to undermine the mandate to protect participants’ best interests.

It has been argued that race and gender biases, among others, account for some of the inconsistency in research ethics committees' deliberations and decisions (de Gruchy & Lewin, 2001; Malone, Yerger, McGruder, & Froelicher, 2006; Sikweyiya & Jewkes, 2011). For example, in South Africa, it is at least partly in recognition of our political history, and the resultant and ongoing asymmetrical power relations between different social groups, that national guidelines regarding the composition of research ethics committees specifically requires race and gender diversity (Department of Health, 2015). While regulatory requirements regarding the composition of research ethics committees vary from one country to the next, there is a growing trend worldwide to ensure that research ethics committees reflect diversity on a growing number of factors which, in addition to gender, race, and ethnic diversity, often also stipulate age diversity and the inclusion of persons with disabilities. Further requirements are to include lay persons qualified to represent diverse community and cultural values, as well as representatives of populations specifically targeted for study (Eckstein, 2003).

While these developments are to be welcomed, it is equally important, we argue, to have ethics reviewers who are au fait with critical theory and methodology (in our case, feminist and queer theory) reviewing ethics protocols that speak to the nuances of ethics in relation to dimensions of social difference. These reviewers need to be able to read with, rather than against, the researcher, making constructive suggestions as to how the ideological and political agenda inherent in critical research may be dealt with in an ethically sensitive manner. Instead of the standard question, 'Is provision made to protect subjects' rights to privacy and anonymity and to preserve confidentiality with respect to data?', ethics review committees should encourage researchers to engage in the question of whether anonymity and confidentiality need to be applied, what the benefits and harms are in each option, and how nuanced forms of identity management can be applied in the context of the particular research and the power relations inherent in the encounter.

Conclusion

We agree with those who have argued that our engagement with research ethics should not begin or end with the ethics review process (e.g. Haggerty, 2004). Indeed, it was only when we sat down to draft this chapter that we first paused to consider how our inclusion and exclusion criteria for the research project on women who had extricated themselves from relationships in which they had experienced intimate partner violence had also undermined, albeit inadvertently, the women's agency to choose whether or not to participate in our research. We must acknowledge, however, that the ethics review process is an important opportunity to think about the potential challenges and dilemmas that our research occasions. We have argued, using our two PhD proposals as examples, that the application of anonymity and confidentiality should, at the ethics review stage of the research process, not be applied formulaically or without deep consideration of the implications thereof, particularly if the research is located in a critical paradigm. We also argue for the benefit of including reviewers with similar research experience who are familiar with critical approaches. Most importantly, however, is the fact that the political utility of critical inquiry is undermined when we are forced to acquiesce to ethics conventions that stubbornly refuse to acknowledge participants' agency and autonomy.

Notes

1. In this chapter 'I' indicates the voice of the first author. 'Our' and 'we' are used to indicate the voices of both authors and refer to our research partnership.
2. Ethics approval was obtained in 2008 from the Research Projects and Ethics Review Committee (RPERC), Psychology Department, Rhodes University.

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Section 4

Researching ‘Down’, ‘Up’, and ‘Alongside’

21

Introduction: Researching 'Down', 'Up', and 'Alongside'

Jacqueline Marx and Gareth J. Treharne

All research is inherently political and reflects differentials in power relationships. What differentiates critical research from other modes of inquiry is that critical social and health researchers commonly foreground a commitment to addressing the inequalities, inequities, and power differentials that impact on personal and social wellbeing. This commitment is demonstrated time and time again in the stories from the field upon which the chapters in this book are based. To focus on ethics in the context of doing critical social and health research also occasions critical reflection on our own conduct and its imbrication in those same relations of power we seek to challenge. The title of this section of the book describes different researcher-researched power hierarchies. In this introduction we outline a debate on the ethics of researching down, up, and alongside and the special contribution of each of the chapters in this section to this debate. The first of these three conceptualisations of research relationships arises from critiques of the disjunctures of power that occur when participants are researched down upon and potentially exploited or harmed. By contrast, researching up is a conceptualisation of power held by individual participants or institutions that hold sway over the research. A steadier balance is sought when researching alongside individuals or

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institutions as partners, though not without opportunity for exploitation or sway without ongoing labour on the part of the reflexive critical researcher. We conclude our introduction to this section of the book by giving consideration to the enactment and limitations of reflexivity and rigour in navigating complex research relationships and the conduct of ethically responsible research.

Researching Down: The Critical Researcher's Power and Responsibility

Researching 'down' is a term that emerges in debate on the powerful position of researchers relative to those who are researched. It is an issue initially taken up by feminist and anti-racist scholars (e.g. Crenshaw, 1991; Kobayashi, 1994; Patai, 1991), but more recently by queer (e.g. Allen, 2010; Schlichter, 2004) and disability scholars (Charlton, 1998; Goodley & Moore, 2000; Stone & Priestley, 1996) who are similarly concerned about misrecognition, misinterpretation, and misrepresentation in research undertaken by 'outsider' (Bridges, 2001, p. 371), 'malestream' (Oakley, 1998, p. 707), 'heterosexist' (Herek, Kimmel, Amaro, & Melton, 1991, p. 1), and 'cisnormative' (Bauer et al., 2009, p. 353) researchers, and the implications of this for the way in which knowledge is mobilised. While these concerns have found their way into relational and situational approaches to research ethics, ethics governance and the bureaucratic assemblages constituted under that mandate are, in the main, geared towards a principalist approach (see Beauchamp & Childress, 1979). Non-maleficence, a principle requiring researchers to minimise the risks of harm or discomfort, is given additional consideration when researching 'down' because of an increased risk for exploitation. In such instances, ethics approval is generally contingent upon researchers having additional safeguards in place. Thus, an interesting aspect of the debate on researching 'down' is that researchers are simultaneously positioned both as a potential threat to participants' best interests and as the people responsible for protecting them.

Emmanuel Mayeza (2018, this section) discusses his experiences of the salience of his gender in deliberations of the ethics of his ethnography of young school children's constructions and experiences of gendered play. Mayeza's story starts with an account of the peer feedback he received early on in the research process, after presenting his research proposal at a faculty meeting. He describes how he experienced feedback that drew unproblematically on assumptions about childcare being 'women's work' to undermine his suitability for undertaking the research, an issue that was further complicated by inferences regarding the presumed threat that masculinity posed which underpinned concerns regarding children's safety. Mayeza's experience is not unique; others have reported on the suspicion with which male caregiving is viewed (Evans, 2002), particularly when it involves children (Scourfield & Coffey, 2006). Moreover, it has been argued that male researchers are likely to have to negotiate additional safeguarding concerns from gatekeepers of access to participants who are children (Duncan, Drew, Hodgson, & Sawyer, 2009; Horton, 2001). It is also argued that, more important than the gender of the researcher, is an ability to recognise when children are anxious or distressed and to respond appropriately (Connolly, 2008). Interestingly, as Mayeza goes on to explain, it was this concern that was at the forefront of the research ethics committee's consideration of his proposed research.

Rather than focusing on the threat that Mayeza's masculinity presumably would pose, his institutional research ethics committee assumed that he would use his 'powers', as an academic researcher, to protect the children. They also expected that his competency to do this would be demonstrated in the safeguards described in his ethics protocol. Mayeza argues that his peers' feedback left him ill-prepared for the expectations of the research ethics committee. He also argues that the research ethics committee's assumptions about the diminished capacity of children to exercise agency and control over their lives, as evidenced in their assumptions about the children's need for protection, left him equally ill-prepared for the field. There, Mayeza experienced children who wished to take control over decisions regarding the ownership of data such as their drawings and in the management of the individually identifying information of their names on the drawings.

Brigit Mirfin-Veitch, Jenny Conder, Leigh Hale, Gareth Treharne, and Georgia Richardson (2018, this section) draw on two studies designed to facilitate the active involvement, in research, of people with learning disabilities. The authors argue that adopting the social model of disability, characterised by an inclusive approach to disabilities research, is an appropriate counter to the mainstream medical model of disability which positions people as passive subjects to be tested, observed, and excluded from the production of knowledge about them. They also argue, however, that inclusive research approaches can be potentially problematic. Specifically, radical inclusivity requiring full participation in each stage of the research process, from conceptualisation through to analysis of data and the presentation of findings, can risk excluding people with disabilities who may not want to be involved at all stages of the research process, or whose participation in any or all aspects of the research requires assistance from third parties. The research outlined in Mirfin-Veitch et al.'s chapter presents two stories which, while intending to be inclusive, also respond to individual needs, preferences, and contexts. Both stories are followed by a discussion of the particular strategies which aim to improve responsiveness, consideration of the ways in which the research could have been more inclusive, and a discussion of the challenges encountered. A particular strength of this chapter is that the authors have drawn on their research experiences to develop a summary of ideas for achieving increasingly responsive research with people with disabilities. These ideas provide guidance on recruitment, informed consent, approaches to interviewing, and communicating research-related tasks.

Researching Alongside: The Critical Researcher as Ethical Research Partner

Guillemin and Gillam (2004, p. 261) distinguish between procedural ethics—the process of ethics review, which is sometimes also referred to as regulatory ethics—and 'ethics in practice', a term they use to refer to ethics in the actual conduct of research. For critical social and health researchers, ethics in practice involves a critical consideration of a range of issues, including the values that researchers bring to the field and the premises upon which they operate. While researchers have historically 'claimed and maintained considerable power over the research process', practitioners of participatory action research argue that 'it is necessary to carry out research "with" people rather than do research "on" them' (Hammersley & Traianou, 2012, p. 51), and this requires 'that the outside researchers and the local community members (practitioners of their own lives) collaborate on a more equal footing than in the traditional [researcher-researched] relationship' (Denzin & Giardina, 2010, p. 117).

Jacqueline Lovell and Jacqueline Akhurst (2018, this section) discuss a participatory action research project that evaluates the impact of various initiatives undertaken by *developing partners*, a social enterprise organisation led and run by people with long-term mental health needs. The evaluation team, consisting of members who had both delivered and used the services offered by the organisation, were committed to delivering an evaluation that reflected diverse individual and collective experiences; they realised that doing this necessitated engaging in a fully collaborative evaluative process. Lovell's and Akhurst's account of the evaluation process demonstrates some of the challenges collaborative research occasions, such as the complexities of negotiating, and re-negotiating, those outcomes that are valued and pursued. It also demonstrates the importance of having a methodology that is flexible and responsive to the diverse needs and abilities of the people involved, the implications of which are not always apparent from the start. Lovell and Akhurst discuss creative methodological amendments implemented 'on the run' so that the people involved remained in control of the evaluative process. Their stories demonstrate that, while the goal of participatory action research is to make practical improvements in people's lives, it also needs to shift the balance of power in favour of those who have traditionally been marginalised. Indeed, it is argued that the commitment to democratic engagement in participatory action research is what makes it a political form of inquiry (Reason & Bradbury, 2001).

Researching Up: Critical Research on the Powerful

Researching 'up' describes researcher-researched relationships in which the researched maintain considerable power. The issue was brought to the fore by Nader (1972) who argued that it is just as important to research the cultures of the powerful as it is those of the powerless. At the time, it had been observed that, although the subcultural lives of 'nuts, sluts, and perverts' had warranted considerable exploration and analysis, researchers had demonstrated little concern over 'the unethical, illegal, and destructive actions of powerful individuals, groups and institutions' (Liazos, 1972, p. 111), an asymmetry suggesting that 'full citizenship and cultural visibility [were] … inversely related' (Rosaldo, 1989, p. 189). Although there are important reasons to examine how power is exercised, there are significant obstacles to doing this type of research. While some fields are relatively easy to access, it is much more difficult to gain access 'when representatives of prospective research sites see their work as being sensitive and would prefer to avoid outside scrutiny' (Monahan & Fisher, 2015, p. 709). In such instances, researchers are likely to have to negotiate access via institutional gatekeepers, and successfully negotiating gatekeeper permission generally involves entering into a contractual agreement describing the conditions under which access to the field is permitted.

Jason Bantjes and Leslie Swartz (2018, this section) tell the stories of two critical organisational ethnographies. In the first story, Bantjes, while working as a school counsellor, witnesses an incident at the school where he works. Believing that the incident raises interesting questions, not just about the behaviour of the group of boys involved, but about the institutional culture of the school, he endeavours to obtain permission to research the incident and the context in which it arose. Bantjes and Swartz describe how, by agreeing on 'safeguards' to protect the school, which included making the school principal the final authority on decisions regarding the publication of the research findings, Bantjes was successfully able to negotiate the requirement for institutional permission. Upon reflection, however, Bantjes realises that although he initially did not foresee significant ethical issues associated with doing the research, neither he nor any other of the stakeholders (the school principal, teachers, scholars, parents, school board) could anticipate the full extent of what might have emerged in the actual conduct of the research. Consequently, in agreeing to the safeguards, he had inadvertently handed over power to censor information that might have been in the public interest, or in the best interests of some of the stakeholders, though critical of others. The story is interesting because insider practitioner research in educational settings is extremely common, but relatively little has been said about the impact of institutional hierarchies and the conflicts of interest such hierarchies occasion on the ethical conduct of research.

In the second story, Bantjes and Swartz discuss critical ethnographic research with in-patient hospital care for people who had attempted suicide. Unlike the school ethnography in which Bantjes negotiated multiple roles (employee, colleague, school counsellor, researcher), the 'outside' researcher role in the hospital ethnography was much more clearly bounded. However, as ethnographic research involves spending significant periods of time in the field, it inevitably results in increasing familiarity and the erosion of an outsider identity; as Bantjes's and Swartz's story illustrates, familiarity makes relationships more complex and introduces a range of competing ethical imperatives. On the one hand, there was the imperative to promote the interests of the public who are affected, positively and negatively, by varying standards of care. On the other hand were the rights of the hospital staff inserted into, and reproducing, institutionalised practices which promote, but at times also undermine, those same standards of care. In both stories, Bantjes and Swartz draw on insights derived from situational and relational approaches to ethics in order to think through competing ethical imperatives.

Marco Marzano (2018, this section) provides a frank and provocative discussion of the ethics pros and cons of covert ethnographic research. This discussion is based on his experience of ethnographic research in hospital wards and charismatic groups linked to the Catholic Church. In each of these settings, Marzano discusses how he began by openly negotiating access to research sites with the official institutional and organisation gatekeepers, just as researchers are required to do. In each instance, however, Marzano encountered gatekeepers who granted access on the condition that he mask his researcher identity which is quite the opposite of common notions of seeking informed consent from participants. On the hospital wards he was to be a medical intern and at the church meetings a new or prospective convert. These roles involved minimal deception in that they were only intended to provide a convenient and plausible cover for his being there (which was essential for him to make the necessary observations), and was not a disguise for tricking people into confiding in him. Nevertheless, it did mean that some of the people who he would be observing would not know the true purpose of his being there. Although Marzano was uncomfortable with the gatekeepers' terms, he acquiesced in order to be able to proceed with research that he believed was in the public interest. This scenario creates an interesting point of distinction from the common assumption that ethnography is covert at the wish of the researcher rather than that of the gatekeeper.

In the history of the development of research ethics, there are numerous accounts of research involving deception and resulting in significant harm to participants (Arras, 2008; Baumrind, 1964; Brandt, 1978; Orne & Holland, 1968). Consequently, as Marzano points out, it is very difficult in the current regulatory environment to obtain ethics clearance to conduct research involving deception. While scandals about deception in harmful research continue to emerge (e.g. Smith, 2011), there are growing calls for a more nuanced debate that distinguishes between different types of harm and the role of power in mitigating both risk and consequence. In the context of research that is located in state institutions, corporations, and other large organisations, and particularly when the focus of the inquiry is on the practices of the organisation rather than on the individual lives of clients or patients, the traditional conceptualisation of research participants as private individuals is potentially problematic. In particular, because it obscures those contexts in which participants act 'as agents which are corporate, collective, social, public or in some other form engaged beyond' who they are in their private lives (Langlois, 2011, p. 148). In such circumstances, agents are afforded greater 'authority, power, prestige, influence, [and] stature' (Langlois, 2011, p. 148). In these instances, Langlois (2011) does not believe that the usual protections afforded to private research participants can, or should, apply. It is argued that institutions, corporations, organisations, and the officials who represent them should not be seen as analogous to private individuals, and that we 'should not assimilate them to the same ethical paradigm used to discuss responsibilities towards [private] people' (Aldred, 2008, p. 12). Otherwise, researchers who discover business, institutional, or organisational practices that put people in harm's way will have to give equal consideration to the likely reputational, financial, and legal harm that would be the consequence of making such information public.

Power and Reflexivity: On the Righteous Simulation of Ethics

It is argued that '[w]ithout rigor, research is worthless, becomes fiction, and loses its utility' (Morse, Barrett, Mayan, Olson, & Spiers, 2002, p. 14). Thus, comparable with rigorous adherence to methodological rules for ensuring validity and reliability in quantitative research, qualitative researchers have been concerned with devising evaluative criteria for establishing the trustworthiness of qualitative research (Riggs & Treharne, 2015). Trustworthiness, it is argued, is 'a matter of persuasion' (Sandelowski, 1993, p. 2) requiring the researcher to provide a decision trail so that readers can verify the soundness of the research process and the legitimacy of the researcher's claims (Sandelowski, 1986). Criteria such as credibility, transferability, dependability, and confirmability are said to be achieved by employing member checks, memo writing, bracketing, peer review, and triangulation. One implication of the development of these methods for establishing trustworthiness is the suggestion that 'it is method and method alone that "produces" findings' (Schwandt, 1996, p. 60). The privileging of methodological concerns, sometimes termed 'method-fetishism' (Koch, 1981, p. 260) or 'methodolatry' (Chamberlain, 2000, p. 285), can suggest that processes of knowledge production do not require 'moral and political speculation' (Schwandt, 1996, p. 61). Unsurprisingly, critical researchers have found this assumption untenable. For Lather (1993, p. 675), validity in qualitative research 'is not a matter of looking harder and more closely, but of seeing what frames our seeing' and doing this requires 'reflexive exploration of our own practices of representation' (Woolgar, 1988, p. 98, cited in Lather, 1993).

In the last chapter in this section of the book, Eric Stewart (2018) engages in a meditation on the difficulties and contradictions involved in representing the other in research, especially when we try to transcend dominant representational practices. In doing so, Stewart also interrogates implicit assumptions about the researcher and, drawing on psychoanalytic notions, explicates how this constitutes an ethical tension. Arguing that it is insufficient to ground notions of ethics in rationality or simplistic humanism, Stewart suggests that we should consider the inescapable complexity, and dangers, at hand in any act of representation. The chapter provides a fitting conclusion to this section of the book because reflexivity is an issue that emerges in debate about our relationships in the field.

To be reflexive is to concede 'that all knowledge bears the impress of the social relations entailed in its production, including the complex power relations between researchers and research participants' (Bondi, 2009, p. 328). By engaging in reflexive practice, critical researchers 'have sought to respond to power inequalities that cannot necessarily be overcome, undone or even predicted, but which can be thought about and acted upon' (Bondi, 2009, p. 328). In holding out the promise of ameliorating at least some of the negative impacts of power differentials on processes of knowledge production, reflexivity has become 'a defining feature' of critical social and health research (Finlay, 2003, p. 5). The increasing prominence of reflexivity is not without criticism however. In the context of our relationships in the field, whilst reflexivity provides a means to examine uneven power relations, it does not necessarily interrupt those relations of power and, as Stewart (2018, this section) argues, can even perpetuate them by reifying the notion of a 'truly conscious' researcher honouring moral and ethical obligations in the conduct of rigorous research.

In writing about their experiences of researching up, down, and alongside, the authors of the chapters making up this section of the book have put into practice what Richardson (1993, p. 516) calls 'writing from our selves'. It is a strategy that is employed to mark one's own voice among other voices and to acknowledge that what is presented as knowledge is constructed from particular authorial positions. We do this to dispel the idea that we are speaking as 'transparently knowable agent[s]' (Rose, 1997, p. 309). But we would also do well to remember that there are limits to reflexive insight. On this issue, Pillow (2003, pp. 188, 192) argues that we should let go of our 'comfortable' uses of reflexivity and should experiment instead with 'uncomfortable' reflexive practices that lay bare the messiness of research that unsettles or disrupts the processes of knowledge production and legitimation. This is what Stewart attempts in the final chapter when, in a deconstructive move, he foregrounds his authorial voice in order to challenge its power to interpret peoples' lives and to critically examine the aetiology of his own psychic investments.

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22

Ethical Research and the Policing of Masculinity: Experiences of a Male Researcher Doing Ethnography with Young School Children

Emmanuel Mayeza

This chapter explores the gendered dimensions of the ethical and relational dilemmas I experienced as a male researcher undertaking ethnographic research with young school children. Drawing on the work of Barrie Thorne (1993), Glenda MacNaughton (2000), Emma Renold (2005), Barbara Martin (2011), and Deevia Bhana (2016), my research used a critical child-centred ethnographic approach with the aim of 'learning from the learners' (Pattman, 2013, p. 119) about gender in the context of a South African primary school. In particular, I was interested in exploring how South African children construct gender identities through play activities in school playgrounds. My research drew on post-structural feminism in which gender is viewed as socially constructed and dynamic, rather than fixed and static (MacNaughton, 2000). Post-structural feminism critiques essentialist approaches to gender which often naturalise different social roles, ways of being, and behavioural patterns (Martin, 2011). In contrast, post-structural feminism challenges the various social mechanisms and processes that restrict options for those designated 'male' and 'female' and which reinforce gender boundaries and inequalities (Mayeza, 2016, 2017). Drawing on post-structuralist feminist thought permitted me to apply critical insight to my research by engaging in a nuanced analysis of gender beyond the constraints and limitations of essentialist thinking.

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Essentialist assumptions dominate public debate on gender in South Africa (Mayeza, 2017). In this debate, dominant assumptions concerning 'normative' masculinity include notions of authority, investment in team sports such as football, the positioning of men as the protectors of women and children, and through differentiation and disassociation from traditionally feminine roles such as nurturing and caring for young children (Bhana & Moosa, 2016). Research on gender violence in South Africa demonstrates that men and boys are positioned as the primary threat to the safety and well-being of women and girls (Bhana, 2012; Mayeza & Bhana, 2017). This is confirmed by reports in which men emerge as the main perpetrators of various forms of violence on women and girls (Department of Social Development, Department of Women, Children, & People with Disabilities, & UNICEF, 2012). It is in this context that I consider ethical concerns about me *as a man* researching gender among children in the primary years of schooling. In doing so, I unpack the different ways in which I was positioned by various people, and reflect on the implications of this positioning for the 'policing' of masculinity and the ethics issues to which this gives rise in research with young children.

Peer Feedback: On Being Positioned as a 'Threat'

I use the term 'policing' in order to highlight how certain gender stereotypes are (re)produced in order to reinforce gendered hierarchies (Mayeza, 2017). The policing of gender can take different forms because it is context specific and situational (Martin, 2011). Here, I refer to the policing of masculinity as it occurred in the context of peer feedback. Early on in the research process I presented my research proposal at a meeting attended and facilitated by student peers and members of faculty. The meeting formed part of a doctoral support programme and was intended as an opportunity to receive constructive feedback on my draft research proposal and ethics protocol. While some feedback was useful, I was taken aback by ethical concerns that seemed to be underpinned by the same essentialist assumptions about gender that I was hoping to challenge. The literature on peer feedback in ethics review processes notes that this feedback can be biased (van den Hoonaard & Hamilton, 2016), and particularly when community representatives are not involved (Shore et al., 2011). In the context of my study, the non-involvement of community representatives meant that the assumptions that my peers were making about how the community in which I was planning to locate my study would respond to my research went unchecked. I have included examples of the peer feedback for the purposes of illustration:

Female peer	I'd like to know what is the inspiration behind the study? Naturally, I would expect a woman to work with the young primary school children. Women are natural carers and nurturers and I think a woman will be better suited for this kind of research on gender dynamics in young children's play.

In the extract above, a female peer points to what she sees as a fundamental incongruity: a man researching young children at play. She questions the 'inspiration' for my undertaking research involving young children and bases her opinion of my lack of suitability on essentialist assumptions about gender in which engaging with young children is conceived of as 'woman's work' and, consequently, an inappropriate topic for a male researcher. MacNaughton (2000) argues that such essentialist thinking is problematic because it perpetuates gender inequalities. Unfortunately, the assumptions of the first extract were not unique and were reiterated in the feedback from male peers too:

Male peer	As a man, how will you deal with the sensitivity of researching young children in the age of paranoia in relation to sexual violence toward young children and women in the hands of men in South Africa? Many parents will see you as a potential threat to the safety of their children and therefore will not grant consent. I, too, as a parent, will be very reluctant to sign a consent letter from a Mister I don't even know who wants to interact with my child in some research about gender.
Emmanuel	But would you still be that reluctant to give consent for your child to participate in this kind of a research study if the researcher was Miss and not Mister as in my case?
Male peer	I'd still be reluctant and concerned about the safety of my child but not as much as I would be if it is Mister that is requesting my consent to interact with my child.

The dominance, in early schooling, of female teachers (Bhana & Moosa, 2016), combined with the popular construction of children as innocent and vulnerable (Bhana, 2016), may provide insights into the responses of my peers. Furthermore, concerns about the safety of children are understandable in the South African context where sexual crimes committed by men are rife against women and children. These concerns operated, in peer feedback, to 'police' my involvement in research with children. Labelling my research as unlikely to succeed, for instance, was intended to prevent my interest in and enthusiasm for the research project. Of course, I recognise that a child's safety and well-being is every parent's priority, especially in an era of escalating violence against children. Even so, the effect of a discourse of 'children's need for protection', and the different standards applied to male and female researchers, also had the effect of (re)producing the essentialist assumption that women are 'natural carers and nurturers' (first extract), and that men are 'a potential threat to the safety of their children' (second extract). I was troubled by different standard being applied to me, and what that signified in terms of my relationship to the child participants. I was also very concerned about the implications of this for gaining access to the field.

Gatekeeping: 'Progressive' Masculinity Position

Contrary to the problems which my peers had anticipated I would experience in obtaining access to the field, I did not experience difficulty obtaining permission to conduct my research at the school. Furthermore, the parents I met to discuss my proposed research, and my brief introductions to the children, indicated that they were receptive and eager to be involved in the research. Some parents said that they thought my research was interesting and necessary while others appreciated my seeking to challenge gender stereotypes and were impressed that a male researcher was pursuing the issue. The contradiction could not have been more stark between the assumptions that my peers had made and the way in which my research was received by the parents and children at the school. Arguably, rather than reflecting the reality of the field, my peers' concerns reflected their own anxieties based on essentialist understandings of gender which they attempted to project onto the community I sought to engage. I argue that, far from seeing me as a threat to the children's well-being, the parents and children welcomed me as a positive role model for what Ratele (2015, p. 145) calls a 'progressive masculinity'.

Research shows that one of the productive ways in which adults encourage children to think beyond the restrictive notions of gender essentialism is through modelling non-stereotypical gender behaviour (Martin, 2011). In developing my research proposal and in making preparations to enter the field (such as the gatekeeper engagement described above), I sought to demonstrate particular commitments regarding my gender identity. My proposal to undertake ethnographic fieldwork indicated that I would be taking a child-centred approach. In doing so, I hoped that the relations I developed with the school children would go some way towards challenging gender stereotypes, thereby offering new ways of thinking about men and men's relation to children and childcare. Even though caring responsibilities continue to be linked primarily with women and considered as 'woman's work' (Bhana & Moosa, 2016; Morrell & Jewkes, 2011; Warin & Gannerud, 2014), my child-centred approach was an attempt to demonstrate that men can care for children too. In doing so, I wanted to show that masculinity is not singular and stable, but is rather flexible and adaptive (Johansson & Klinth, 2008).

In the light of the fact that the peer feedback that I had received was very different from the ways in which I had envisioned my involvement in the research, I was concerned about how the University Ethics Committee would evaluate the suitability of my involvement in research with children. Would they assume that I posed a threat to the children's safety and well-being, or would they view me as a model of a progressive masculinity?

The Process of Ethics Review: On Being Positioned as 'Protector'

The procedural approach to research ethics is simplistic in that it tends to focus on the potential harm to participants and on the researcher's obligation to reduce the risks associated with participating in their research (Oliver, 2010). Consequently, much of the discussion on research ethics focuses on informed consent and protections regarding anonymity and confidentiality (Mertens & Ginsberg, 2009; Oliver, 2010; Strydom, 2005). Notwithstanding the relevance of concerns regarding harm and the management of risk, the procedural ethics approach often fails to examine the variegated ethical issues that emerge in the complex relational dynamics that characterise researcher–participant interactions in the field. In considering my application for ethics clearance, the University Ethics Committee focused on an examination of any potential threats of harm and violence that I, through my research, might cause to the young school children who they positioned, within this protectionist discourse, as innocent, docile, and vulnerable.

While recognising the need for ethics committees to protect children, Bhana (2016) notes that some of the mechanisms intended to protect 'childhood innocence', often pose obstacles to conducting research with child participants. In procedural ethics, research involving children positions them as passive and vulnerable subjects who lack agency and autonomy. Arguably, this positioning of child participants is the antithesis of a child-centred approach in which children are viewed as autonomous, self-determining subjects. A child-centred approach is concerned with 'putting the children first'

(Bhana, 2016, p. 14), and this involves developing relationships with children so that they view the researcher as an ally rather than as an adult whose authority cannot be challenged. It is in the context of this sort of egalitarian relationship that child participants are said to be able to talk openly about their concerns (Frosh, Phoenix, & Pattman, 2003; Pattman, 2013). From the perspective of a child-centred approach, what should be considered during ethical review is that children are active agents in the research process and have the capacity to negotiate, challenge, and even reject adult authority if it is perceived as oppressive or exploitative (Martin, 2011).

The University Ethics Committee expected that I would obtain the parents' informed consent and the children's assent and that this would be formally documented. In this documentation, the University Research Ethics Committee required that I provide reassurances that confidentiality and anonymity would be maintained. There was some concern pertaining to the fact that my fieldwork activities involved collecting visual data, for example, the children's drawings. With regard to these drawings, and all the other data that I would be collecting, the University Ethics Committee put me in charge of ensuring that none of it could be used to identify any of the children. In other words, rather than my presenting a model of progressive masculinity, the University Ethics Committee was determined to position me in the traditionally masculine role of 'protector' of the vulnerable. It is also ironic that this requirement to 'protect' the children was the exact opposite of my peers' positioning of me as a potential 'threat'. Although I realised that the requirements of the University Ethics Committee were incompatible with a child-centred approach, I acquiesced because it enabled me to obtain the ethics clearance that I needed to be able to proceed with the research.[1]

In the Field: Ally and Authority Positioning

It was essential for me to be viewed by the children in the study as an ally so that they would feel comfortable talking to me openly about their experiences of gendered play. To facilitate the children's opening up and being comfortable with speaking to me, it was important for me to reduce their perceptions of adult, and particularly male, authority. To do this, I would have to develop a relationship with the children that inverted my presumed position of authority. As I entered the field, my first attempt in this regard was to spend time playing with the children in the playground during lunch break. In doing so, I hoped to become a familiar presence although I did not want them to see me as an adult whose presence on the playground was of a supervisory nature, as was the case with some of the female teachers who were there to oversee the children's play. I had also observed that the presence of an adult male among the children on the playground was restricted to periods of organised sport, during which time a male teacher would take on the role of coach. The problem with these conventions was that they reified gendered and generational power hierarchies, and I would have to be careful not to position myself as being complicit in this if I was to engage with the children on an egalitarian basis. Therefore, when I interacted with the children on the playground, I took care to play *with* them rather than merely observing or supervising their play, and by positioning them as the 'experts', for example, with regard to scoring and the application of rules, in the various games we played.

Mandell (1988, p. 433) coined the term 'least-adult role' to describe researchers' attempts to distance themselves from adult roles by adopting child-friendly roles. Unfortunately, despite my best efforts, and despite the fact that the children had welcomed and included me in their playground activities, they lapsed into a habit of calling me 'coach', particularly when I played football with the boys. As football, and the coaching of football, is an activity that many South Africans associate with masculinity, this mode of address alerted me that I was being positioned in a traditionally male role. Although I appreciated that this mode of address was well intentioned, I was not altogether happy about it because of the assumed power that accompanies this label. I wanted to disrupt power hierarchies, and being called 'coach' only reinforced them. In an attempt to resist this positioning I pretended to be a clumsy novice, forcing the children to take charge by providing me with guidance and advice.

While the boys anticipated my participation and easily included me in their football matches, the girls did not anticipate that I would participate in their skipping games, nor did they approach me to join in. This is because skipping is a traditionally 'feminine' game, a fact that was underscored later on in my research in the drawings that the children produced illustrating their involvement in these various play activities. Thus, I was being positioned in a traditionally male role by being both included and excluded from particular types of play activity. Interestingly, when the girls did approach me, it was for assistance in resolving squabbles in which gender hierarchies were a salient feature. In these instances, my assistance was sought to 'put a stop' to conflicts that had escalated and in order to observe and to report these incidents to the teachers in charge. While these requests also invoked and made apparent gender and generational hierarchies, I felt obliged to respond. Unfortunately, this sort of ethical responsibility was never discussed during the ethics review process. I intervened because I wanted to help the children who were being victimised, but I was also careful to be explicit about the fact that my involvement was limited to stopping the immediate bullying, and that the matter would be handed over to a teacher in charge.

As my research progressed, it was interesting to observe that although the children were quick to confer the status of coach or protector on my role in our playground engagements; this was far less likely to happen when we were in the classroom. Teachers would sometimes ask me to keep an eye on the class while they stepped out to attend to something else. While I expected that being put in charge of the children would, once again, undermine my efforts to establish relationships with the children that did not reify child–adult and student–teacher hierarchies, I also felt that some reciprocity was in order. I was, after all, appreciative of the teachers' cooperation and for being allowed to sit in their classrooms and observe the children. As it transpired, however, these were analytically important moments.

When I was left in charge of the class, the children seemed to have little regard for the responsibility and authority that had been conferred upon me, as this extract from one of my field notes illustrates:

> 2/10/2013 The most challenging part in the school today was when I had to supervise one of the foundation phase classes after the class teacher requested me to do so while she went out. Among other things, supervising the children meant maintaining order in the classroom. Phew, I couldn't control the chaos that erupted the moment she left the classroom! All along the children were sitting quietly, but most children just stood up and roamed around the classroom the moment their teacher left. Some got up to drink water and within seconds the classroom corner sink was crowded with children competing over a turn at the water tap. Meanwhile, quarrels and fights started to break out. The level of noise went quite high with the shouting, screaming, and laughter as some children were chasing each other and running around the classroom as if they were in the playground playing on their own. When I instructed them to sit down and keep quiet, they didn't listen. There was chaos as the children played. I noticed when the teacher was returning to class the sudden change of behaviour among the children. I saw them quickly return to their seats and this movement was accompanied by repeated whispers: 'There she is, Miss is coming, shush! Everyone' and I witnessed all the children try quickly to sit down silently before she entered the classroom.

It is argued that the classroom operates as a space which produces docile child subjects through forms of regulation and control (Dixon, 2011). This episode is interesting because it demonstrates the fluidity of the assumed power differentials between adults and children (Martin, 2011), as well as the transient nature of my positioning in the field. Despite my best efforts to negotiate an equitable relationship with the children, my ally status dissipated quickly in the case of playground bullying, when the children needed me to assume an authoritative and protector role, but this status could be destabilised just as quickly when we were left alone in the classroom. By positioning me in these various ways the children were exercising a degree of agency and power over their situation and, while this was impressive, it could also be very challenging.

The view of children as passive, innocent, and docile is drawn upon in the research ethics literature to construct children as vulnerable research subjects (Strydom, 2005). Such a view is problematic because it focuses on power as the exclusive domain of the adult researcher, without recognising children's capacity for agency and the complex ways in which power relations between a researcher and child participants plays out in the field (Martin, 2011). In the context of my ethnographic research with school children, this assumption resulted in a situation in which I was inadequately prepared to respond to the children's attempts to exercise agency and self-determination regarding the ownership of 'data'. The extract below is taken from another of my field notes:

12/3/2013 Some children wanted to keep their drawings. This emerged after I had instructed them to leave the drawings behind at the end of an exercise in which they had drawn pictures of themselves at play. I was going to use them to stimulate talk about their perceptions of gender and how these inform their play patterns at school. Not all children in the group were happy to leave their drawings with me. Recognising this, and taking it seriously as an ethical concern, I called everyone together and explained that I needed to have copies of the drawings for my research. I asked who else wanted to retain their drawings beside the two girls who had started the conversation about the ownership of the drawings when they had asked, 'Why are we leaving our drawings behind?' When more hands were raised, I explained that I needed to take the drawings so that I could copy them, but after this I would return the original drawings to the respective owners. This confusion might have been avoided had I negotiated all of this properly from the start: if I had taken time to explore and understand the children's opinions and feelings about this rather than taking it for granted that, as a researcher, I have control and ownership of the data produced in the context of my research.

The children's challenge of my instruction to leave their drawings behind brings to the fore an ethical concern regarding the ownership of data. Arguably, ethical concerns regarding the children's ownership of their drawings, and my 'data', should have been raised for discussion in the ethics review process. Perhaps, if this had been the case, I might have developed an ethics protocol that better recognised the children's right to make informed decisions about their participation in my research. Unfortunately, one consequence of undermining children's agency and autonomy in the context of a dominant, regulatory approach to ethics is that it diminishes opportunities to give proper consideration to the ways in which children might be meaningfully and respectfully engaged (Bhana, 2016).

The issue of the children's ownership of their drawings was further complicated by the fact that upholding the requirements of the University Ethics Committee with regard to confidentiality and anonymity meant that I was expected to remove the children's names from their drawings. This became a contentious issue because once the children understood the importance of their drawings for my research, they were not happy to hear that I would remove their names from their drawings in the process of making digital copies. I realised that this further undermined their claims to ownership of the data. However, as some of the children's drawings depicted playground bullying, there were clearly risks associated with not masking their identities.

Reflexive Research with Children: Negotiating Child Assent and Ownership of Data

Ethically responsible research is best achieved when the researcher is critically reflexive throughout the research process (Guillemin & Gillam, 2004). Critical reflexivity involves being mindful of our role, positioning, and the nature of our relationships in the field (Guillemin & Gillam, 2004). In the context of research involving child participants, this includes being especially reflexive of the assumptions underpinning ethical processes. It is argued that negotiating child assent is an important opportunity for researchers to recognise and respect children's agency. 'Assent is the term used to convey a sense of agreement obtained from those who are not able to enter into a legal contract' (Ford, Sankey, & Crisp, 2007, p. 19). In the context of research involving child participants, child assent is obtained in addition to parental consent. Child assent is 'an explicit, affirmative agreement to participate' (Vitiello, 2003, p. 89) and, in line with obtaining informed consent from adult participants, 'rests on access to sufficient and appropriate information to support an informed decision' (Dockett & Perry, 2011, p. 234).

Researchers should provide appropriately detailed explanations of the research process and then allow children the time and opportunity to ask questions and to have those questions answered to their satisfaction. This is to ensure that child participants have an adequate understanding of the research and what is expected of them in terms of their participation (Phelan & Kinsella, 2013). Importantly, this should include an explanation of how their information will be used and the ownership of 'data' such as drawings and other works of art. The researcher's descriptions and explanations of the research and the responses to the children's questions are necessary for children to make informed decisions about their participation. It is also argued that child assent should be an ongoing negotiation rather than a once-off event (Dockett & Perry, 2011). According to Phelan and Kinsella (2013), understanding assent as a process requires that the researcher begin each data collection activity with a discussion of what the activity is about and how it is done, followed by questions designed to check that the children are in agreement and willing to take part. Constantly reassessing a child's assent to participate in research is critical because it recognises that child participants also have a right to withdraw their assent and to stop participating in the research at any time (Dockett, Einarsdottir, & Perry, 2012). In the case of my research, I think that it would have been better to have had this conversation before the drawing activity began rather than afterwards when the children were unhappy about letting me have their drawings.

Ongoing researcher reflexivity in research with children plays a crucial role in creating opportunities for children's expressions of agency. And, while 'ongoing conversations with children about the research contribute to the process of building friendly and trusting relationships', researchers must also acknowledge that such conversations need to be endorsed by an understanding that 'conversations involve a two-way exchange of information' (Dockett & Perry, 2011, p. 243). In other words, researchers are not only responsible for allowing the children's voices to be heard, they are also required to be responsive to what the children have to say. The children's question 'Why are we leaving our drawings behind?' was an 'ethically important moment' (Guillemin & Gillam, 2004, p. 261) in my research. It prompted me critically to examine both the assumption that I had made about the ownership of the data and the children's agency and their right to assert a claim to ownership. The fact that I was ill-prepared to respond to the question reflects the limitation of an ethics review process in which deliberation on these issues is not considered to be particularly important. I am, admittedly and also, implicated in this because, in endeavouring to comply with the requirements of the University Ethics Committee, I had also overlooked these issues.

Although the ownership of data and the right to claims of ownership were not given due consideration in the review process, they were clearly important to the children and thus deserving of a considered response from me. In the moment in which the question was put to me, I was immediately aware of how brave the children had been to ask a question that essentially challenged my assumption of ownership of their drawings. In that same moment I was also uncomfortably aware of the fact that I was in a position in which I could simply impose my authority (as an adult, as a man, as a researcher) to seize their drawings without any further argument, and the fact that the children were likely aware of this too made it even more awkward to acknowledge. For these reasons, I was especially concerned to respond appropriately.

Undertaking to return the children's drawings to them was an important part of the process of negotiating consent to my use of this 'data'. The difficult part of our negotiations concerned the removal of the children's names in order to protect their identities. For the children, having their names on their drawings was material to claims regarding ownership. In order to have them understand why I needed to remove their names from the digital copies of their drawings, I would have to address the issue of the risks associated with being identified. This would mean talking about the depictions of bullying, for example, and what the consequences of other people seeing those depictions might be, particularly if they could identify who was involved in those depictions. This was going to be very tricky and I felt that I was unprepared to have this conversation with the children. In the end, I skirted around the issues by explaining that I 'had' to remove their names and that I had little choice in the matter, which was also true.

If I were to conduct similar research in future, I would take more time and care in negotiating child assent at the start of the research, and I would seek out the advice of the teaching staff and the children's parents in this regard. Scholars have commented on the important role that teachers can play in the planning of research activities (e.g. Morrow, 1999, 2001). I think that the input of teaching staff is potentially very valuable in so far as researchers have to find the right balance between providing children with too little or too much information during the assent process (Alderson, 2004; Crow, Wiles, Heath, & Charles, 2006), and researchers have to ensure that this information is aligned with the children's level of comprehension (Bruzzese & Fisher, 2003; Lindeke, Hauck, & Tanner, 2000). Arguably, the children's teachers would be very well placed to give advice on this issue. I also think that the teachers and parents could have assisted with the discussion of the ownership of data and the issue of removing the children's names from their drawings. It has been observed that young children often do not have a clear understanding of the rationale for keeping information confidential (Pyle & Danniels, 2016). Consequently, even when researchers have sought to give child participants some control over the identity-masking process by allowing them to choose their own pseudonyms; confidentiality is breached when the children choose their friends' names as pseudonyms or tell others which pseudonyms they chose (Epstein, 1998). I believe that, had I consulted the children's teachers on the issue, they would have been able to advise me on how to talk about confidentiality in a way that the children would be better able to understand. I also think that parents can play a role in facilitating ongoing conversations with their children about some of the issues underpinning concerns about confidentiality.

Conclusion

In this chapter, discussion of my experience of undertaking ethnographic research with children illustrated how normative conceptions of children as vulnerable and lacking agency underpinned peer feedback and the ethics review process. These conceptions of child participants were used to position me both as a potential threat to the children and as the person responsible for protecting them. I argue that this left me ill-prepared to respond to those moments in the field in which the children wished to assert their agency through claims to the ownership of their drawings and my 'data'. Concerns about the appropriateness of male researchers in research involving child participants are not new (e.g. Troman, 2000) and, as it is likely to persist, we should be prepared to respond to these concerns. We should also not let these concerns distract us from other important ethics considerations. As my story from the field illustrates, it is also important to be able to identify those moments when children are uncomfortable about an aspect of the research process and to know how to respond appropriately.

Notes

1. Ethical clearance was granted in 2012 by the Research Ethics Committee: Humanities Faculty, University of Stellenbosch, clearance number: HS844/2012.

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Challenging Methodological and Ethical Conventions to Facilitate Research That Is Responsive to People with Learning Disabilities

Brigit Mirfin-Veitch, Jenny Conder, Gareth J. Treharne, Leigh Hale, and Georgina Richardson

The active involvement of people with learning disabilities[1] in research can be achieved by challenging traditional conceptions of the role of research participants. While normative conceptions in research ethics value the notion of individual autonomy as a guiding principle, relational ethics values concepts of relationship, reflexivity, and responsiveness (Etherington, 2007; Gunzenhauser, 2006; Halse & Honey, 2007; Lahman, Geist, Rodriguez, Graglia, & DeRoche, 2011). Some researchers applying a relational ethics approach have specifically recognised the research context 'as relational, situational, and emerging' (Øye, Øvre Sorensen, & Glasdam, 2016, p. 455). This conceptualisation of the research context acknowledges that it is not always possible to predict all the ethical issues that might emerge during the research process, and that researchers must remain alert and responsive to matters as they unfold. The tenets of

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relational ethics have particular relevance to research involving people with learning disabilities as relational ethics is a means to challenge research approaches that exclude people on the basis of their impairment.

By adapting research methodology to be responsive to the person, people with learning disabilities can be included in research. Research that is termed ‘inclusive’ occurs on a spectrum. It can refer to studies in which people with learning disabilities have control of both conceptualising and conducting the research, to research in which people with learning disabilities are simply participants with no further direct involvement beyond data collection. Varying degrees of inclusivity have implications for ethical imperatives. Drawing on Bigby and Frawley (2010), we argue for the necessity of a relational approach to ethics when undertaking inclusive research with participants who have learning disabilities. In this chapter we reflect on two of our own studies that were conducted with the intention of meeting the communication and learning needs of participants and entailed modifying our research practices to be responsive. Our experience alerted us to four aspects of the research process in both studies that highlighted the importance of ethical considerations that take into account inclusivity, recruitment, informed consent, communicating research-related tasks, and interview approaches. We also offer practical guidance about each of the four issues based on the lessons we have learned. The chapter concludes with a discussion of how the strategies we have implemented to enhance inclusivity are consistent, in turn, with relational ethics.

Inclusive Approaches to Disabilities Research and Relational Ethics

Traditionally, disability research has tended to take a medical model approach (Oliver, 2009). Many studies concerned with disability focus on disabled people in ways that pathologise, and overemphasise, people’s physical, cognitive, or mental impairments (Goodley & Lawthom, 2005; Walmsley, 2001). This is because the medical model of disability tends to position people as passive subjects to be tested, observed, and excluded from the production of the views or stories produced about them (Goodley & Lawthom, 2005; Walmsley, 2001). Traditionally, little emphasis has been placed on the lived experiences and views of people with disabilities themselves (Walmsley, 2001). Defining people according to their impairment continues to have a presence in the broad field of disability research but is now challenged by contemporary approaches which draw on the social model of disability (Walmsley, 2001). The social model places importance on the sociopolitical and cultural impacts of what is termed ‘disability’ (Goodley & Lawthom, 2005).

Underpinned by the social model of disability, inclusive research has emerged as a paradigm through which research can be carried out *with* and *for* disabled people while at the same time challenging the harm and oppression they may have experienced. Walmsley and Johnson (2003) define inclusive research approaches as being 'research in which people with learning disabilities are active participants, not only as subjects but also as initiators, doers, writers and disseminators of research' (p. 9). Inclusive research involves re-envisioning how research could be conducted, and subsequently, the nature of research itself and the evident power dynamics in it. Researchers, however, differ in their interpretations of how radically inclusive research should be. Townson et al. (2004), for example, argue that inclusive research is people-led wherein people with disabilities are 'fully included' (p. 73), retaining both control of the research process and ownership of knowledge outputs. Anything less than this, in their view, represents only conditional inclusion, or, in their terms, people having been 'partly rejected' (p. 73). This understanding would not, for example, consider research that demonstrates inclusion primarily through advisory roles or collaborator roles on some tasks as meeting the criteria for inclusive research. Some disability researchers have even asserted that anything less than fully inclusive research is inappropriate because it continues to be *about* people with disabilities (Oliver, 2009). Conversely, it could be argued that there is an inherent risk associated with being dismissive of research that does not meet this standard. People with disabilities who are not able to be, or do not want to be, fully involved in all stages of research production may be prevented from contributing in ways that are meaningful to them. That is, research that is fully inclusive may result in some individuals inadvertently being excluded (Frankena et al., 2016). This risk of exclusion is significant in the case of people with learning disabilities, some of whom may require assistance from third parties in order to be engaged in any or all aspects of a research process.

The two research projects described in this chapter demonstrate a commitment to inclusive research. We also openly acknowledge that these particular projects do not meet the aspirations of wholly inclusive research as outlined by Oliver (2009) and Townson et al. (2004). Our two studies took place in Te Wai Pounamu, the South Island of Aotearoa New Zealand. The studies were titled *The Mental Health and Wellbeing of Women with Intellectual Disability Study* (Conder, Mirfin-Veitch, & Gates, 2015) and *The Prevention of Falls for Adults with Intellectual Disability Study* (Hale, Mirfin-Veitch, & Treharne, 2016). Concrete examples from both these studies are included to enhance the practical utility of our suggestions for working in a relational ethics perspective (Etherington, 2007; Gunzenhauser, 2006; Halse & Honey, 2007;

Lahman et al., 2011). While it is important to keep in mind that there is no single blueprint for applying relational ethics, the studies described in the chapter highlight a range of responsive practices that are consistent with relational ethics in that they adapt commonly accepted ethical research standards to meet the diverse communication needs of people with learning disabilities.

Relational ethics is underpinned by the notion that ethical action occurs through attentive relationships. To be ethically and methodologically responsive within research contexts requires researchers to accommodate the individual circumstances and needs of the individuals they are seeking to understand, *and* to recognise that research is mutually constructed (Etherington, 2007; Gunzenhauser, 2006; Halse & Honey, 2007; Lahman et al., 2011). In this chapter, we focus on the following four aspects of the research process as being some of the most significant ethical and methodological issues to address. All these areas require attentiveness to relational, situational, and emerging issues (Øye et al., 2016) when one seeks to be as inclusive as possible in research with people with learning disabilities. The four aspects are (1) recruiting people as participants in disability research; (2) obtaining informed consent from people participating in disability research, including support workers and assistants; (3) communicating research-related tasks to people participating in disability research; and (4) approaching interviews in ways that are responsive to the diverse communication needs of participants.[2]

The *Mental Health and Wellbeing of Women with Intellectual Disability* Study

The *Mental Health and Wellbeing of Women with Intellectual Disability* study was a qualitative research project undertaken in Aotearoa/New Zealand between 2009 and 2011. The study responded to concerns that had been raised by a local branch of a self-advocacy group called People First about the provision of mental health services for people with learning disabilities. Members of People First were concerned about a lack of responsiveness of generic mental health services to the mental health needs of women with learning disabilities. Having attended meetings and heard the concerns of People First, a reference group was established comprising two women with learning disabilities (one of whom experienced life-long depression), a female clinical psychologist, and a research team. The reference group was tasked with refining the research topic and planning the research project. Our research team was comprised of three female disability researchers with backgrounds in sociology, psychology, nursing, and ethics.[3] In discussion with the reference group, we agreed that the scope of the study should be broadened to include women with learning disabilities who were living with or without mental illness. This expansion of the research focus demonstrates the value of reference group involvement and input into decisions about the purpose of research at an early stage, rather than waiting until the design of the study is complete.

The extended focus on mental illness provided an opportunity to explore how this impacted on mental health and well-being and vice versa (Conder et al., 2015). Insights that emerged during reference group discussions informed how we planned to proceed through key stages of the study. This included devising appropriate strategies for participant recruitment, informed consent processes, the development of an interview schedule that took participants' needs and abilities into account, and how research dissemination should be managed. In keeping with the standard requirement for ethics approval, planning for this study also included written protocols to guide the researchers in the event that the women participants shared information that suggested they or someone else might be at risk of personal harm, or indicated that they had suffered personal harm in the past. In Aotearoa New Zealand all health and disability research requires approval from an accredited ethics committee.[4] The ethics procedures developed for both the current study and the study that is discussed later in this chapter responded to a standard template but were influenced by our commitment to relational ethics principles as outlined in the introduction.

Twenty-five women aged between 20 and 65 years enrolled as participants in the study. Each participant was interviewed three times over two years. To recruit research participants, we attended local People First branch meetings. We began by presenting information about the study to everyone who was present. Our verbal presentations were supported by more visual presentations with slides written in accessible language. Providing information to everyone in one big group meant that women were able to hear questions asked by other women, be privy to the answers, and have the opportunity to ask their own. In this way, a greater amount of information was available to guide their participation decisions than may have been the case if one-on-one meetings had been the only strategy for sharing the aims of the research. Following the group information session, we then met with women individually or in small groups to restate the research aims, talk about what taking part would involve, and to respond to any additional questions that they had about the study. Women who indicated that they were interested in contributing to our research were encouraged to take a few days to think about their decision. To facilitate their further consideration of the decision to participate, we gave the women plain language information sheets and participant interest forms to take home with them. Some women preferred to complete the participant interest forms before they left the group meeting. Although this was unplanned, we deemed it to be acceptable because it respected their wishes to register immediately their interest, or not, in the research.

These participant recruitment processes evidence our commitment to inclusive research and relational ethics. In developing our recruitment strategy, we were guided by women with learning disabilities as to how effectively to inform potential participants. Thus, the combination of verbal and visual presentation of research information and the opportunity to engage with other prospective participants about being involved in the research were planned strategies designed to facilitate informed decision-making. However, there is always a chance of unanticipated matters arising. By contrast with the planned recruitment processes, the acceptance of participant interest forms at the first information session had not been planned. Nevertheless, doing ethically responsible research also requires that we take appropriate action in the moment.

The next step after the initial information session was the formal informed consent process. Upon receipt of an interest form, one of the research team contacted the potential participant to arrange an interview. Formal informed consent was registered before the first interview commenced. Following suggestions from Griffin and Balandin (2004), we were satisfied that the woman had given informed consent if she could relay, in her own words, both what the study was about and what participation entailed. In the process of obtaining informed consent, one woman indicated that she preferred the person interviewing her to record information with written notes rather than an audio-recording of the conversation. This was another instance of an unanticipated ethical issue emerging in the research process. We accommodated this request and, later on in the research process, came to see that it had been an important moment because it enabled the woman to build trust and confidence in her research relationship with us. Although the initial formal informed consent process provided permission to proceed with each woman's first interview, we re-evaluated their consent at each interview throughout the interview period and at the time of analysis by discussing with each woman how her contributions would be used. Revisiting consent in this way fits with a relational approach to research ethics. It acknowledges research as situational and participants as having the right to revise their consent decision at any time prior to the publication of findings (Griffin & Balandin, 2004; Øye et al., 2016).

When embarking on the data collection phase of the research, we planned the first two interviews in close succession so that participants remembered the researcher and that a positive research relationship could develop. Interviews were conducted by one of the three female researchers either in the participant's home or at a disability service site, depending on her preference of interview location. The women were encouraged to use photographs or items that were meaningful for them as a way to help them remember earlier life events. Photo-elicitation and photovoice are two photography-based methods that are used in qualitative research to encourage and support the co-construction of data collection and analysis (Lahman et al., 2011; see also Ashdown et al., 2018, this section). We did not seek to implement either method to a comprehensive extent in this study. We only hoped that inviting the women to bring photos or other meaningful artefacts to the interview would enable additional insight into what was important to them. Only a few participants were able to do this as many did not possess such personally meaningful artefacts, including photographs.

Researchers have offered other ideas about how to establish positive research relationships with people with learning disabilities, and to support their effective participation in qualitative research interviews. For example, Hollomotz (2017) highlighted a range of strategies, including taking time to understand people's daily routines and communication styles and keeping interviews to shorter timeframes, scheduled to occur in close proximity. These are examples of relational and situational responses. As previously described, we attempted to engage similar strategies in our own research while acknowledging that practical considerations meant that we were not always as flexible with regard to time and scheduling as we would have liked.

In an attempt to meet the relational ethics principle of responsiveness, we also adapted the way in which we presented the women with their data. Specifically, the assigned researcher wrote each participant's data into a story format, rendering it a meaningful and tangible outcome of her participation. This process is a departure from the typical ethical convention in qualitative, interview-based research of simply handing back a person's verbatim transcript. Transcripts are typically 'text dense' and can be inaccessible to people with learning disability. To ensure the women in this study were aware of the data that we were planning to analyse, we provided their information in a structured format, following the chronology of their lives. The women's stories were then posted to them about one month before the third interview, enabling them to seek clarification, make changes, or add information that they thought was important.

At the end of each interview, participants were provided with information about when subsequent and final visits would occur. The women were also given the contact numbers of the researchers in the event they needed to speak to a researcher in between visits. This was important because it enabled one researcher to be responsive to a participant who requested the researcher's assistance in negotiating a change in the disability services support that she was receiving at that time. Having provision for this sort of assistance written into the approved ethics protocol enabled the research team to respond to a situational dynamic that emerged in the research process. This sort of provisioning is central to relational ethics (Øye et al., 2016). In this instance, the outcome was that the participant accessed the required support, while the researcher was able to access supervision from a psychologist to guide her interactions with the participant. Relational ethics explicitly acknowledges the participant and the researcher as being in a relationship and can therefore accommodate interactions that extend beyond prescribed research tasks (Halse & Honey, 2007; Øye et al., 2016).

The *Prevention of Falls for Adults with Intellectual Disability* Study

The *Prevention of Falls for Adults with Intellectual Disability* (PROFAID) study applied a physiotherapy approach to falls prevention for people with learning disabilities.[5] Falling, and the injuries sustained as a result of falls, has been recognised as a significant problem among people with learning disability (Cox, Clemson, Stancliffe, Durvasula, & Sherrington, 2010). Not only do people with learning disabilities fall more frequently than those without learning disabilities, but they also start falling at a younger age (Enkelaar, Smulders, van Scrojenstein Lantman-de Valk, Geurts, & Weerdesteyn, 2012). While research has been successful in identifying the range of factors that contribute to the higher prevalence of falls (Pal, Hale, Mirfin-Veitch, & Claydon, 2014), it has been harder to establish what kind of falls intervention might reduce the risk of falling.

The PROFAID study aimed to develop and test an intervention that addressed two of the known physical factors contributing to falls: reduced balance and poor leg strength (Hale et al., 2016). It took the form of a mixed-methods research design that included a quantitative assessment of gait and balance before and after receiving a physiotherapy intervention, and a qualitative appraisal of the acceptability, utility, and feasibility of the physiotherapy intervention. Most importantly, the PROFAID study was specifically designed to respond to the learning needs and styles of adults with learning disabilities. This responsiveness was not limited to research-related tasks; it also included a consideration of ethics procedures such as participant recruitment procedures and processes for obtaining informed consent. People with learning disabilities contributed to an advisory group that was set up to guide the research and they met on a regular basis during the study.

The study, which involved the participation of 27 adults with learning disabilities, took place in a small city in Te Wai Pounamu, the South Island of New Zealand and was conducted from 2013 to 2014.[6] We decided to use a process of third-party recruitment in this study because it appeared to the research team to be the most effective way of alerting people to the research and the opportunity to participate in it. Third-party recruitment involves intermediaries who tell potential participants about the research. They can also play a role in assisting prospective participants to complete the processes required for formal involvement in research. Utilising third parties to assist with participant recruitment in this way is a common strategy in learning disability research (Ouellette-Kunntz, Lunsky, Lysaght, Martin, & Saaltink, 2013). This is because people with learning disabilities are unlikely to respond to advertisements in community newspapers or to access other information-sharing platforms often used to invite people to participate in research.

In the case of the PROFAID study, several different learning disability residential service providers agreed to act as third-party locality organisations.[7] The researchers met with staff with decision-making authority in each of these services, provided them with information about the study, and outlined how to introduce the purpose and key elements of the study to potential participants. Third-party recruitment ensures that people have the opportunity to participate in research that may interest or concern them. Conversely though, this approach also runs the risk of 'filtering' or creating a situation in which only those individuals whom recruiters perceive as 'suitable' for the research get entry to it (Øye et al., 2016). This highlights that unequal power between researchers and the participant is not the only power dynamic at play in the research context. It is critical that researchers using third-party recruitment methods ensure they spend a significant time with potential participants to be sure potential participants are in fact interested in taking part in the research.

Many people with learning disabilities experience literacy and communication difficulties. This means that conventional written and oral forms of consent can, in some cases, be difficult to implement. In order to be responsive to this, the PROFAID study was described pictorially and in accessible language, and consent was accepted from people who could describe in very simple terms what the study was about, and what they were being asked to do.

Although all the participants in this study could communicate verbally, some participants experienced difficulty with verbal communication and most did not have strong literacy skills. In these cases, third parties were involved beyond recruitment and had a role in the information and consent phases of the research. Our commitment to the notion of informed consent required vigilance throughout the study regarding signs that participants continued to want to be involved. Ongoing consent was also read as being expressed through the interest and engagement they showed in research activities and tasks. Equally, however, this engagement could also be perceived as the person simply enjoying the activity rather than communicating informed consent. This ambiguity requires ongoing attention in research with people with learning disabilities as it highlights the complexity of informed consent, particularly when working with people who may communicate in alternative ways.

Relational ethics in the research context extends beyond the collection of data to that of the actual intervention (Lahman et al., 2011), and this was the case in the PROFAID study. In intervention studies there is an expectation that participants follow a standardised programme of activities. At the same time, in seeking to be responsive to the physical needs and particular learning and communication styles of the people who took part in this study, we had to incorporate flexibility into the programme. For example, to facilitate sustained engagement in the programme, we encouraged face-to-face interactions with the physiotherapists responsible for delivering the intervention. We supplemented this contact with easily readable information to which participants could refer daily to remind themselves of what they were being expected to do as part of their participation in the PROFAID study (Hale et al., 2016).

The PROFAID programme was refined with each of the participants to ensure it was appropriate to their needs, complemented their daily schedule, was not too onerous, and ensured the people participating in the study had as much choice and control as possible over their exercise routine (Hale et al., 2016). In order to encourage continued engagement in the PROFAID exercises, photographs were taken of the people performing their exercises in their specific living context. This aided understanding of how to do the exercises and where to do them. We supplemented pictorial references with a calendar style chart to remind people to do their exercises so that they could record their completion of the exercises each day. These strategies were further supported by regular telephone calls from the research physiotherapists. The calls served a number of purposes. One purpose was to prompt people to keep engaged in the programme which was important given its reliance on sustained exercise to achieve improvements in strength and balance. The other purpose was to answer any questions about the exercises or the exercise routine, and to be informed of any problems related to doing the exercises.

Support staff and family members also received training in the PROFAID intervention. This is because people with learning disabilities often require assistance to be actively engaged in managing their health-related issues. In addition to this, we also tried to be responsive to individual needs (and this is contrary to many evidence-based physical interventions) by allowing exercises to be adapted if a person participating in the study indicated being bored with an exercise, or found it too challenging. Although this kind of flexibility is often necessary in research with people with learning disability, it can place serious restrictions on options regarding methodological approach.

Quantitative methods that call for a strict level of standardisation can result in some groups of people being seen as 'unsuitable' for participation in the research. Furthermore, if procedures are altered in an attempt to meet individual needs, the rigour of the research can be compromised. As the PROFAID study took the form of intervention research, we were required to provide evidence of effectiveness through quantitative analysis. As such, we found that having to achieve a sufficiently high level of standardisation impacted on our ability to complete our relational ethics commitments (Halse & Honey, 2007). That said, in comparison with most quantitative protocols, we incorporated a significant degree of flexibility in order to be responsive to relational, situational, and emerging ethical considerations throughout the research process.

Practical Suggestions for Ethically Responsive Research

In the remainder of the chapter we provide practical suggestions for ethically responsive research. In doing so, we revisit the four aspects of the research process that sparked off our reflection. The rationale for these suggestions can be found in theories of relational ethics and respect for persons, as promoted by Gunzenhauser (2006) and Halse and Honey (2007).

Recruitment

Recruiting participants who will best inform the research question or aim can be a challenge for researchers when the overall pool of relevant people is small. When planning to recruit, it is important to consider a range of factors including how best to connect with a particular group of people. When working with people with learning disability, written forms of information should be supplemented with alternative media such as videos, oral presentations, and easily readable leaflets. Consideration of how to distribute research information is also important. In some cases, sharing research information directly with potential participants is possible, while in other situations invitations to take part in research are more appropriately extended through third parties. We recommend that when using third-party recruitment methods, enough time is spent with participants to ensure that they wish to be involved, or not to be involved, in the research.

Informed Consent

In the case of informed consent processes, opinions about the participation abilities of people with learning disability vary internationally. Individual countries have different ethical regulations about research participation for people who are considered to lack the capacity to consent. For some people, the level of their cognitive impairment will make it difficult for them to confer informed consent. Regardless, all researchers should approach their inquiry with consideration as to how they can recruit all appropriate informants rather than to exclude, automatically, categories of people by assumption. Gunzenhauser (2006), for example, argues that in relational ethics all people are knowing, and the research relationship should be centred around recognition of this principle. In the case of research involving participants with learning disability, adjustments may need to be made to standard processes of providing information and accepting consent to ensure people have the tools to provide informed consent. Researcher reflexivity also may be required in the area of informed consent to ensure that there is a balance of benefit over harm and procedures in place if the situational context changes this balance during the course of the research (Etherington, 2007).

Informed consent includes understanding the purpose of the research, knowing what taking part will mean, feeling free to agree or disagree to take part, having available other people and communication aids to help to understand. In this way, informed consent procedures must be underpinned by accessible information. In addition to using easily readable information or other accessible formats to convey research information, alternatives to written consent, including verbal consent or augmented and assisted expressions of consent that are recorded or independently witnessed must also be accepted.

If informed consent is conceptualised as a process rather than a discrete act, as we postulate in this chapter, people have the right to withdraw their consent at any stage in the research process up to the point of publication. In keeping with this understanding, it is important to readdress the issue of consent if a sensitive issue is raised, or when the disclosure of personal information during a research exchange means that outside assistance needs to be sought. In such cases, only information essential to the request for assistance should be shared according to the safety protocols developed and agreed with participants before research commences. Finally, methodologies that include the participant having the opportunity to check their contribution before it is analysed should do this in a way that is accessible to the person and with ample time to address feedback before publication.

Interview Approaches

Critical research regularly relies on interviews as a way of collecting data required to explore participants' perspectives on phenomena of interest. Selection of participants will take into account the ability of the person to provide an in-depth account. It is important to note that this can sometimes be at the cost of excluding the voice of those who have reduced expressive language or who require more guidance to share their perspective.

Researchers need to be attentive to the use of language. Rather than giving precedence to oral expression as a mode of subjective expression, researchers are challenged to consider a myriad of ways in which participants express themselves. The presence of a support person can be a positive strategy for assisting a person to feel comfortable, but this must not be assumed to be the person's preference. It is also critical that the support person understands that the role is one of support, and perhaps to provide additional detail where helpful rather than to be the dominant voice in the interview. This last point relates to a need to be cognisant of and responsive to the power dynamics that are inevitably present in research relationships, both between the researcher and the participant and also between the participant and other people present at the interview, or in or near the space in which it is occurring.

Communicating Research-Related Tasks

The difficulties that people face in participating in research often relate to learning and communication. This can impact on their ability to be, or to be seen as, active agents in research that concerns them. For this reason, it is sometimes necessary that researchers adapt more conventional strategies for communicating research-related tasks regardless of what methodological approach is being taken. In general, the most appropriate way to communicate with people involved in the research might be through alternatives to written information such as easily readable written material, film, or oral presentations. The use of these strategies should extend throughout the research, not just be confined to the early information and consent processes. The implementation of accessible formats, for example, also should be used to remind people of what is expected in the particular study, and when research-related activities, particularly interviews, are scheduled to occur. Commitment to accessibility must extend into the dissemination of research findings and results in order to ensure that people with learning disability are able to understand, and potentially benefit from, the research they have informed.

Conclusion

The aspirational goals of inclusive research outlined in the introduction to this chapter are promising for progressively shaping the way disability research develops. What we have illustrated here is that even in cases in which research does not reach the goal of being fully inclusive, it is possible to be responsive to people with learning disability and to be reflexive in practice within a range of research paradigms, including those often perceived to be unsuitable for adaptation. We argue that relational ethics is central to efforts to be responsive to people with learning disabilities in all research contexts. Relational ethics highlights the mutual construction of research processes and outcomes. While it may challenge traditional understandings of ethical and methodological processes, and require a greater degree of time and resourcing, more inclusive disability research will result in more rapid progress towards resolving issues of social justice and achieving social change for which most researchers are motivated.

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Notes

1. People First New Zealand, a self-advocacy group, has challenged disability researchers and the wider disability sector to use the term 'learning disability' instead of 'intellectual disability'. They feel the term is more reflective of the

difficulties they experience, respectful to them as people, and easier to say. Therefore, 'learning disabilities' is used instead of intellectual disabilities throughout this chapter, except when intellectual disability was used in the original title of a study.

2. In order to limit the extent to which we 'other' the individuals to whom we are referring when referring to our experiences of working with people with learning disabilities in research contexts we have, as much as possible, used the terms people (or women specifically) to refer to those we were inviting to take part in research, and participants to refer to those who were taking part in our research.
3. Two of the authors of this chapter, Brigit Mirfin-Veitch and Jenny Conder, were research team members on the *Mental Health and Wellbeing of Women with Intellectual Disability* study.
4. The research was approved by the New Zealand Multi Region Ethics Committee (reference: MEC/09/05/054).
5. Leigh Hale, Gareth Treharne, and Brigit Mirfin-Veitch were research team members on the *Prevention of Falls for Adults with Intellectual Disability* study.
6. The study received ethical approval from the New Zealand Upper South A Regional Ethics Committee (URA/I1108104).
7. Locality organisations are organisations that have agreed to be involved in research, usually with regard to participant recruitment, or as a site for data collection. In New Zealand, ethics committees require signed evidence of each locality organisation's agreement to act in such roles.

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24

Whose PARty Was This? The Dilemmas of a Participatory Action Research Process of Evaluating a Social Enterprise

Jacqueline Lovell and Jacqueline Akhurst

Participatory action research (PAR) aims to support transformation, and this is in contrast to more traditional research approaches that often only provide explanatory accounts of the status quo (Martín-Baró, cited in Aron & Corne, 1996). Practitioners of PAR work alongside others in solidarity with collective struggles for social and economic justice. An important emphasis in PAR is the active involvement of people who are most affected by problems that they themselves have identified as needing to be addressed. PAR promotes democratic engagement and is distinguished by the positioning of all stakeholders as co-researchers (McIntyre, 2008). From a PAR perspective, transformation becomes possible through the active involvement of community members at each stage of the research process, from conceptualisation through to analysis, dissemination, and implementation of the findings. However, as we shall demonstrate, this commitment to sustaining the involvement of all can be difficult to maintain in PAR practice.

The ethical imperatives of PAR require the needs of involvement to be balanced with practical benefits for participants. In accounts of participatory research, however, explicit descriptions of the complexities of sustaining democratic involvement often are not given, so our chapter addresses that gap. In this chapter we[1] discuss a PAR evaluation of the work undertaken by an

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organisation known as *developing partners* (*dp*) in order to illustrate how our commitments to democratic participation were tested in the tensions arising in the processes of data collection, analysis, and in the final write-up of the research. The guiding question, 'whose PARty was this?' frames our discussion of the challenges of conducting PAR. In this chapter we identify three key tensions that emerged in our efforts to work democratically: we describe the methodological tools that we developed in order to better suit our aims and to ensure that participants' voices were integral to both the research processes and the products of the research. We also give consideration to the ways in which our own investments in the research—a research qualification for the first author and supervisory responsibilities of the second—complicated the negotiation of appropriate processes for generating and analysing 'data'.

Background to the Evaluation Project

In 2006 the Labour Party-led government undertook a number of initiatives geared towards the privatisation of the government-funded National Health Service (NHS) in the UK.[2] One of these initiatives is the Pathfinder Programme, the purpose of which is to fund a number of social enterprises[3] to undertake work previously undertaken by the NHS (Leadbeater, 2008). I was an enthusiastic supporter of a programme that appeared to transfer a degree of power and control to stakeholders who previously had been viewed only as 'service users'. I was a founding member of *dp*, a social enterprise established in 2007 for the purposes of participating in the Pathfinder Programme. The aim of *dp* was to develop and provide user-led training for health workers and user-led research and evaluation of health services. It was a relatively small community organisation located in the North East of England. In it's six years of existence *developing partners* had many members who brought with them a vast range of lived experience, many of whom had migrated to the North East of England and some of whom had been born there.

All the participating members in *dp* had experienced mental distress, which influenced the decision not to capitalise the first letters of the name of the organisation; the intention was to emphasise the organisation's solidarity with people who are often viewed as being low down in the social hierarchy. The organisation's logo, '*recovery through discovery*' indicated an alignment with the recovery model approach to mental illness which counters the deficit approach of the medical model by focusing on what people can do (Jacobson & Greenley, 2001). In the organisation's engagement on various projects, a primary objective was to ensure that the voices of people who were least often heard were listened to and taken account of in any process that was undertaken by the organisation.

Members of *dp* had all experienced multiple layers of discrimination and exclusion. For example, members' experiences of mental distress were often linked to their having been people seeking asylum or granted refugee status, or to discrimination based on gender or sexual identities. Therefore, in addition to responding to the needs of people who had experienced mental distress, *dp* also endeavoured to operate in a socially inclusive manner and to be responsive to people's experiences of a range of social marginalisations and exclusions. In addition to providing user-led training for health workers and user-led research and evaluation of health services, *dp* also endeavoured to provide direct support to its own members. This support was provided through initiatives such as *Experiential Human Rights Training in Action*, which provided members with training in human rights activism, and *Partners in Education and Empowerment for Social Inclusion* (PEESI), comprising a number of short, skills-based vocational training courses such as jewellery-making, computer training, and English language classes.

Organisations such as *dp*, which had been selected to receive funding from the Pathfinder Programme, needed to evaluate their work. This means that *dp* were also a research cohort and in a position to collect evidence about the benefits of social enterprise organisations that are led and run by people with lived experience of mental distress. Among the members of *dp* we established a team tasked with evaluating the work of the organisation. We called our evaluation team the 'So What's Changed? Evaluation Team', or SWC?ET for short. The purpose of SWC?ET was to evaluate the impact of the work undertaken by *dp* from the perspectives of its diverse members who had both used and delivered the services that the organisation offered. As a founding member of the organisation, I was particularly invested in this evaluative process. I decided, with the approval of the other members of *dp*, that the evaluation would also serve as the topic of my PhD research.[4]

Our commitment to representing the diverse perspectives of our members was in accordance with the recommendations of the British Psychological Society (BPS) to promote the inclusion of people who use the services being evaluated. According to the BPS (2008), this should include working with and seeking independent views of minority-group members about their experiences of accessing services. The BPS (2008) also recommends being critical of those who define which outcomes are valued and pursued, and whether these reflect the diverse needs of the people who use such services. Central to our undertaking of evaluation was a commitment to the democratic participation of all members of the evaluation team. To do this, we recognised the importance of employing an appropriate methodology.

Three Tensions Challenging Our Commitment to a Participatory Ethic

Fals Borda (1995) described PAR methodology as 'community action', meaning that participatory methods are underpinned by a commitment to democratic engagement. The central intent of democratic participation is 'rule by the people' who are involved. Diverse interests and concerns lead to challenges when striving for consensus decision-making at every step in the research process. Whilst the generation of data may be negotiable and transparent, the analysis and representation of findings requires expertise, or otherwise requires knowledge sharing in discussions that are time-consuming (and potentially not of crucial interest to all participants, or to those who may not see the personal benefits of such an investment of time and energy). In democracies, such challenges are often resolved through stakeholder representation, but in the case of PAR, decisions being taken without careful dialogue subvert the very essence of participatory engagement. PAR processes are supposed to be influenced by co-learning and mutual decision-making, and by giving attention to social and relational dynamics. In the remainder of the chapter we discuss three tensions that challenged our commitment to a participatory ethic and the ways in which we responded to them.

Tension 1: Voice and the Requirement for Anonymity

In my capacity as a member of the evaluation team, I proposed using participatory video production, an activity that facilitates the participation of marginalised groups; members of a community are brought together to create a video that explores issues that are of concern to them (White, 2003). Unlike professional movie-making projects, participatory video is primarily about the process rather than the final product (Dudley, 2003). Its purpose is to empower individuals and groups to take action to solve their own problems (Bery, 2003). In the context of the aims of SWC?ET, members of *dp* agreed to produce videos that focused on aspects of their everyday experiences and the impact of their involvement in the organisation.

Before we attempted to produce a video, we spent time learning how to use the video cameras and developing storylines. In the process, it emerged that the topics of interest to some of the members, as well as the content that they wanted to explore, were not immediately suited to the evaluation task. This prompted discussions during which we revisited the aims of the evaluation project, and how the participatory video production activity could be used to document *dp*-related outcomes in a way that also reflected what mattered most to *dp* members. At this point, the process stalled. It was difficult for members (including those participating in SWC?ET) to see properly how this methodology complied with the evaluation task whilst simultaneously also enabling them to articulate important aspects of their individual experiences. It was clear to me that we needed to explore alternative methods.

I came across a reference to body-mapping exercises in literature on participatory video production (Lunch & Lunch, 2006) and was interested in exploring its potential. Body mapping involves tracing an outline of the body as a starting point for exploring issues of personal significance. The method was developed in South Africa to help people talk about the social, emotional, and physical aspects of their experiences of living with HIV (Brett-Maclean, 2009). Body maps are life-size human body images created through a process of

> using drawing, painting or other art-based techniques to visually represent aspects of people's lives, their bodies and the world they live in. Body mapping is a way of telling stories, much like totems that contain symbols with different meanings, but whose significance can only be understood in relation to the creator's overall story and experience. (Gastaldo, Magalhães, Carrasco, & Davy, 2012, p. 5)

Members of SWC?ET were enthusiastic about trying the body-mapping method, so the team decided to incorporate into the body-mapping process questions that would enable members to reflect, not only on their current, but also on their past circumstances and hoped-for futures. These questions were co-developed by members in a diagrammatic representation of a body map recreated in Fig. 24.1.

Members worked together over a number of days to produce their body maps. It was remarkable seeing how successful this process was in engaging members in the difficult work of recounting personal experiences that were hard to talk about. Furthermore, because the body mapping exercise allowed members to share their experiences with others in the group, it created opportunities to receive empathetic responses from each other. This was important because concern for their well-being had not always featured in other people's responses to them. It was notable that, in the process of creating the body maps, some members communicated traumatic experiences through various visual depictions, which they were not always willing to talk about in the group discussion of the body-mapping process.

When the body mapping process had been completed, it occurred to members that their engagement in this activity could be used as the material

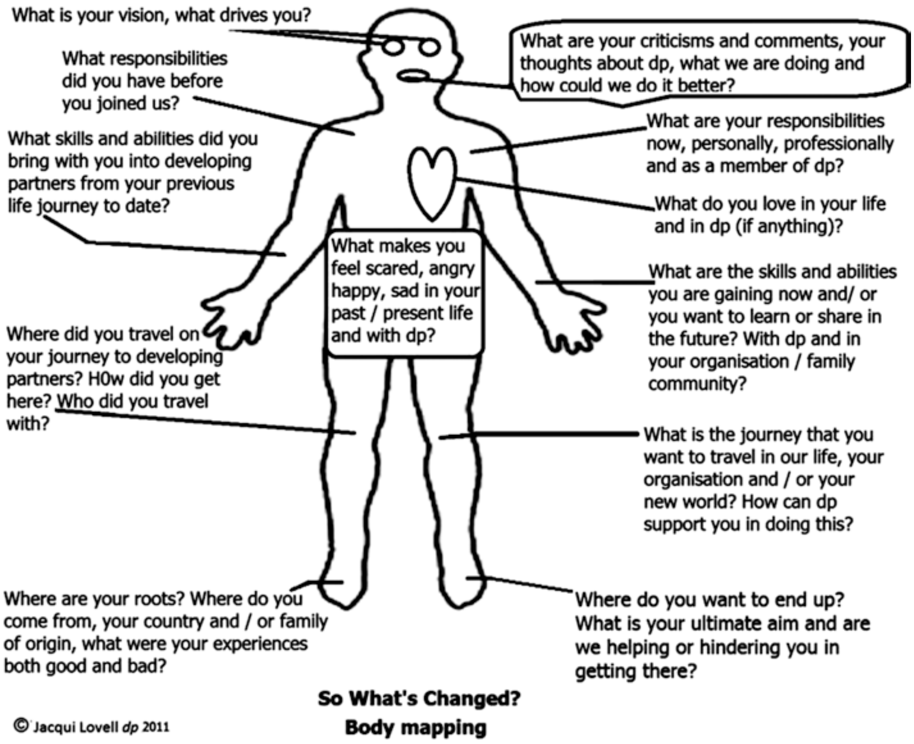

Fig. 24.1 Body mapping evaluation tool (Bm-ET)

for participatory video production. Members then set about co-creating videos that documented their experiences of participating in the body-mapping process. A member of the group who had professional editing skills assisted members with adding additional material to their videos, such as music and narration, to complement the visual information. The body-mapping and video production process were useful methods for engaging members, to enable their voices to be heard, that afforded them a level of control over the construction and presentation of their personal narratives. These methods, however, also raised ethical concerns regarding anonymity because such visual data makes it possible for people to become individually identifiable.

While anonymity is intended to protect participants from the harms associated with being identified, Parker (2005) argues that one consequence of our attempts to conceal participants' identities is that it denies them 'the very voice in the research that might originally have been claimed as its aim' (p. 17). In such instances, Burton (2013) recommends that we prioritise relationships between the people involved in the research over administrative protections, especially when working with the 'vulnerable, marginalised, oppressed, excluded and invisible' (p. 804). Following Burton's (2013) advice we engaged members in discussions of the various concerns regarding the risks associated with being individually identifiable and the strategies that we might employ to protect members' identities.

Members felt very strongly that their stories were best documented through the body maps and videos that they themselves had co-produced, although they had different opinions about whether or not they wanted to be identified. Two members insisted on claiming ownership of their stories and did not want any individually identifying information to be changed or removed. In fact, these members went so far as to upload their videos on the internet. Other members wanted to share their contributions with their partners and with people in their intimate social circles. While it was important to these members to be identifiable to their own social circles, they did not wish to be identifiable in the public dissemination of the research. By contrast, one member decided to remove her video from the data corpus altogether. Instead of forcing a one-size-fits-all approach to issues of confidentiality and anonymity, as is often required in ethics protocols wherein every participant is regarded as needing the same protection, we chose to tailor these according to the wishes of each participating member. I have undertaken to remain in contact with the members who took part in these activities and continue to seek permission from each of them prior to my sharing data in any way. This illustrates the ethical imperatives for gaining ongoing consent for any new use of material not previously negotiated. The commitment to the right of participants to make decisions regarding the use of their data has continued beyond the lifetime not only of the evaluation, but also of the *dp* organisation, which sadly closed in 2013.

Tension 2: Analytic Complexity and Interpretative Authority

Following the body-mapping and participatory video production process, we conducted a focus group discussion in which members were invited to reflect on their experiences of taking part. The discussion was recorded and then transcribed verbatim. We then conducted a thematic analysis (Braun & Clarke, 2006) of the focus group discussion, yielding a summary of members' accounts of the participatory process. I presented this summary to the members who had participated in the body mapping and participatory video process with a view to obtaining their views on the emergent themes. In participatory inquiry, member checks are an important strategy for verifying findings. Unfortunately, members found our academic approach to the analysis to be dry and unengaging. We realised that we would have to explore alternative methods of analysis so that members could be involved properly in this part of the research. The trick was to come up with a method that would provide for systematic and sufficiently rigorous analysis while still being meaningful and engaging. And, in addition, we were also concerned about remaining as close as possible to each person's voice. How could all this be achieved with minimal intervention on our part?

The Listening Guide (Gilligan, Spencer, Weinberg, & Bertsch, 2003) is an analytic method that focuses on voice and relationality. It argues that '[t]he collectivity of different voices that compose the voice of any given person … is always embodied, in culture, and in relationships with oneself and with others' (Gilligan et al., 2003, p. 157). The Listening Guide process involves sequential listenings, 'with each listening tuning into a particular aspect' (Gilligan et al., 2003, p. 159). It is an appropriate approach to analysis in research concerned with members' diverse perspectives and experiences. This is because each listening guides the listener 'in tuning into the story being told on multiple levels' (Gilligan et al., 2003, p. 159). It also requires listeners 'to experience, note, and draw from his or her resonances to the narrative' (Gilligan et al., 2003, p. 159). In order to proceed with the Listening Guide method, we asked members to formulate an 'I-poem'. This involved reading through the focus group transcript and tracing how they had represented themselves in the discussion. Members were asked to pay attention only to the use of the personal pronoun 'I' and then to identify how they had positioned themselves in each instance. I-poems are an invitation to speak in the first person, and it was heartening to see how the trial of these 'I-poems' led to members' enthusiastic engagement as they began to hear their voices in the analysis of the focus group transcript.

Whilst the I-poems process was underway, I happened to read something that Judith Butler (2001) had written regarding the recognition of the self, and it resonated with me. According to Butler (2001, p. 22):

> [R]ecognition cannot be unilaterally given. In the moment that I give it, I am potentially given it, and the form by which I offer it is one that potentially is given to me. In this sense, one might say, I can never offer it, in the Hegelian sense, as a pure offering, since I am receiving it, at least potentially and structurally, in the moment, in the act, of giving.

For Butler (2001), recognition is only possible in the context of a relationship with an other. This led me to the realisation that one cannot have 'I-poems' without having 'You-poems'. Furthermore, as the 'you' is sometimes a collective, consideration also should be given to 'We-poems', and that 'They-poems' would be necessary for understanding the person in relation to the collective experiences of others. I also thought that 'It-poems' would be useful for exploring the 'objectified I'. I put these ideas to the group and the members agreed that it would be useful to explore what we termed 'Expanded I poems'.

An interesting observation that emerged from our experimentation with the 'Expanded I poems' was the comparisons that they afforded. For illustrative purposes, we have included two 'You poems' that were developed during the data analysis phase of the evaluation project. The first poem is a reflection on the experience of participating in the body-mapping and video production process. It suggests that the member experienced these activities as enabling relaxed engagement, and that the member was more willing to self-disclose when they felt that they were not being judged.

> You know I don't mind doing it
> you have some control over what
> you want to keep inside, yeh, hmm ….
> you feel quite vulnerable
> you put everything down
> you see when
> you see
> you know … weird talking to the camera
> you know just amongst friends just talking
> you put the film there in the background
> you know and just talk about it
> you feel more relaxed

Of particular relevance to the evaluation research were the comparisons that emerged between members' lives inside and outside their involvement in *dp*. This is illustrated in the next poem in which a member reflects on the experience of vulnerability inside and outside involvement in *dp*.

> You're not being judged as well
> you know because
> you're able to talk about
> you see, because
> you know that people doesn't judge
> you, but then
> you won't be judged that much as
> you are outside
> you know in the public

Montero (2000) calls for the researcher's role to be redefined in relation to the 'other' during PAR processes, recognising others in their own right as both the subject and the object of research; Freire (1970) describes the constantly shifting dialectical processes between objectivity and subjectivity as being necessary for counteracting and challenging oppression both within and without. With these ideas in mind, we counted the number of lines each member contributed to each of the expanded I-poems in order to observe the input of each member relative to the input of each of the other members. From this we ascertained that the participation of individual members in the focus group was skewed in relation to their gender and ethnic identity. The members whose voices were least heard had experienced the greatest levels of exclusion. Through this, we became aware of the subtle ways in which some people's voices may continue to be less evident in research products, even in approaches that are explicitly designed to be inclusive. Interestingly the level of participation of individual members when checked was not skewed in this way within the body-mapping and participatory video production processes.

Tension 3: Confronting the Limits

Writing up the formal evaluation report, my PhD thesis felt disconnected from the realities of the processes in which we had been engaged. I recalled that connection, and disconnection, had emerged as important elements of members' experiences. This prompted me to reflect on the implications, for a participatory ethics, of writing in isolation from the others with whom I had journeyed up until this point. Montero (2000) notes that in PAR one needs a systematic returning of the knowledge produced to those who co-produced it, thus exchanging the knowledge and know-how of the people, and the knowledge and know-how of the researcher. This co-production yields both new scholarly knowledge and new 'ordinary knowledge to be applied in everyday actions' (Montero, 2000, p. 141). This requirement also prompted a dilemma that could not be overcome. Although it was important to me to keep members informed of the new insights I was gaining as I wrote up the material, they were confident that we had met our responsibilities in terms of the evaluation, and felt that the academic write-up was my responsibility rather than theirs.

Writing this on my own gave me an opportunity to reflect on my own thoughts and feelings, and particularly as they pertained to the writing process. It was at this juncture that I encountered a sense of shame emerging from feelings of inadequacy. Fossum and Mason (cited in Pattison, 2000, p. 5) describe shame as:

> [A]n inner sense of being completely diminished or insufficient as a person. It is the self judging the self. A moment of shame may be humiliation so painful or

> an indignity so profound that one feels one has been robbed of her or his dignity or exposed as basically inadequate, bad or worthy of rejection.

The feelings of shame that characterised my experience of the writing process made me pause and consider whether the members had felt the same way about their own contributions. I also wondered how useful it was to dwell on these feelings. Freire (1970) argued too much subjectivity makes us sentimental, leading to a lack of effectiveness, while too little subjectivity makes us distant and lacking in sufficient attachment for a thorough engagement in the liberatory struggle. Martín-Baró (cited in Aron & Corne, 1996) argued that liberation is first and foremost a practical task, but how do we liberate others without first liberating ourselves from our own internalised oppression and the attendant thoughts and feelings that foster it? Perhaps the answer lies in his observation that the truth 'can become a task at hand: not an account of what *has been done*, but of what *needs to be done*' (Martín-Baró cited in Aron & Corne, 1996, p. 23, italics in original).

Finally, I also had to confront the difficulty of constructing a coherent narrative of findings that were stubbornly contradictory. For example, connection-disconnection was one of the salient continuums (themes) in members' accounts of fostering interpersonal relationships. Knowing-not knowing was a continuum related to members' accounts of learning and skills development, and taking part in paid and unpaid work were both important to members' sense of self, as were their experiences of living with and more often without certain material possessions. Perhaps these contradictions are not so much things to be overcome as a reflection on the outcome of the democratic participation of diverse members. Reason and Torbert (2001, p. 5) encourage practitioners of participatory research 'to forge a more direct link between intellectual knowledge and moment-to-moment personal and social action'. Similarly, Grande (2004), a Native American scholar, has argued that 'one of our primary responsibilities' is to 'link the lived experience of theorising to the process of self-recovery and social transformation' (p. 3), and Parker (2005) has called on critical researchers to engage in ways that 'open up alternative accounts rather than shut things down' (p. 148). Presenting alternative accounts in both the form and content of my thesis was my way of striving towards these ideals.

Conclusion

We need to devise a more complex ethical framework to accommodate our needs; one that facilitates interdependent, democratic, and negotiated participation that is able to evolve during the research process. We also need to be critically reflexive of the methodologies we employ. As we have demonstrated, whilst PAR aspires towards democratic and inclusive engagement, practice always falls short of the ideal. This highlights the importance of being attentive to the participatory process whilst it is taking place. In telling our story from the field, we describe instances in which we had to negotiate, and then renegotiate, the process of the unfolding research. We also recount moments in which being ethically responsive to the abilities and interests of the members required revising and co-developing new methods that would facilitate equitable and meaningful engagement. We describe the methods that we co-developed through tapping into members' creative potentials. We also reflect on members' willingness to take risks and to experiment with new ways of doing things, thereby showing the power of individual participants to influence what unfolded. So, whose PARty was this? Clearly, without the involvement of the members of *dp*, there would have been no party to begin with, but this does not obscure the fact that I obtained significant personal benefit through the successful completion of my PhD. Rather than achieving this 'on the backs' (Mampani, 2014) of the participating members, I do think that the resulting tools and products illustrate the embodied and interconnected nature of our journey of knowledge co-creation that we undertook alongside one another.

Notes

1. In this chapter, 'I' indicates the voice of the first author. 'Our' and 'we' are used to indicate the voices of both authors and to refer to our research partnership.
2. This remains a key policy objective of the current government.
3. Social enterprises are similar to charities and not-for-profit organisations in that they trade goods and services that have a social betterment purpose. Unlike charities and not-for-profit organisations that rely on grants or donations, social enterprises are income generating and are expected to become financially self-sufficient.
4. Ethical approval for this project was granted by the York St John University Research Ethics Committee on 15 February 2011 (UC/15/2/11/JL).

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25

When Ethical Procedures Can't Do the Job: Ethical Dilemmas of Undertaking Critical Organisational Ethnographies in Social and Health Research

Jason Bantjes and Leslie Swartz

Organisational ethnographies are an important mode of enquiry in critical social and health research (Reeves, Peller, Goldman, & Kitto, 2013; Savage, 2000; Yanow, Ybema, & van Hutst, 2012). The value of organisational ethnographic research lies in its potential to draw analytic attention to the symbolic significance of practices in institutions such as schools and hospitals to illuminate how shared systems of meaning act as interpretative schemes which shape practices within these social systems (Morgan, 1986). Organisational ethnographies can highlight the socially constructed relationships between institutions and their environments and make explicit key values which shape the behaviour of the individuals who inhabit them (Morgan, 1986). They also can be instrumental in exposing injustices and disrupting unfair and potentially harmful practices thereby having a special relevance for addressing fundamental questions of transformation of institutions in unequal and oppressive societies (Carspecken, 1996; Madison, 2005). Their deeply political nature, however, brings ethical challenges which are not always easy to resolve. In this chapter, we describe our experience of undertaking critical organisational ethnographies in a school and a healthcare unit to illustrate how the political dimensions of this work led us into a minefield of potential ethical conflicts and dilemmas. Our stories show how we were challenged into reconsidering conventional ideas about informed consent, privacy, confidentiality, and nonmaleficence. They also demonstrate how our responsibility for protecting

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research participants is complicated by our responsibility accurately to describe what is observed. We discuss the challenges of balancing 'social good' against the interests and rights of the individuals inserted into and reproducing institutions. Furthermore, while traditional approaches to research ethics are commonly predicated on the assumption that the researcher is separate from the field being researched, our stories illustrate how critical ethnographies can render permeable the boundaries between researcher and researched, and relationships potentially complex.

Ethical Considerations in Ethnographic Research

Traditional approaches to research ethics are commonly predicated on the assumption that we, as researchers, are separate from the field being researched, that research participants are strangers with whom we have no prior relationship and plan no future interaction, and that our primary ethical responsibility is to protect the privacy of participants and to do no harm. This approach to research ethics, which fits comfortably with clinical trials and outcome studies, positions research participants as vulnerable, in need of protection, separate from the researcher, and at the centre of the research inquiry. This obscures the reality that critical social and health research sometimes has a relational component, often has a broader social and political context, and that researchers may have social and political advocacy responsibilities that extend beyond the individual rights of research participants. Social science researchers, as agents of social change, have a moral responsibility to explore, describe, and theorise about the nature and function of organisations (Chari & Donner, 2010). This is a responsibility that may entail exposing practices and injustices for a greater social good that extends beyond the narrow self-interests of the institutions being studied. Critical ethnographies, and especially those with a participatory component, often make the boundaries between researcher and researched permeable, and relationships potentially complex (Rosen, 1991). In the narrative which follows, we draw on the first author's personal experience of conducting ethnographic research in a school and in a medical setting to illustrate these ethical considerations and to discuss the ethical implications for critical social and health research. As is the tradition in ethnographic research, the personal experiences of the first author are presented as a first-person 'I' narrative of the process as it was experienced. 'Our' and 'we' indicate the voices of both authors.

Disruptions and Permissions

Early in my career as a researcher, I had the opportunity to conduct an ethnographic study of a school[1] (Bantjes & Nieuwoudt, 2011, 2014) at which I was employed as a consultant psychologist. My job entailed promoting the psychological well-being of the pupils, which, of necessity, required that I confront and challenge practices at the school that compromised the pupils' psychological health. During my time at the school there was a rather bizarre incident in which a group of senior boys engaged in disruptive behaviour that included the destruction of school property and verbal attacks on members of staff. These incidents were startling, particularly as the behaviour was uncharacteristic of the boys concerned. The incident perturbed the school community and sparked numerous conversations and questions about what might have prompted the boys to behave in this way. It occurred to me that the incident, as unfortunate as it was, revealed something important about the culture of the school, something, perhaps, that the boys were trying to bring to the attention of the school management.

As an insider, I was uniquely positioned to examine the cultural context in which this behaviour had occurred and to explore its symbolic meaning. Suspecting that the culture of the school was in some way implicated in precipitating this event, it occurred to me that it would be most appropriate to employ an ethnographic method of enquiry. Importantly, by employing this methodology, I would need to consider my position and role in the school. In other words, I would have to acknowledge that I was part of the system and culture that had given rise to the behaviour I wanted to examine. Reflection led to a decision to include an auto-ethnographic component into the research design, thereby allowing as data personal observations, experiences, and reflections. The appropriate methodology was clear but the ethical dilemmas that this project could occasion were less clear perhaps because of my lack of information.

The first dilemma encountered was a concern about permission to conduct the study. Did I need the school's permission to research and write about the incident? Did being a member of the school community entitle me to report on what had been witnessed, or did the school have sole claim to the story because it had occurred in the geographic boundaries of the institution? I knew that writing about the incident with insider knowledge of the culture of the school might expose aspects of the everyday functioning of the school to public scrutiny. Furthermore, because the form this scrutiny might take could not be predicted, it was impossible to determine the exact risks for the school.

Did the risks that public scrutiny occasions compel me to seek permission before embarking on the study? And, assuming that permission was required, who had the legitimate authority to grant it? Furthermore, being an insider meant I was positioned differently from outside researchers who would approach gatekeepers of institutions. How would this complicate the endeavour to obtain institutional permission?

I was aware that I had a relationship with the school which should be preserved. Maintaining this relationship meant that I could not press on with research without consulting the school principal. Thus, apart from an ethical responsibility to seek permission, the decision to consult the school principal was based as much on an ethical imperative as it was on a pragmatic and self-serving desire to maintain a good working relationship and also my employment. Seeking formal permission was, at least in part, an attempt to minimise the risks to myself which were the direct result of insider status.

I met the school principal and explained what I wanted to do, but it was not possible to describe exactly how data would be collected or what the potential risks might be. In truth, I did not believe that there were serious risks. It only occurred to me much later that the concept of informed consent might be meaningless in the context of institutional ethnographic research. How can any institution be sure of what an ethnographic study would reveal, or what might be exposed by placing institutional culture under the microscope? Even if an institution gives permission for research, can it be said that this consent is informed? I could not articulate exhaustively the risks and benefits of the research, nor could I define research questions nor determine methods of data collection without first engaging in preliminary investigation. When describing their approach to ethnographic research, Bosk and De Vries (2004, p. 253) note:

> [W]e cannot state our procedures any more formally than we will hang around here in this particular neighbourhood and try to figure out what is going on among these people. We want to know how they make sense of their world, how they navigate in it, and how understanding their world helps us better understand our own.

Because I could not articulate all the possible risks associated with the study, it was mutually agreed that the school principal and I would discuss and agree safeguards to protect the school,[2] and that the best way to do this was for the school management to be enlisted as co-researchers in the process of setting the research agenda and helping to make sense of the findings. We also agreed that the school principal would have the power to veto key decisions. Among other things, this meant that the school principal could decide that particular findings should not be published in a form available to the public. At the time, this seemed a reasonable solution to concerns about management of possible risks. How else could the school safeguard its own interests? With hindsight, I had been naïve to imagine that there could be a shared set of interests in a large and complex institution. There was in fact a real possibility that my research would be used to further the interests of some stakeholders at the expense of the interests of others. I could not imagine, however, how else to proceed with the research.

I rationalised the decision to allow the school principal to have the power of veto by convincing myself that partnering with the school was akin to participatory research, and that there might be the added advantage of improving the trustworthiness of my findings through member-checking. It later became apparent how problematic this arrangement was. What if I discovered something that had significant social and political implications, but was potentially damaging to the school's reputation? As a researcher, do I have an ethical responsibility to report the findings regardless of what those findings are? Does this outweigh an ethical responsibility to avoid doing reputational harm? I had resolved one ethical problem (that of obtaining institutional permission for the study) by agreeing to allow the school principal to censor the findings, and, in doing so, I seemed to have created another problem. How would I deal with my responsibility to report honestly and accurately what I observed? Is it ethical for an ethnographic researcher to agree to suppress findings in order to protect an institution?

Although I realised that I needed to obtain permission to conduct the study, I am not sure how I would have proceeded if this had been denied. Would I have tried to seek permission elsewhere? Does the management of an institution have the exclusive right to grant permission for an ethnographic study of the organisation? Surely schools, even private schools, are essentially public institutions with many stakeholders beyond the immediate management team? By their nature, public institutions belong to society and hence to everyone. Should the management of such an institution, which may itself be invested in maintaining the status quo, be solely responsible for granting permission and access?

If organisational ethnographies in the social sciences are to be critical and are to take on the important work of drawing attention to harmful or unjust practices, then we need to find ways to deal with the problem of permission and access so that it does not elicit potential censorship. At issue, though, is more than that of censorship. There is the serious question of who may be seen to speak legitimately for and on behalf of institutions, and on what grounds. In the case of my school ethnography, I chose to liaise with the existing formal school governance structure (those with recognised decisional authority) and hence, despite the critical intention behind my work, implicitly to reinforce and legitimatise this power hierarchy. But what if the pupils, or their parents or teachers, held different views about whether the research should take place and how, if at all, the findings should be disseminated? Would it be ethical to conduct organisational ethnographies when the management was supportive but the majority of the other stakeholders in the institution were opposed to the research? Similarly, would it be ethical to go ahead with research vetoed by management but supported by other stakeholders in the institution?

In institutional contexts, different stakeholders are likely to have different investments (which may be diametrically opposed) in what is known and not known about the institution. Sexual abuse in the Roman Catholic Church is a useful example in this regard. For a long time senior clergy had actively prevented the public disclosure of cases of sexual abuse because of personal investment, whereas many ordinary members of the church had strong feelings that the stories of abuse needed to be told (Robinson, 2003). If a critical ethnography of the church had been conducted at that time, whether or not institutional permission was obtained, the ethnographer would have become a participant in deeper institutional questions about what may or may not be said by different stakeholders in the church. Similarly, in my work with the school, it was incumbent upon me to think critically about how research decisions would contribute to power struggles in the school about what constitutes an appropriate, accurate, and legitimate narrative of the school and who should speak on behalf of it.

Boundaries, Care, and the Problem of Representation

Later in my career I became the lead researcher on a large project on deliberate self-harm. The project was another organisational ethnography, this time exploring the organisation of care for self-harm patients in a public hospital in South Africa (Bantjes et al., 2016).[3] I was assisted on the project by Annemi Nel, a postgraduate student with whom I worked to observe practices in the hospital, attending ward rounds, interviewing medical staff, and talking to patients who self-harm, about their experience of receiving care. Data was collected for this project over the course of a year. During this time I became well known to the medical staff in the hospital, and developed a reputation as a psychologist who was interested in suicide and self-harm (there is an association between repeated acts of self-harm and increased risk of suicide).

Initially, it was easy to maintain my role as a researcher. I was an outsider to the hospital, with no clinical responsibilities and no professional standing in the formal hospital hierarchy. As time passed, however, I became familiar to the staff and my presence on the ward became routine; my positioning as an outsider began to erode. One benefit of this was that the medical staff became comfortable talking to me about their experiences of caring for self-harm patients, and this facilitated the research process. It also created expectations regarding reciprocity, and I found myself being consulted about some of the patients. Medical staff knew that I was interviewing patients who had been admitted to the hospital for deliberate self-harm and began to recognise that I might have particular expertise in the assessment of patients at risk of attempting suicide. I had also facilitated a number of professional development workshops on suicide risk assessment during the study period which had been attended by some of the medical staff.

What was the ethically correct response when medical staff engaged me in conversations about the care of patients? It was easy enough not to betray confidences or to share the personal details of my conversations with patients, but did my role as a researcher prevent my offering opinions about the appropriate management of care for these patients? Was it unethical to blur the boundaries between my role as researcher and my role as psychologist by being drawn into these conversations? Alternatively, would it have been unethical not to discuss the care of patients, especially since I believed that offering my opinion was likely to be in the patients' best interests? It is important to note that there is a considerable shortage of access to psychologists in the South African healthcare system, and psychological input is not routinely available in general medical settings (Bantjes et al., 2016). It seems inevitable that boundaries will be contested whenever researchers undertake organisational ethnographies over prolonged periods of time. Does this potential for boundary transgression in ethnographic research threaten the neutrality and separateness of the researcher to such an extent that the ethical integrity of the research is compromised? How can these boundaries be maintained? Can boundaries ever be transgressed ethically?

The write-up of our research in the hospital brought with it additional ethical considerations. I knew that it was important to provide sufficient information about the hospital for readers to appreciate the context framing the research findings. I also knew that I had to take steps to safeguard the identity of the hospital. This, it turned out, was almost impossible to do. It was simple enough to withhold the name of the hospital, but the moment I identified it as a large inner-city academic hospital, it would be obvious to most South African readers that the study site was one of a handful of institutions. If I provided any additional information, such as the annual admissions rate or number of beds, a quick internet search would enable readers to identify the hospital. Knowing this made me cautious about how to represent the findings. I was no longer writing about a disembodied and abstract institution but about a hospital that could be identified and, once the hospital was identified, it would be possible to identify individual medical staff, the doctors, and nurses with whom I had worked.

I encountered further ethical quandaries when considering what to include, and exclude. I could not describe everything that I saw or recount all that I heard behind closed doors. This would not only draw attention to practices in the hospital that were socially unjust, but would be likely to hurt and offend staff of the hospital. A completely uncensored description of what I experienced might have made the stressful, demanding, and fractious work environment even more tense and difficult for the nurses and doctors who do their best under difficult circumstances. The South African healthcare system is critically under-resourced and under considerable strain as a result of four colliding epidemics: HIV and tuberculosis; a high burden of chronic illness and mental health disorders; deaths related to injury and violence; and maternal, neonatal, and child mortality (Mayosi et al., 2012). I had, in a sense, created the ethical problem of how much to reveal in the write-up by allowing myself to be sensitised to the very difficult working conditions in the hospital and by developing relationships with the hospital staff. But how else does one do ethnographic research without developing these relationships? This is partly a tactical question because these relationships gave me access to the information I needed, but, as these relationships deepened, it became difficult to separate the institution from those who worked in it. Consequently, we argue that this is an issue of relational ethics which is elaborated on later in this discussion.

When it came to publishing the study, I chose to describe the setting and present the findings as carefully and as accurately as I could, having weighed every word in an effort not to offend or expose any individuals in the hospital. Was it unethical to provide detail about the hospital that might identify it? Would it have been unethical not to do the research simply because anonymity could not be guaranteed? To what extent should a commitment to protect people working in the hospital prevent me from describing everything that had been observed? These ethical complexities were compounded by the fact that the research was funded by the South African Medical Research Council. In accepting a substantial grant to conduct health systems research, had I assumed an ethical responsibility to advance the collective public good? Did this outweigh my obligation to be respectful of the medical staff? I was also aware that disclosing some information might compromise future access to the public healthcare system, and that this would have implications for my career as a health systems researcher. Did sources of funding and future career prospects compromise my integrity?

Contamination and Control

I was once consulted by a colleague who worked in a medical laboratory. He knew I had an interest in researching organisational dynamics and wanted to know how to go about documenting his experience. He had observed a number of practices that raised questions about the safety of laboratory technologists and their potential exposure to infectious agents. He told me he had tried, in various ways and within the appropriate organisational structures, to question and to bring attention to these practices, but that he had encountered resistance to change. He knew the resistance was not due to a lack of knowledge about safety standards and appropriate operating procedures. In his opinion, it reflected a much more serious problem that was in some way related to the organisation's values, institutional culture, and the way in which decisions are made in medical settings. He did not know it, but he was actually asking me how to conduct an auto-ethnography about laboratory safety in the public health system.

I did not know how to respond to him. I could easily tell him about the methodology, but I did not know how to advise him to overcome the problem of obtaining permission to document his experiences and to publish his findings. There was a clear public health interest in examining this issue. However, the information that he had gathered implicated his work colleagues. Feelings and professional reputations would be more than bruised if he wrote about the things that he had described to me. It would impact on his relationship with his colleagues and employer, and some disclosures might even violate the terms of his employment contract. Not writing about his experiences would leave his working relationships intact, but would leave the unsafe practices unchecked and would compromise the health of laboratory technologists. The problem was that permission to conduct the research would require the formal approval of his line manager, and his application would be subject to a process of departmental ethics review. Thus, the very same department that had resisted confronting the issue of laboratory safety had the power to approve (and reject) the research. Had the departmental ethics review committee denied permission to conduct the research, would it have been in order for him to publish his experience of having permission denied? Is it ethical to stay within the bounds of an institution's ethical procedures even when one is forced to remain silent, or is one obliged to ignore institutional procedures to make one's observations public?

Conclusion

There are no simple solutions to the ethical dilemmas inherent in ethnographic research, and ethical review processes in universities do not always facilitate resolutions to these ethical issues. There is an established literature describing how discontented ethnographers have become with the review of their research proposals by institutional ethics committees (Bosk & De Vries, 2004). In part, the problem is that ethical review processes often focus on procedural ethics and mandated procedures to address informed consent, confidentiality, the right to privacy, and the protection of human subjects from harm (Guillemin & Gillam, 2004). Unfortunately, it is often the case that ethnographic research occasions ethical dilemmas that cannot be solved easily with checklists and consent forms. Instead, these dilemmas test the extent to which a researcher acknowledges and values mutual respect, dignity, and connectedness (Brooks, 2006; Lincoln, 1995).

As ethnographers, the ethical issues we face are likely to be situational ethics; the context-specific, unpredictable, and subtle ethical decisions have to be confronted in the field and on the run (Goodwin, Pope, Mort, & Smith, 2003; Guillemin & Gillam, 2004). The stories described in this chapter illustrate how situational ethics require ethnographers to balance a range of competing ethical imperatives, such as their responsibility to individual research participants balanced against the collective public good and social justice. Beyond procedural and situational ethics, ethnographers also have to confront relational ethics which demand that researchers acknowledge their interpersonal duty to others and take responsibility for their actions and for the consequences of their research. Slattery and Rapp (2003) describe relational ethics as a reflexive process of conducting research in such a way that one remains 'true to one's character and responsible for one's actions and their consequences on others' (p. 55). Relational ethics focuses on the role of relational context and on the experience of relationships in influencing moral choices (Bergum, 2004). Relational ethics has much in common with the ethics of care (Gilligan, 1982; Noddings, 1988) and is well aligned with principles of respect (Bergum & Dossetor, 2005) and with advocacy work (MacDonald, 2007).

As the examples sketched in this chapter illustrate, in organisational ethnographic research boundaries become blurred and roles shift as we submerge ourselves in the daily life of institutions, as we develop relationships with the individuals who people these institutions, and as we allow ourselves to become part of the cultures and systems we investigate. These endeavours force us to navigate ethical dilemmas that are not adequately addressed in ethics conventions premised on the emotionally detached application of universal and contextual ethics principles (Gadow, 1999). Vague and generic prescriptions such as 'do no harm' and 'obtain informed consent' do not always help to guide the decisions we confront in the field, or the decisions we make when documenting our findings. Fortunately, as Ellis (2007) has noted, the increasing documentation of researchers' experience in ethnographic work can help us identify those ethically important moments and guide us through ethical decision-making processes (Adams, 2006; Carter, 2002; Etherington, 2005; Kiesinger, 2002; Marzano, 2007; Perry, 2001; Rambo, 2007). It is important that, as ethnographers working in critical social and health research, we continue to write in an authentic, open, and non-defensive way about the ethical challenges we confront and the decisions we make to resolve them. Being reflective about our practices and inviting others to witness and comment on our decisions is an important ethical safeguard integral to a relational ethics.

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Notes

1. This research was conducted for a doctoral study in the Department of Psychology at UNISA. The relevant ethical permissions were obtained in accordance with the ethical procedures of the Department of Psychology in 2009.
2. This research was conducted at a private school so I did not need to obtain permission from the provincial Department of Education—which would have complicated matters even further.
3. Ethics approval to conduct this study was obtained in 2013 from the Health Sciences Research Ethics Committee at the University of Stellenbosch (HREC reference: N13/05/074) and the University of Cape Town (HREC reference: 645/2013). Institutional permission for the study was obtained via the Department of Health.

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26

The Ethics of Covert Ethnographic Research

Marco Marzano

Covert ethnography is a feature of some of the most notable sociological research, and it is this feature of sociological inquiry that has occasioned considerable debate. In this chapter, I draw on examples from my own research to argue that it is possible to conduct ethically responsible covert ethnographic research. Research is deemed to be covert when researchers do not reveal their identity, as researchers, to those whom they are observing. In such instances, while people are likely to be aware of the fact they are being observed by others in their company, they are unaware that there is a researcher among them and that they are being observed for research purposes. Research is also deemed to be covert if a researcher reveals their researcher identity but deliberately withholds certain information about the research from the people being observed. The fact that those being observed are either unaware that they are being observed or unaware of the true purpose of the researcher's observations is said to undermine the ethics principle of respect for persons and the right to informed consent (e.g. Faden & Beauchamp, 1986), and this is at the heart of the presumption of the unethicality of covert research.

Over the past 40 years, a mounting critique of covert ethnographic research from within mainstream sociology suggests that there is no room for covert methodology in modern sociological inquiry (e.g. Beauchamp, Faden, Wallace, & Walters, 1982; Bok, 1978; Bulmer, 1982; Erikson, 1967). This is despite the fact that covert ethnography has, as Calvey (2017) observes, been

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a feature of some very significant sociological and anthropological research, including Goffman's (1961) *Asylums*, Festinger, Riecken, and Schachter's (1956) *When Prophecy Fails*, Dalton's (1959) *Men Who Manage*, Rosenhan's (1973) *On Being Sane in Insane Places*, and, more recently, Scheper-Hughes' (2005) *The Last Commodity: Post-Human Ethics and the Global Traffic in 'Fresh' Organs*. The critique of covert ethnographic research has emerged in the context of research environments in which a regulatory ethics has expanded rapidly (Haggerty, 2004; Marzano, 2012a). In this context, one implication of the criticism of covert ethnographic research is that it is now generally discouraged, and in some instances, even completely prohibited (e.g. Iphofen, 2006; Tysome, 2006). I provide a brief overview of some of the debate on covert research before proceeding to a discussion of my own research.

Arguments for and Against Covert Ethnographic Research

In a dominant regulatory approach to ethics it is assumed that covert research is damaging to everyone: both those subject to it and those who conduct it. Covert research is deemed to be harmful to research participants because they are deceived, their trust is betrayed, their integrity and their right not to be studied is violated, their interests, and sometimes their reputations, are seriously damaged (Faden & Beauchamp, 1986). This is deemed to be true even in cases in which the participant's identities have been masked. Because it is not difficult, it is argued, for the people involved to know who is concealed behind the fictitious identities of ethnographic narratives (Herrera, 1999), the consequences thereof can be very unpleasant (e.g. Vidich & Bensman, 1964).

Detractors have also warned that covert methods cause numerous difficulties for researchers themselves. It is argued that, when researchers become accustomed to lying to and deceiving the people whom they engage in the field, they may begin to do this in other spheres of life as well (Homan, 1991): at home, in the classroom, in their writing. It is also argued that covert ethnographic research can impact negatively on scientific integrity, particularly when it impedes access to information that might have been easily obtained had the researcher been upfront about the research (Homan, 1980). Those employing a covert methodology may also find that it inhibits their ability to return to the field to obtain participant feedback or properly to validate their findings (Homan, 1980). Furthermore, there is a risk, in covert research, for researchers to become involved (albeit inadvertently) in actions or events that are deemed to constitute illegal or even criminal activity (Pool, 1995).

There is concern that, as revelations regarding the conduct of covert research can foster suspicion and distrust, it has the potential to damage relations in the communities studied, as well as to damage relations between research communities and society (Homan, 1980). It is for these reasons in particular that covert methods have been critiqued for threatening to discredit sociology and anthropology, disciplines in which covert research traditionally has been employed (Erikson, 1967; Homan, 1991).

In recent years, those seeking to defend covert research (e.g. Calvey, 2008, 2017; Lauder, 2003; Lugosi, 2006; Spicker, 2011) have argued that debate on the ethics of covert ethnographic research has, at times, been overly simplistic and should be handled with nuance and careful consideration of the different implications of covert methods in different types of research. In other words, the ethics of covert ethnographic research need to be assessed on a case-by-case basis (Barrera & Simpson, 2012; Ferdinand, Pearson, Rowe, & Worthington, 2007; Lugosi, 2006) and in relation to the specificities of each research context (Marzano, 2012b). For example, while special caution needs to be taken to protect vulnerable populations such as those who are very young, sick, or destitute, it would be inappropriate to apply these same cautions in the evaluation of covert research involving the participation of individuals in the general population. I am also sceptical of assuming that researchers ought to apply the same considerations afforded to very vulnerable participants, as they would to individuals who are less vulnerable.

Covert research is sometimes necessary to counter the Hawthorne Effect (Landsberger, 1958), which occurs when the researcher's presence alters participant behaviour, causing distortion of the research data. Covert research can also shed light on the most hidden aspects of some social settings which would otherwise be inaccessible to the gaze of the researcher (Calvey, 2008). In these instances it is argued that the advantages of the knowledge gained far outweigh the costs occasioned by a lack of transparency.

There have been calls for a distinction to be made between covert research and deceitfulness. According to Spicker (2011), disclosure is a positive act; it is the steps a researcher takes to inform people of the purpose of the observations being undertaken. Not taking these steps, however, is not the same as intentionally misleading research participants or intentionally misrepresenting the research to them. In some instances, research is covert simply because it is not always possible to inform everyone concerned about the research. It is not feasible, for example, properly to inform all the spectators in a sports stadium or all the shoppers in a market square of the researcher's presence (Gold, 1958). It has been pointed out that research is sometimes only temporarily covert. This happens, for example, when a researcher believes it prudent gradually to reveal their identity to participants as they get to know them (Lugosi, 2006). Gradual disclosure helps researchers establish a degree of familiarity with participants before disclosing that they are doing research. One benefit of this is that it often makes it easier to know how to describe the research in ways that participants are most likely to understand. As Lugosi (2006) points out, non-disclosure is sometimes not so much a consequence of the researcher's failure adequately to describe the research as it is the participants' lack of interest in hearing what the researcher has to say. Describing his own research experience, Lugosi (2006, p. 553) says, 'I gave elaborate explanations to individuals who were prepared to listen, but inevitably abridged my accounts to people for whom clarification appeared superfluous'.

It has been argued as well that overtness and covertness are not distinct or mutually exclusive but a matter of varying degree (Calvey, 2008). According to Punch (1986), it is unlikely that ethnographic research is ever entirely overt because it is difficult to imagine instances in which all participants, without exception, completely understand the full extent of what participation in research entails. Ethnographic inquiry generally depends on the researcher having at least one ally, a participant who is the researcher's accomplice and who plays a significant role in the conduct of the research. A chance encounter with Ernest Pecci (aka 'Doc'), for example, led to Whyte's (1943) groundbreaking study of everyday life in an Italian ghetto in Boston, in the United States. The point is that, in ethnographic research, participant roles can vary and are not always clear from the start. Furthermore, ethnographic research is an open and flexible methodology that can change and adapt as the research progresses. Consequently, it is interesting to consider to what, specifically, participants have agreed when concurring with the presence of the ethnographer. How can they be sure of what the ethnographer is investigating if the ethnographer does not have conclusive research questions or a clear direction of inquiry? Does this not constitute a degree of concealment? And, what of our other habits in the field, the small and seemingly insignificant lie, 'I'm fine', the simulation of friendship, or a quick peek into a confidential document?

On the issue of harm, it is difficult to deny that risk exists. Risk, however, is not particular to covert methods of inquiry. What about those who, in homage to an ethic of sincerity, do not hesitate to tell the brutal truth, and who betray participant's expectations of a more flattering portrayal of their lives? The naked truth may hurt even more than deceit. In Goode's (1996, p. 25) words:

> Complex portrayals of real people in the real world offer a view most subjects are likely to experience as betrayal—betrayal not so much because details of the

> portrait are empirically false as a ‘warts and all’ image is the last thing the subjects want presented to the reading public … the subject wants to read a flattering portrayal, not an accurate one. A research report’s lack of flattery is what is most likely to cause pain and discomfort, not the practice of deception the researcher may have used to gather information.

Debate on the benefits and drawbacks of covert research is interesting, but it has some limitations. One concerns a degree of ethnocentrism and historicity that gives insufficient consideration to the social contexts in which ethical standards are, or were, not applied stringently, and where there have not been the same obligations regarding the necessity for obtaining informed consent. Another limitation is that there is little or no consideration of the often complex and conflictual nature of the social arenas in which ethnographic research is located, which makes simple determinations regarding the ethics of covert research difficult to accept at face value.

The concept of the field as a place in which the researcher meets a homogeneous population with the same interests and expectations who share similar values provides an adequate description of only a few, exceptional research contexts. Most of the social situations that ethnographers study are inhabited by social actors with very unequal access to resources and who are bound together in relationships of unequal power, in relations characterised by subordination and domination. Ethnographers who study work places encounter executive personnel and office janitors, those who research schools encounter teachers and pupils, those who study religion encounter priests and bishops but also their faithful congregations. In each case, social life is characterised by profound asymmetries of knowledge, resources, and power. And, in these contexts, we must give pause to consider what the implications of these asymmetries are in the shaping of ethnographic inquiry. This is because concrete material differences and the role that these differences play in shaping the interests of different social groups will come to be reflected in all aspects of the research, including how access to the field is negotiated and the activities thereof that follow.

Gatekeeper-Imposed Identity Masking

Some years ago I initiated research on doctor–patient interactions in the treatment of people who were terminally ill with cancer (Marzano, 2007). I was trying to understand why, in Italy, it had become commonplace for doctors not to inform terminally ill patients that their cancer was incurable. At the time there was no requirement, in Italy, for social science researchers to obtain ethics review and approval. Ethics considerations were left entirely to the discretion of individual researchers. Gatekeeper permission was a requirement, however, and my University expected that I would obtain permission from the appropriate authorities at the hospital before proceeding with the research.

My first step was to contact the Chief Consultant of a cancer ward at the hospital where I was planning to locate my research; he provided me with the requisite permission to conduct the research, but his permission was provisional: I had to sign an official document in which it was stated that he could instruct me to stop my research on the cancer ward at any time and that, if so instructed, I would leave immediately. This made it clear that access to the field was contingent upon maintaining a cooperative relationship with the Chief Consultant. It was not long before I began to realise that maintaining a cooperative relationship was going to be tricky.

My first request, after obtaining permission to access the cancer ward, was to observe doctor–patient consultations. In response to this request the Chief Consultant advised that, in order not to disrupt these consultations in any way, I would have to disguise myself as a medical doctor. I was to do this by donning a white coat and accompanying the duty doctors as they did their ward rounds. I acquiesced to this request and was interested to discover that this made me almost invisible to most patients. I do not know if this was due to their deference to the medical staff or a lack of interest. I, on the other hand, was very aware of my disguise. I was concerned that my silence, which was strange behaviour for a doctor, would be noticed. I also often felt embarrassed and blushed, and invariably wore a coat of the wrong size (either too big or too small). The novelty of being in disguise wore off quickly and, as time went on, being in disguise made me feel complicit in the deception of cancer patients and became increasingly intolerable. I could not bear to witness doctors purposefully withholding information about the severity of their patient's illness: treating them like children who could not be trusted to make properly informed decisions regarding their treatment. At one point I wrote in my field notes: 'I don't want to make any more visits because I don't like masquerading as a doctor, watching the vivisection of those poor wretches, avoiding any fully human relationship with them. Yesterday I took off my white coat and ran away. I couldn't stand its weight on me any longer'.

Some months later, my observations shifted to the palliative care ward. As the Chief Consultant on this ward did not require that I disguise my researcher identity, I was able to introduce myself to the patients and to be open and frank with them about my research. Free of the burdens of my previous disguise, it was much easier to engage with the patients on the palliative care ward than it had been in the cancer ward. I was able to speak to patients and the general tone and openness of these discussions was qualitatively different to the ones I had conducted on the cancer ward. Some of these interviews were very difficult because the trauma of their illness and the anxieties of being terminally ill were tangible. However, it made a difference to me and to the people whom I was interviewing that we could talk openly and honestly.

A few years after my hospital research concluded, I initiated new research which examined charismatic spirituality in the Catholic Church in Italy (Marzano, 2009). I was interested in understanding the appeal of a Catholic charismatic spirituality imported from Pittsburgh in the United States to a country with an ancient Catholic tradition. My first step in negotiating access to the field was to enlist the help of mutual friends in arranging an introduction to Don Patrizio, a pastor in a charismatic Catholic group called *Rinnovamento nello Spirito* (Renewal in Spirit). Don Patrizio gave me permission to proceed and invited me to attend several events in which his parish was participating. Attending these events gave me a sense of some of the practices that charismatic spirituality involves, such as healings, prophecies, and glossolalia. As interesting as these events were to observe, they provided little insight into the meaning and significance of the practices for those who participated in them. I also had a sense that everything that I had observed had been fairly superficial and that there were other practices that were being deliberately kept hidden. I had a suspicion that Don Patrizio and other elders in the group wanted to keep some of their practices private because they were controversial, possibly deviating in some significant way from the practices sanctioned by the orthodox Catholic Church, to which the group's members still claimed to belong.

My research reached a turning point one evening when, on the margins of a prayer meeting, Don Patrizio introduced me, quite by chance, to a group of elders from a different parish who were organising an event which they called a 'Summer Course for Evangelizers'. The elders were friendly and a few days later invited me to dinner where they told me they were happy for me to attend the summer course they were organising. This was to be on the condition that I did not reveal the true purpose of my presence, as a researcher, to the other participants, who, they said, 'might feel themselves being observed like guinea pigs! No-one likes being a subject of study! Also because you'll see that the people reveal many intimate and secret details of their lives'. I protested for a bit arguing that I preferred to be honest and sincere about my reasons for attending the course, but the elders could not be persuaded otherwise, and I eventually agreed to this condition.

In recent years my research has focused on the activities of a fundamentalist Catholic group called *Cammino Neocatecumenale* (Neocatechumenal Way[1]) (Marzano, 2012c). Once again, I obtained permission to conduct the research from elders in the group. As was the case in my previous research, gaining access to some of the activities I wished to observe was granted on the condition that I did not disclose my researcher identity. In this study, in order to accept an offer to attend a 'Course for Initiates', I had to acquiesce to the elders' request that I attend the course in the role of a prospective convert and not disclose my researcher identity to the other people attending the course. Once again, the elders reasoned that course participants would not be pleased to know that they were being observed and that the intimate aspects of their spirituality would form part of an ethnographic account of the work undertaken by the group.

Thus, in each of the studies described, the role of partially covert observer (Adler & Adler, 1987; Hammersley & Traianou, 2012) was imposed on me by powerful institutional gatekeepers as a condition for obtaining access to the field. In each instance gatekeepers who were also powerful stakeholders in my research sought to cooperate with me and were willing to facilitate access to the field, while at the same time maintaining considerable control over my engagement in the field. In doing so, they prevented less powerful stakeholders (patients, parishioners) from being informed about the research and, consequently, of an opportunity to shape the inquiry in ways that might have been important to them. I have given a lot of thought to what the patients on the cancer ward and the religious converts might have chosen to disclose if they had known that I was a researcher and had they been informed of the focus of my research. Granting me access to the cancer ward and invitations to attend the religious courses gave the stakeholders the appearance of openness. If that had really been the case, however, there should have been no reason to conceal my researcher identity. I believe that my disguise on the cancer ward was far less effective, if effective at all, in minimising the discomfort of terminally ill cancer patients than it was in controlling what they were likely to disclose to me while I was disguised as a doctor. This observation is justified by the qualitative difference of the engagements with patients in the palliative care ward where I was not in disguise.

With regard to my research on charismatic and fundamentalist groups in the Catholic Church in Italy, I believe that I was able to obtain permission to conduct the research because the elders who granted the permission were significantly invested in, and thus motivated to advance, the mainstreaming and greater acceptance of these new but also fairly contested groups. I was aware that the new charismatic and fundamentalist groups were viewed with suspicion by many in the Catholic Church and that there was a considerable need for them to gain validity. In this context, my sociological research was viewed perhaps as constituting formal recognition from an academic community. I also believe that they had hoped that I might become a convert. I sometimes had the impression that there were elders who believed that I had chosen to observe their group partly because I was attracted, consciously or unconsciously, to their teachings. Perhaps, by inviting me to attend the courses and in obliging me to take on the role of convert, they thought that I might come to pursue that path. If so, they would have viewed that eventuality to be advantageous.

Whatever their reasons for granting me permission to undertake the research, it is clear that my acceptance of the conditions under which access was permitted had made me an accomplice. Non-disclosure had safeguarded the interests of powerful stakeholders to the detriment of others. In acquiescing to gatekeeper demands to conceal my researcher identity, I had further undermined the agency and self-determination of the patients and parishioners whose relationships to those gatekeepers were already characterised by dependence and subordination. Acknowledging this made me determined to take action that would in some way compensate for the imbalance of power and the unequal protection of personal interests.

In a chapter in my book (Marzano, 2004) based on the hospital ethnography, I narrated, in great detail, and in confessional mode, the entire process of gaining access to the hospital wards, including the demand that I conceal my identity. I also explained how deceit had become normalised on the cancer ward where doctors routinely withheld important information from their patients about their illness. These revelations caused an uproar among the hospital administrators and medical staff. In particular, this was because my book had revealed that the doctors had breached many of the legal and ethical principles guiding medical practice, not least of which is a patient's right to informed consent, not only in terms of research participation, but also throughout the medical treatment they received.

In the book based on my research of the charismatic group *Rinnovamento nello Spirito* (Renewal in Spirit) (Marzano, 2009), I was even more determined to reveal the ugly underbelly of the group I had been observing. I recount the process by which I had gained access to the field and how this had been contingent on me disguising as a religious convert. I describe how the leaders mocked their parishioners as childish and easily manipulated. In some ways there were parallels here with the doctors on the cancer ward who had infantilised their patients. There was, moreover, another issue that had emerged in the process of my engagement with the charismatic group that I felt morally obliged to make public so I recounted an episode I had witnessed which illustrates a predatory dimension in the group's leadership that converts had been groomed to overlook.

The incident occurred during a 'healing' ritual that was part of the 'Summer Course for Evangelizers'. During this ritual, course participants knelt in prayer with their eyes closed and, as they prayed, the elders walked around the room and embraced each participant in turn. An elder would kneel beside a participant to whisper words of comfort, and often would caress the participant's head in a paternalistic fashion. However, as the healing ritual continued, I noticed one of the elders perform the ritual differently. When an elder called Mario embraced a young woman, he started by caressing her head, as had been the case with the other participants, but then he moved his hands down to her chest and touched her breasts. The young woman did not move, and from where I was seated I could not see her face, but I was sure that his attention was unwanted. I was aware too that Mario's wife, who was also a group elder, was present in the room.

Troubled by what I had witnessed, I decided to talk to a female elder who had not been at the meeting, to whom I had spoken previously, and who I trusted would be forthright with me. I was shocked when she told me that she knew about Mario's behaviour, and that it was known that he routinely behaved in this way. This, apparently, was why many people in the group were careful to keep him at a distance. When I asked why the new converts attending the course and the other elders tolerated Mario's behaviour, the woman told me that Mario's wife held a high position in the group and that her position, and the status of the group, would be put in jeopardy by a scandal. In my book I argue that sexual harassment is an inevitable consequence when worshippers are taught to subjugate themselves while at the same time misdeeds are swept under the carpet to protect powerful interests.

Many aspects of the research that I had undertaken on the cancer ward and in the charismatic group were troubling. In each of these studies, I felt that acquiescing to gatekeeper requests to conceal my researcher identity made me complicit, to some degree, in practices that conflicted with my own values. These experiences also taught me the importance of digging deeper into the practices of powerful stakeholders. In my research on the fundamentalist group, *Cammino Neocatecumenale* (Neocatechumenal Way), I consulted with former members of the group because I knew that they would be disenchanted and I was interested to know why. I also knew that I would not need to disguise myself in order to engage with them.

In each of the studies, powerful stakeholders systematically deceived the people for whose well-being they were responsible, including myself. I, in turn, deceived them. In the field I had led the gatekeepers to believe that I understood their position, signified partly by my willingness to participate in their deceit, but I maintained no loyalty or commitment to them in my write-up of the research. In this I have endeavoured to be faithful only to the facts I witnessed. I know that I am compromised by my participation in the deceit, but I am not convinced that it would have been more ethical not to have proceeded with the research at all. It is argued that the value of the knowledge our research gains cannot justify the means by which we come to it (Hammersley & Traianou, 2012). While I do not disagree with this, I have also learned of the awful consequences of allowing injustices to remain hidden. Is it not also important to consider whose interests silence serves? After all, and ultimately, who would have benefited had I not proceeded with my research?

Speaking Truth to Power

By way of conclusion, I draw on Foucault's (2001) deliberations on *parrhesia* presented in the last of his lectures at the College de France. *Parrhesia* means 'to say everything'. Foucault (2001) traces the evolution of the meaning of the word and argues that, although it had sometimes described idle chatter, it came to refer specifically to speech that is honest and sincere: a modality of 'truth telling'. It also signifies a particular relationship between what is said and the person who speaks. In other words, *parrhesia* refers to a particular kind of truth telling, as speaking what we personally know to be the truth. Another important characteristic of *parrhesia* is that there must be some danger in telling the truth. A person who speaks the truth must be taking a risk. Thus, the person using *parrhesia* must be courageous. A forced confession does not qualify as *parrhesia* because the truth can only be spoken out of a sense of duty and moral obligation. In sum, *parrhesia* is speaking truth to power.

I think that *parrhesia* can sometimes be used to describe critical social inquiry which is often a matter of coming upon 'truths' which some view as inconvenient, or which contradict received wisdom, or challenge the status quo in which a few are privileged at the expense of the many. This can be a risky business because tenure, funding, and editorial committees can be fickle (and for some the risks have been considerably greater), but we persist because of a personal conviction that it is important to expose the various machinations of power and the often undeclared interests of individuals of status and the powerful institutions they represent.

Almost half a century has passed since Jack Douglas (1976, p. 9) wrote these words, but they are as true today as they were then:

> People are extremely adept at constructing complex and convoluted forms of falsehoods and deceptions to front out others, such as researchers, and sometimes even themselves, from the most important parts of their lives. Researchers have to use more in-depth and investigative methods to get at these private regions of life than they would to study the public realms which are open to almost anyone. It is precisely to get at these most important and pervasive parts of our lives that we have developed the methods of investigative social research.

In this context, the small lies told in the field are gestures functional to revealing truths of greater significance (Hammersley & Traianou, 2012). A recent example is Nancy Scheper-Hughes' (2004, 2005) multi-sited research exploring the illegal and covert activities surrounding the global traffic in human organs. On her choice of research topic, Scheper-Hughes (2004, p. 34) observes that '[i]n these radical exchanges of body parts and somatic information, life-saving measures for the one demand a bodily sacrifice and self-mutilation by the other' and

> [i]n general, the circulation of kidneys follows the established routes of capital from south to north, from poorer to more affluent bodies, from black and brown bodies to white ones, and from females to males, or from poor males to more affluent males. Women are rarely the recipients of purchased or purloined organs anywhere in the world. (Scheper-Hughes, 2004, pp. 36–37)

In undertaking this research Scheper-Hughes sometimes passed herself off as a patient, or a relative of a patient, or introduced herself as Dr Scheper-Hughes knowing very well that hospital administrators would assume that she was a medical doctor and that this misunderstanding would work in her favour in terms of justifying her presence on hospital wards and waiting rooms and that it would be easier to ask questions without arousing suspicion. By employing various covert methods Scheper-Hughes (2004, p. 33) discovered that while the procurement transactions sometimes took the form of consensual contracts, they were very often coerced deals and even involved 'criminal trafficking verging on transnational kidnapping by local and international brokers involved in a multi-million-dollar business'. In relation to this, can we still say that because covert methods are ethically questionable that they are necessarily unjustifiable?

It is interesting that Scheper-Hughes (2004) was given permission from her own institution to conduct the research by applying for an exceptional dispensation from the University of California Human Subjects Protection Committee to undertake the research in the capacity of an investigative journalist with the same rights and responsibilities as her colleagues in the School of Journalism at Berkeley. Scheper-Hughes (2004) argues that she applied for this special dispensation precisely because there was no prospect of obtaining ethics clearance from a research ethics committee. On the issue of the ethics of covert research, Scheper-Hughes (2004, p. 45) asks, 'How else, except in disguise, could I learn of the hidden suffering of an invisible, silenced and institutionalized population like the patients of *Montes de Oca* mental asylum? What alternative methods of investigation exist in tortured circumstances like these?' As there are clearly instances in which the prohibition of covert research is advantageous to those who would prefer that the truth of what they are doing is not told, we must challenge assumptions regarding the presumed unethicality of covert research or risk becoming complicit in the murky business of powerful elites and the organisational and institutional interests they serve.

Notes

1. This is a direct translation. It can also be interpreted as a 'Guide for New Catechumens', but the group makes use of the direct translation in its English communications.

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27

Subjects and Objects: An Ethic of Representing the Other

Eric Stewart

A while ago, when I was conceptualising a qualitative study of women recovering from traumatic brain injury, I did not know anybody living with brain injury. The research, which I was undertaking towards a doctorate in psychology, would take the experiences of actual people with disabilities as a vehicle for examining universal questions about identity and expert knowledge, and abstract questions about 'the self' in 'the world'. Subjects recovering from brain injury would provide a context—worse, a metaphor—to engage in intellectual questions about discourses and practices, the constituted subject, agency, experience, and identity politics. I was sure that my project and my approach to it, which were informed by my personal and professional experience of the fraught intersections of medicine, social science, politics, and identity in relation to HIV/AIDS, were aligned with critical liberatory commitments. It transpired, however, that both the project and my approach to it were aligned quite comfortably with the traditional subject/object arrangements of scientific inquiry. I should have realised this from the start. My inquiry was, after all, predicated on the assumption that although the women participating in my research might not know 'the truth' of their circumstances, I could undercover the truth through a theoretically informed analysis of the information that they disclosed to me, even if that truth was revealed from behind their interpellated backs. The effects of this configuration reverberated in a variety of ethical

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dilemmas over the course of the study. This story retraces questions about the interpretation and representation of the women's experiences and 'selves', and about the representation of my knowing self in taking them as instrumental others/objects. In telling the story of this research I am suggesting that the sense of occupying the place of a *knowing subject* is perhaps a fundamental ethical problem.

What Constitutes an Ethical Problem?

As a novice critical qualitative researcher, I was not alert to the ethical problem that the idea of the knowing subject presented. In the psychology department where my research was located, ethics concerns tended to focus on not harming research subjects, and this was generally determined by means of a costs/benefits analysis in which the potential for harm to the subject is weighed up against the expected value of the contributions to scientific knowledge and human welfare more broadly. In progressive circles of my programme we worried about the 'voice' of mis-represented or under-represented populations, about the importance of escaping reductionism, and the need for participatory and reciprocal research methods and relationships. Across these traditional and transformative ideological landscapes the value-free and apolitical position of the psychological researcher, concerns regarding standardisation and normalisation, individualisation, and the pathologisation of difference were the ethical problems that I was called upon to address. I felt defensive about the epistemological value of qualitative research and about the generalisability of a few 'voices', no matter how deeply theorised or 'thickly' represented. When I considered the ethics of ethnographic representation, it was mainly in terms of authentic relationships with my research participants, equitable collaboration, and of political consciousness and liberatory commitments. Underpinning my concerns was an assumption that they would assure ethical fidelity and progressive ends. With hindsight I realise how naïve this sounds, and perhaps inexcusably so given that I was reading some of the scholarship that challenges those assumptions (e.g., Christians, 2005; Corker, 1999; Crimp, 1992; Davis, 1997; Kogler, 1999; Nelson & Grossberg, 1988; Venn, 2000). But such was the power of situation and relationships, of being positioned as, or idealising the position of, critical researcher in psychology. So much is determined by what one opposes. So much is invested in being the critically insightful subject.

The Formal Ethics Review Process

No substantial ethics concerns were raised about my research in the psychology department or the clinical-community doctoral programme for which I had undertaken this research. This is because they did not view life story interviews as posing a potential harm to the storytellers. Nevertheless, my proposal still needed to be reviewed and approved formally by three institutional review boards (IRBs). IRB approval was first obtained from the human subjects' review committee at my university, the University of Illinois Urban-Champaign (UIUC), and then from the two hospitals where my research was located.[1]

UIUC does not have a medical school, and I have come to realise since that this had a significant impact on the research ethics review process because the committee included representatives from the social sciences and humanities, and also included community representatives. The committee asked for clarification about which questions I would be asking participants, and there was some discussion about the fact that I had declined to give them an interview protocol outlining all the interview questions. 'Might some of my questions cause discomfort or distress to the research subjects?' the committee asked. Fortunately, and due primarily to the intervention of the anthropologists on the committee, this concern was addressed with the inclusion of a statement outlining my broad areas of inquiry. More significant concerns centred on the participants' capacity to give informed consent. This was an obvious ethical question, but it was also an epistemological question about how the women who would be participating in my research were or were not considered competent and capable of giving consent, often according to shifting and unstable situations and standards. In the end, that dilemma was resolved through a set of checks. For those participants who were still at an inpatient or acute stage of recovery, their doctor would have to agree to my making contact with them and that a family member would have to provide proxy consent in addition to the participant's assent. For those women who were identified through, but were no longer in, medical settings, their physiatrist or psychologist would approve my contact with them and would be able to give informed consent at our first meeting. For those living 'in the community' and not under guardianship, the usual process of recruitment and consent would apply. The committee was fairly explicit about the fact that I had received latitude because I was a trained clinical psychologist, a therapist's pass, which I took even though it meant benefitting from the kinds of institutionalised authority and practices that I had taken pride in critiquing.

A final skirmish emerged over the question of participant anonymity and confidentiality. I thought that it was important to give the women participating in my research the option of being anonymous, to choose to use a pseudonym to mask their identity, or to choose to use their own names and thus to participate more fully as collaborators rather than they being only the objects of study. In any event, it seemed likely that the extended accounts on which the study would rely might mean that the women (and the people and settings they described) potentially could be identifiable by the people close to them. In my opinion the limiting of confidentiality and anonymity needed to be discussed and negotiated openly with the women. My university IRB did not share this view, however, and in order to be able to proceed with the research I had to agree to take full responsibility for protecting the participants' identities.

In the two medical IRB review processes, ethics concerns focused on how I would make contact with potential participants without compromising medical confidentiality and how I could establish a satisfactory intermediary process for participant recruitment. Informed consent and research anonymity were also concerns, but the ethics clearance obtained from my university IRB seemed to settle those concerns without the need for further discussion or consideration. Interestingly if I had presented my research to my university IRB as an oral history or journalism project, it would have been exempt from IRB review because these projects are not recognised as constituting research, but because I was in the psychology department, this strategy would not have passed the department review process. It would not have allowed me to gain access to medical settings either.

The Problem of the Knowing Subject

Nobody asked about how I would represent the women participants in my research, or how I would frame the nature or origins of their difficulties, at least not until I started talking to the women themselves. The women who volunteered to participate in my research were all concerned immediately and thoughtfully with the kind of story I wanted to tell and why, who else I was talking to, and where the story would be told. Perhaps being a clinical psychologist was a good thing after all in that it was possible to establish reflexive and critical flexibility in those conversations. I have written elsewhere about the details of this research procedure (e.g., Stewart, 2014). Where I found myself under pressure, or perhaps not pressured enough, was when I had to turn the interviews and field notes into a text, into a representation of the women's accounts and meanings, and a theorised and authorial product of a knowing subject. This was my ethical problem, the thing that I had difficulty in confronting. The brief dissertation version of my research was easy enough to produce because it felt fairly private and enclosed. It was written with a small audience in mind whose critical concerns were relatively unchallenging, at least on the fronts that were beginning to worry me. The intention is not to turn this chapter into a confessional, or an instance of 'me-search', but to explore the idea of creating a public act of representation of the women participants, of these others, that most concerned me. At the root of this concern was a nagging question regarding the resolution, or lack thereof, of subject/object relationships and an ambivalence about myself as the knowing subject.

The ethical problem is not the sense that one can take another person as an object of knowledge, come to know them somehow, to represent, or, be their representative, or re-present, capture, and deliver, them in some, if not objective, then at least honest or true, way. My concern is partly about the other as knowable object, but it is also about the other in some deployments of critical research—as *not even* an object but as constituted in discourse, as subject effects, the empty place of the subject, and therefore not a ground of anything, least of all of their own experience. At the same time it is about another kind of subject effect: that critical theory, in considering identities and experience as discursive formations, or at the very least arbitrary closures, implicitly leaves less disturbed the position of the critical researcher as a self-same, self-constant self, as one that can reflexively know itself *through*, or even *as* the other. This is an ethical problem.

Perhaps the reader has now realised the problems inherent in representing and analysing the experience of people living with cognitive impairments as in some way unqualified to know or speak of those experiences. Tobin Siebers (2008) articulates the costs of a free-wheeling or one-sided poststructuralist interpretation of the experiences of people with disabilities, and particularly those with cognitive disabilities, by describing the ways in which such applications replicate the arrangements of medicine, rehabilitation, and cultural configurations of disabled persons. This reminds me of a point that Gayatri Spivak (1988) made about the closures imposed on people when a 'theory of pluralized subject effects' is imposed upon them by the 'concealed Subject' of Western philosophy (p. 271). One knows these things, or believes one knows.

When the time came to write up my research for publication, to give an account of ten women's experiences of traumatic brain injury, what I felt most immediately was not so much a trouble with knowingness as a trouble with the imperative to *be* knowing. Our face-to-face interactions had been turned into a considerable amount of text, which I needed to turn into a 'creative representational project' (Smith & Sparkes, 2008, p. 18). It is well known that this is not a matter of reporting what happened or what was said but about positioning oneself, and what are now fragmentary, past-tense representations of the participants, in relation to a range of perhaps only partially identified (or owned) ends, interests, and audiences. For me, this was crucial and challenging; it marked a shift from being in relationship to specific people in specific interactions that were transitory and open ended, to knowing, objectifying, and fixing their meaning. This in turn occasioned a consideration of how I understood myself in relation to the women and my encounters with them. It seemed that the question and the dilemma was, how to manage my own investment in these relationships to objects and audiences which seemed to be bound up, not just in questions of theory, but also in desire.

Up until this point I had viewed critical theory, as it is deployed in cultural disability studies, feminist methodologies, and poststructuralist scholarship, as an epistemological tool that would also function as an ethical weapon to protect against the objectifying, pathologising, and disempowering discourses and practices regarding disabilities, and cognitive disabilities in particular. Now, however, it seemed to work as a discourse of disqualification and objectification. What was I to do with the women's accounts of their struggles to reclaim or recreate their identities, or their discussions of impairments as disabling and problematic in themselves rather than as symptoms of culture? What was I to do with the class and race privileges underpinning some of the women's discussions of solutions for access to healthcare, transit services, or employment? What was I to do with the deployment of religious beliefs in some women's constructions of injury and suffering as the path to immanent transcendence? What was I to do when the women distanced themselves from people with different disabilities, or inscribed a hierarchy of disabilities that placed physical disabilities above and apart from cognitive impairments? Now, the reflexive, familiar, and allied relationships I believed I had established with the women, if these did not quite evaporate, developed into a doubled, chimeric relationship. The distance between self and other, subject and object that I thought I had bridged through thoughtful and collaborative methodology, opened up again as the women's accounts reverted to objects of knowledge.

The assumed protections that critical theory offered failed as I broke apart the women's narratives and reconstructed them in carefully crafted theoretical accounts that spoke over the bodies and experiences and selves of the women, such that they become mere displacements of discourse mattering more as signifiers of culture than as subjects in their own right. But, even as theory failed me, it was hard to resist its seductions. What else would authorise my research endeavour and my interpretative authority? In this moment, in the act of representing the selves and knowledges and relationships of others, I had to confront the unstable and fragmentary nature of my self and my knowledge and relationships. What I am outlining here is both an epistemological dilemma and an ethical problem. The position of a unified, self-same, and knowing subject that is denied to, or at least seriously compromising of, those we research, our 'cultural dopes', is maintained and untroubled for the critical researcher. That is, the same subject/object relationship that structures 'normal' science is preserved in much critical research, even when that work is characterised as reflexive. The trouble was, although I was aware of that, the sense of lack that this awareness evoked only intensified the desire to find and occupy a position of a knowing subject; one must solve the problem after all.

In the remainder of this chapter I offer two different perspectives on the ethics of representation at which I have arrived. One is from the perspective of postcolonial theory and another from a particular reading of psychoanalytic theory. They are possibly best read as stories in that they describe particular dilemmas and a particular protagonist's strategies for dealing with them. I like to think of them as stories because, as Hurst (2008) suggests, they help to employ concerns without suggesting closure.

A Story Informed by Postcolonial Theory

Writing in the context of Caribbean cultural studies, Susan Harewood (2009) suggests that researchers should think of themselves as 'moving in the midst' of their research, rather than as the 'self-certain researcher subject who journeys out to stand and view the Other' (p. 168). She calls on us to forsake the privileges of being an outsider, the deep ethnographer who hopes to be 'allowed inside', even though it means giving up 'the need to map an inside and outside in order to justify one's efforts to chart one's way "in"' (p. 168). Being in the midst not only checks our tendencies to act as unified selves in delimited fields, but reminds us that our knowledge is:

> [S]played out across constantly expanding and contracting fields of different experiences. Our understandings come through the myriad communication encounters that go on (both those we think of as being 'part of the research' and those encounters in our 'real lives' that do not seem to be). (Harewood, 2009, p. 168)

Harewood (2009) goes on to argue that recognising this movement in the midst of movement relieves us of a burden:

> How can one go on with the charade of omniscience when it is so clear that we get merely a fragment of the complexity and that fragment is itself in the process of change as are we, the putative observers? (p.168)

In relation to the ethical dilemma that I have been developing here, it is no small thing to accept that our knowledge and understanding is necessarily fragmentary and transitory given the power of institutionalised knowledge and its material effects. Representations and theorisations of living with brain injury are formed and deployed in asymmetrical relationships of power/knowledge that in some, often unpredictable, way affirm and consolidate particular social orders that impact on people's lived experiences. We must guard against the seductive power of institutional knowledge and the various acceptances of its terms. As I have tried to illustrate, we can still be imbricated even when we stand in opposition. This happens when we, wittingly or not, hide behind claims of objectivity, or appropriate reflexivity to mask our claims to a stable and unified subject position. Harewood (2009) also warns against certain interpretations of a relational ethic. On the question of the distance and difference between self and other, Harewood (2009) argues:

> It is very possible that this challenge to difference can result in a misdirected assumption that the other is easily knowable and easy to represent (particularly if we eschew the cold, hard language of social science in favour of the passion of the poetic) because he/she is us. Such an assumption actually maintains the unity of self and other, but it also, just as importantly, glosses over power relations. (p. 168)

Harewood (2009) is referring to the unexamined assumption that reflexivity enables or authorises recognition of the other. Knowing the other is, after all, characteristic of the colonial impulse. But this is not an argument to abandon practices of representation. Although there are considerable challenges and limitations to reflexivity in representational practices we must persist because absence is not the solution to problematic presence. We must, however, be vigilant and must constantly challenge the 'simple narratives of knowing' (Harewood, 2009, p. 168).

A point that needs to be made before the next story is told is one which relates to the unity of self and other, to the subject and object of knowledge, but more directly to the unity of the self/subject. Meaning is unfinalisable

(Bakhtin, 1984), and the idea of ethics as fundamentally the discourse theorising the relation to the other, or any other idea of how to conceptualise and found the ethical, is in a sense conventional and is located within specific traditions. Our praxis or apprenticeship in ethics, then, includes learning to deal in situated ways with both the liminal and the material side of beingness; we learn to deal with the fact that we learn to give meaning to our experiences in 'terms of a whole set of rules and stories, beliefs and values inscribed in performative as well as in reflexive practices of becoming, instituting particular subjectivities' (Venn, 2000, p. 35). That is, if our knowledge is fragmented, incomplete, bound up in power, history, practices, and convention, so too is our relationship to any other, and so too is the self or subjectivity that seeks to know and know ethically. We normally avoid this aspect of our fragmented, virtual nature, and yet this praxis is what ethical learning is all about (Varela, 1999).

A Story Informed by a Particular Reading of Psychoanalytic Theory

If ethics, and particularly the ethics of critical qualitative research, is, in important ways, about self/other relationships, including the many questions about knowledge and knowingness that rest on subject/object relationships, then I would like to develop another question related to the knowableness of the other. I move now to the psychoanalytic and consider Jacques Lacan's (1979, p. 35) statement that '[t]he unconscious is ethical at its core'. Francisco Varela (1999) has argued that the significance of this statement lies in its departure from viewing ethics as being in the domain of rational deliberation or logical deduction which presumes a conscious subject. Instead, Varela (1999) argues that when Lacan says that it is the *un*conscious that is ethical, what he means is that 'the ethical implies putting the status of the knowing subject into question' (p. 64). Varela (1999) observes that 'in contradistinction to theories that posit a unified central self', psychoanalytic theories of the subject 'exploded the self into pieces, both within the person and between persons' (p. 65). Consequently, a psychoanalytic perspective on ethics invites us to 'suspend the temptation to be identified with the other and, instead, undertake the journey of learning to see ourselves and others as inescapably transitory and fragmented' (Varela, 1999, p. 65). What this demands is not the crafting of an (illusory) 'ideal centre or moral principle' but rather in 'always attempting to reveal to the subject that all the traits he takes as ideal in himself or in others are subsumed entirely in the unrealisable desire to make whole and substantial that which is forever fragmentary and virtual' (Varela, 1999, p. 65).

I am not suggesting that psychoanalysis or psychoanalytic theory should necessarily be the basis of a method for ethical practice. Rather, that it offers ways of understanding how the knowing subject constitutes an ethical dilemma. When Varela (1999, p. 65) says that the (knowing and ethical) self is exploded 'into pieces, both within the person and between persons' it problematises the normal deployment of reflexivity as a means to know the other or to close a gap between self and other, subject and object. To understand why this is important, I return here to Harewood's (2009, p. 165) observation that

> categories that are often characterized as being in opposites are, in fact, deeply enmeshed. It is actually the deep imbrication that is a danger in Western art and science's imperious and imperial efforts to deploy difference to self-serving and brutal ends.

All knowledge or attempts to know an other are implicated in questions of power/knowledge. I take this to include the desire to finalise knowledge and meaning, to finalise or stabilise the many momentary and arbitrary closures our research practice moves us to impose, to align ourselves with authority, to use our participants and their experiences to make 'substantial and whole that which is forever fragmentary and virtual' (Varela, 1999, p. 65). I also take it to mean that we should trouble ethics strategies that are founded in sympathy or caring, at least to the extent that these are founded in an identification with an other that is based on a notion of unity within and between self and other.

This invocation of psychoanalytic theory is not an argument for an ethics grounded in an enshrinement of alterity because this would obscure the ways in which the other authorises the self, the margin defines the centre, and the object reifies the subject, and so on. Asserting the inaccessibility of the other in this way has the effect of re-centring a foundational, albeit a lacking, self. At the same time, such metaphysics of alterity seems to invite us to a space beyond the data of history in which an ethics of existence could somehow find its foundation, as if in some true rapprochement with the other, we could be 'uprooted from history' (Levinas, 1969, p. 52). If the critical researcher's efforts to get *inside* are aimed at a better view of the other, that is, the paradox of achieving both distance and unity, Levinas would have us chart our way *outside* history and difference as authorising ethical knowingness. But both strategies seem to rely on a colonial logic in which the other is simply a means by which we constitute our own unified subjectivity. The 'bourgeois righteous simulation of excellence' (Yearly, 1991, p. 67), presented as the constant and knowing subject is the enemy of ethical practice as well as a wrench in any relationship between self and other. If ethics is not a matter of principled or rational thought or the logic of pure reason, it is also not found in a grandmotherly kindness or the self-validating merger with an other that passes for caring.

Conclusion

This chapter began with my confrontation with the ethical dilemmas that the representing of an other occasions. In my research on living with brain injury, I formed relationships with women participants that were quite personal and enduring, and I experienced the process of reformulating these encounters as 'text' as a kind of (ethical) betrayal, while at the same time also presenting a couple of (ethical) obligations. The first obligation was to avoid a simple recounting of their experiences and their ascriptions of meaning as if any of these were straightforward and uncomplicated in a way that suggested some kind of unity or knowingness within or between the parties, or to suggest that the simple re-presentation of their accounts would constitute a kind of direct speaking of experience. The second obligation was to direct the readings of such texts towards an understanding which at the very least would challenge oppressive configurations of people with disabilities. These obligations were occasioned when I took on the roles of the academic, the researcher, and the ally.

In my research about living with traumatic brain injury it seemed that any of the tactics that I might employ would occasion some degree of closure, some act of representation, some suggestion of a rational or unified subjectivity. In the end, and I write this with self-consciousness at the naïve optimism and desire for closure it implies, I aimed for a more or less unsettled set of conversations in which the women were depicted as encumbered but still critical and agentic theorists of their personal and social worlds and, as much as I could, I granted roughly the same status to my voice as I did to theirs. My strategy was to take the women's experiences of living with brain injury, as well as my own endeavour to understand and convey those experiences, in the same way that I understand ethical praxis: as progressive and fragmentary in nature, grounded in ordinary life and action, and in 'a first-hand acquaintance with the virtuality of self' (Varela, 1999, p. 63).

Notes

1. Ethics clearance obtained from University of Illinois Urban-Champaign (UIUC) (first in 1996, with renewals for eight subsequent years); at Carle Hospital in Urbana, Illinois (1996); and at the Rehabilitation Institute of Chicago (1996 and 1998).

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Traversing Ethical Imperatives: Learning from Stories from the Field

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What lessons stand out across the four sections of this handbook? How do the rich, storied examples of research shared in each chapter take critical researchers forward in thinking through the complexities of conducting ethical research? In this conclusion, we home in on some of the implications of the grounded exercise in which we engage throughout this handbook.

The stories from the field shared in each chapter form a series of critical interventions that invite discussion about the status quo and the future of research ethics as applied to critical research. Stories about critical research have the effect of creating an opportunity to reflect on ethically important moments in the unfolding research processes. Rarely is there an opportunity for detailed ethical reflection in empirical research articles, and as Brinkmann and Kvale (2017) note, ‘In today’s handbooks and textbooks of psychology and other social sciences, the ethics chapter is often a small and marginal chapter, if included at all’ (p. 260). That is not to say that there is not a vast

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and growing literature on research ethics applied to critical methods; indeed, this literature is drawn upon throughout this handbook, but stories of ethical challenges and conundrums benefit researchers by providing a detailed consideration of how we might work through such dilemmas.

The four sections of the handbook focus on the challenges that surround particular ethical imperatives relating to: (1) systems within which research is conducted, (2) boundaries to research relationships, (3) anonymity of participants and organisations, and (4) the relative power of participants and researchers. Each of these sections is preceded by a framing introduction in which the key issues highlighted in the chapters are foregrounded and discussed. We do not reiterate these issues in this chapter, but rather speak to overarching concerns that cut across the four sections.

Many of the challenges exemplified across the whole handbook are the result of the increasing governance imposed by the research ethics assemblage and from colonisation of research ethics by imperatives arising from biomedical research, which are, in many instances, incompatible with the aims and methods of critical health and social research. We have framed the handbook within the notion of traversing ethical imperatives. This works at two levels: firstly, critical researchers are frequently required to traverse ethical imperatives at particular moments during research, as exemplified by chapter authors; and secondly, critical researchers as scholars using a diverse conglomeration of epistemologies and methodologies have a collective need to traverse ethical imperatives by compiling ethical processes that fit the challenges faced in critical research. The primary function of the handbook is as a resource for researchers who are applying critical methods and seeking guidance. The primary message of the handbook is that ethical guidance cannot be reduced to a closed set of principles; instead, the chapters provide nuanced considerations to inspire researchers to be creative and transparent when facing their own ethical challenges. This chapter covers four overarching concerns addressed throughout the handbook relating to: (1) learning how to navigate process ethics in critical research, (2) constructions of vulnerable subjects in critical research, (3) seeking social justice through participation in critical research, and (4) reimagining ethics review for critical research.

An Agenda for Learning About Ethical Conduct in Critical Research

Critical researchers apply a range of methodological and analytical skills, as featured throughout this handbook. Researchers learn about research methods and ethical processes in many ways. We learn about research and ethics by being schooled and socialised into our particular cultural understandings. We learn about research ethics during tertiary education, but this is often limited to hearing about the implicit norms of mainstream research methods. There is, of course, no requirement for critical researchers to have undergraduate or postgraduate qualifications, but for critical researchers with tertiary qualifications in social sciences or health sciences, learning about critical research has often been secondary to being taught about positivist epistemologies and associated research methods (Hale, Treharne, & Kitas, 2007; Lyons & Chamberlain, 2006, 2017; Murray, 2014b). We also learn as we go about our own critical research often by a process of trial and error. We learn through stories shared by other critical researchers who analyse their experiences and make recommendations as do authors across all chapters of the handbook. The burgeoning bureaucracy of research ethics can include training requirements. Below, we outline some of the contingencies involved in learning about the ethical conduct of critical research in terms of: induction into the field; communities of practice; and researcher reflexivity.

Induction into the Field

One of the entry points into learning about a particular field is to gain insights into a lexicon of terms, their meanings, uses, and the debates to which they allow access. Across this handbook, authors use a diversity of terms relating to research ethics that readers can apply when planning and conducting research; when supervising, examining, or reviewing research; when teaching research methods and ethical practice; and when musing on, debating, or publishing research. Within this lexicon of terms, there is a broad distinction. On the one hand is the hegemonic neutral-normative model of procedural ethics that gets transcribed into research protocols and presented to ethics committees as a tool of risk avoidance. On the other hand, there is a more flexible norm-critical model of ethics that is required in the field and is referred to variously as situated or situational ethics, process ethics, micro-ethics, everyday ethics, ethical mindfulness, or applying an ethical sense or ethical principles (see, e.g., Haggerty, 2004; Hammersley, 2015).

The processes through which researchers are formally inducted into an ethical sense and ethical ways of researching merit attention. Many of the authors featured in this handbook highlight how ill-prepared they felt to face the challenges they encountered once in the field. Brinkmann and Kvale (2017) note that '[h]istorically, what we call social science emerged from moral philosophy, and the student of social science had to acquire moral dispositions as part of the curriculum' (p. 260). With the current influence of natural science and positivism in the social sciences, a key concern is the extent to which ethics, as a contextual, ideological, and moral process, is integrated into the training of critical researchers or in teaching content that draws on the findings of critical research. Ethics is often considered only prior to entry into the field, and likewise ethics is frequently viewed as an added extra in teaching about research.

Realist literature reviews of 'ethics training interventions' demonstrate that researchers can learn to follow ethical approval processes or apply specific ethical principles (Steele et al., 2016), including application to community-based research (Quigley et al., 2016). But these training interventions do not exist outside particular institutional goals and national requirements for compliance of researcher training. Prescribed research ethics training may not, however, fit with methods of critical research and may not teach critical researchers much other than how to manage ethics review systems that were, for the most part, not formed to account for the methods that critical research involves nor the specific ethical challenges that critical researchers can face (see in particular Carter, Chew, & Sutton, Section 1). Inserting critical research principles into ethics training means understanding these power relations and helping researchers think through dealing with the need for compliance.

In addition, realist models of learning contribute to the construction of a lay/professional divide between participants and researchers, particularly in relation to ethical principles. For example, van den Hoonaard (2011) highlighted how '"beneficence" implies paternalism, that "only medical researchers would know what's good for you"' (p. 116). Even the word 'beneficence' is paternalistic in its complexity. Similarly, formal induction into ethical conduct of critical research should highlight the importance of ethical processes as negotiated, ongoing, and respectful.

Communities of Practice

Many authors throughout the handbook describe having to seek ethics clearance or ethics approval but found that the bureaucratic processes cannot account for critical research because it does not fit into a positivist and/or biomedical frame of research. Critical research is often stalled and, in the worst cases, a project may never proceed (e.g., Marx & Macleod, Section 3). As discussed in depth later in this chapter, the aim of this handbook is not to call for an imminent and radical rejection of ethics clearance procedures. What becomes clear across the chapters in this handbook, however, is that the seeking of ethics approval is often encountered as a hurdle instead of it providing critical researchers with a much-needed opportunity to learn from ethical advice given by a person with experience. What this means is that we are not seeing formal institutional 'communities of practice' that can support critical researchers in learning about research ethics. Arguably, this should be a central function of ethics committees, but this handbook outlines ways in which critical researchers are misunderstood by ethics committees and have to defend themselves during ethics review processes rather than their being supported by a community of practice.

There are, however, networks of researchers outside and across academic institutions that support researchers and radically question the directions in which ethics bureaucracy is being taken. For example, the Ethics Rupture network was formed at their 2012 conference which initiated several academic volumes (Iphofen, 2017; van den Hoonaard & Hamilton, 2016). Likewise, many academic societies such as the International Society of Critical Health Psychology (ISCHP) are dedicated to the development of critical perspectives on research, including research ethics, and it was at the 2015 ISCHP conference in Grahamstown that this handbook was conceived. Likewise, the field of bioethics includes many academic societies and has a long history of contributions to critical scholarship (see, e.g., Reubi, 2010; Twine, 2005).

Critical researchers frequently find that they are required to learn about and defend the epistemology of their approach because of the inequitable interrogation of critical methodologies as is highlighted in many of the chapters featured in this handbook. While this may be difficult, a benefit of this inequitable pressure is the mutual learning that goes into positioning critical research in the wider constellation of epistemologies. In response to this, it is increasingly necessary for critical researchers to learn collectively to resist ceremonial bureaucracy such as irrelevant training and irrelevant questions on ethics applications and reporting forms (Carter et al., Section 1). This resistance also entails developing a sense of which ethical issues in critical research can be expected, planned for, and detailed in ethics applications. Critical researchers also have a role to play in collectively resisting the coopting of criticality, particularly when the notion of 'critical' is employed to mean doing better mainstream research (Ogden, 2012).

While this handbook was enabled by the community of practice of ISCHP (established at a conference in 1999), the handbook itself represents a community of practice. Through sharing their stories of struggles, challenges, reflections, conclusions, and actions, the authors create a community of practice with which researchers may engage in relation to their own critical research encounters to develop strategies to deal with restrictive ethics review processes.

Researcher Reflexivity

One of the greatest challenges for all researchers, and critical researchers in particular, is 'how to learn ethical research behaviour' (Brinkmann & Kvale, 2017, p. 260). The notion that to be ethical is embedded in an individual's 'behaviour' requires deconstruction. Speaking of research participants, van den Hoonaard (2011) argued: 'It is an important philosophical premise to see individual human beings as primarily 'autonomous' entities. Such a premise conjures the view of a human being without relation to others' (p. 61). The same should be argued of researchers: there is both a need to recognise autonomy and to recognise that ethical considerations do not occur in a social vacuum. For example, Whiteman (2017) raised the concern that critical analysis of research ethics continues to be individualising and interiorising, both of which are critiques that critical researchers are more used to making of mainstream research than of our own analyses. But, like the chapters in this handbook, analyses of research ethics can be reoriented to give consideration of institutionalised interrogation 'to avoid falling back on the autonomy of the person whilst maintaining the openness of ethical negotiation' (Whiteman, 2017, pp. 14–15).

Nevertheless, reflexivity in conducting research is an important aspect of researcher learning in ethics. One of the guiding features of criticality is a constant return to the self-criticism of one's praxis and one's field (Lyons & Chamberlain, 2006, 2017; Murray, 2014a; Murray & Chamberlain, 2014). The chapters in this handbook apply this self-criticism, sometimes drawing effectively on the notion of confessional reflexivity to demonstrate moments of learning (e.g., Carter et al., Section 1; Harvey, Section 2; Naidu, Section 3; Mayeza, Section 4).

There are several other facets of learning about research ethics that are evident across the chapters. The ethics of insider/outsider positioning (Wilkinson & Kitzinger, 2013) are brought to attention in the work by Harvey (Section 2) on being a researcher with a visible disability who interviewed mothers whose children have a disability, which resulted in assumptions of shared understanding and a sense of being researched back. Hay-Smith et al. (Section 2) also address the insider/outsider positioning of health professionals who conduct research and the ways the duty of care and relationality extend to other critical researchers. Many ethical issues of critical research are unpredictable and require nuanced learning about very specific applications of research and processes (Edelman, Section 1; Feltham-King et al., Section 1; Stewart, Section 4). The chapters throughout the handbook also draw attention to various stages of fieldwork. Entering the field requires learning how to develop relationships that are authentic and mutual whilst avoiding exploitation, whether intentional or unintentional, and maintaining professional boundaries. Being in the field requires learning how to recognise and work through ethical dilemmas. And exiting the field requires learning how to share feedback on findings, how to successfully finish research relationships, or how to remain in the field forever in some ways when there is no clear distinction between the fieldwork and the researcher's daily life.

Conceptualising Vulnerabilities and Harms

In this handbook a range of what could be considered vulnerable participants formed part of the stories of research: people living with HIV/AIDS in environments in which the HIV stigma is high; pregnant and mothering teenagers accessing services in under-resourced settings; survivors of sexual violence; psychotherapy clients; people with disabilities; mothers raising children with visible disabilities; women with problematic drug use; participants with a history of criminal offence; and dogs who are seen as pets or as being owned by humans. As 'vulnerabilities' and 'harms' are so central in the consideration of research ethics, it is clearly important for critical researchers to ask questions about taken-for-granted assumptions underpinning these notions. What is at stake in labelling a group of people as vulnerable? Who makes the decision, and on what basis? And in relation to what kind of social or personal benefit or well-being are 'harms' understood and assessed? How are the remedial steps defined in relation to the ways in which harms are conceptualised? Under what conditions are harms recognised or erased? These kinds of reflections are essential in terms of the manner in which critical researchers engage with the signifiers 'vulnerability' and 'harm' in their research protocols and research reports.

Researchers are often required to demonstrate that they have put protective mechanisms in place to ensure that the research does not compound vulnerability or, where it does, that there are remedial steps in place to manage the increased risk. In addition, in those situations in which vulnerabilities mean that autonomous decision-making is circumscribed—for example, in the case of refugees seeking asylum or other legal status determinations (Pittaway, Bartolomei, & Hugman, 2010)—researchers are required to put in place additional processes of confirming or affirming consent.

Given that ethics committees emerged from a history of multiple abuses in research that involved human beings subjected to unethical research, it is understandable that vulnerabilities and harms are foundational principles underpinning research ethics. In order to justify the conduct of their research, researchers are tasked with outlining the benefits of the study and to answer questions regarding the balancing of the harms and benefits so that ethics committees can determine whether the benefits outweigh the harms or vice versa. Problems arise, however, when benefits are viewed at an individual level only. Questions on ethics clearance applications regarding direct and indirect benefits are not neutral. Working in the shadows of bioethics means having to navigate the special status afforded to direct benefits that privilege individuals participating in the study rather than communities, social groups, or society at large, or where these broader benefits are considered secondarily to vulnerabilities and harms. When research committees foreground vulnerabilities and start to fetishise the possibilities of, for example, embarrassment or discomfort, then the balancing of benefits and vulnerabilities is out of kilter. Furthermore, when benefits are not cast within a framework of social justice, then these may be reduced to mundane questions such as whether participants receive a gift or reimbursement for participating in the research. A central question that critical researchers and ethics committees need to ask is: where research can be shown clearly to be of social benefit or to contribute to social justice (e.g., highlighting multiple abuses), what level of individual harm (e.g., to people perpetrating the abuses) can be tolerated in the conduct of critical research?

Too frequently, vulnerability is taken to mean individual risk on account of attributes internal to the participant. As disability scholars and others have pointed out, however, vulnerability is also a function of the environment within which we live. Barriers to accessing buildings, for example, *make* people with physical impairments vulnerable (see Harvey, Section 2; Rice, LaMarre, & Mykitiuk, Section 3). A shift from thinking about vulnerability as an internal quality to understanding vulnerability as always already socially constructed and maintained requires researchers to understand vulnerability as multiply relational and located at the intersection of various power relations. In this view, a 'vulnerable person' becomes 'a person with vulnerabilities' or even 'a person positioned as vulnerable' or 'a person made vulnerable'. Vulnerability, thus, is seen as a socially located praxis rather than a personal characteristic, and not as something that defines particular individuals at all times and places. How researchers view and approach their participants matters, not only in terms of the validity of the study, but also in relation to what potential outcomes the interactions have. Particular interactions, mostly paternalistic, are enabled by a view of vulnerability as an inevitable component of participants' lives, or alternatively as a material and fixed reality. Different interactions are possible when vulnerability is viewed as firmly located in multiple, intersecting power relations and where agency, even when limited, is acknowledged and understood as located in contexts that either enable or hinder it.

One ironic possible consequence of a conventional approach to understanding vulnerabilities is that researchers may encounter participants through a rigid and potentially debilitating frame. This kind of framing may be seen as necessary in order to construe those features within the category as 'worthy' of research. That is to say, researchers may unwittingly find themselves problematising participants, rendering them vulnerable in discursive terms, in order to justify funding or approvals for the research or to facilitate recruitment (e.g., Feltham-King et al., Section 1).

The Politics of Vulnerabilities and Harms

While harms are generally understood in relation to actions undertaken (in this case research), lack of action may also result in harm. When researchers avoid undertaking particular kinds of research or research with particular participants, it tends to be because: the participants in question are viewed as 'too vulnerable'; the bureaucratic hurdles of ethics committees are too onerous (Richardson & McMullan, 2007); or researchers fear that ethics committees will fail to understand the proposed critical research method (Marx & Macleod, Section 3). The result is that harms may accrue owing to lack of action when research does not proceed (Juritzen, Grimen, & Heggen, 2011). As Rucell (Section 3) so poignantly asserts, a range of institutional abuses may go unchallenged as a result of the notions of 'vulnerability'. The question of 'harms' may be put to use to prevent critical research being undertaken in these spaces.

In addition, the very act of protecting participants through foregoing sensitive research may mute or deny the expressions of marginalised people (McKenzie-Mohr & Lafrance, 2011). As Edelman (Section 1) points out, particular participants may be prevented from being part of a research project on the basis of their 'vulnerabilities'. Edelman argues that in some of these cases, neoliberal notions of harms take precedence over social justice aims, which would include the provision of spaces within which marginalised voices may be heard, and the recognition of the agency of the oppressed in deciding on participation despite possible individual 'harms'.

Children or minors present a particular case in point. Most ethics application processes will inevitably mark child participants as vulnerable no matter how benign the research question or data collection method. Purely on the basis of age, children are deemed to require protection. The result of this is that 'researchers have tended to undertake research on the least vulnerable/ most adult-like children' (Carter, 2009, p. 858). These 'tick-box' responses to child participants overlook the increasing trend towards child rights and participation, and the fact that children are not a homogenous group. Mayeza (Section 4) highlights, for example, how gender intersected with age in the construction of vulnerability in his research. Ashdown et al. (Section 3) demonstrated how children can take on active roles in research through methods like photo-elicitation; in this instance, the children became responsible for gathering consent from people who appeared in their photographs as part of their acknowledged contribution to the research.

If, as discussed in the main introduction of this handbook, critical research is about power relations, then questions of empowerment, emancipation, and liberatory practices need to be considered alongside an ethic of 'do no harm' in research. Authors of chapters in the handbook have explicitly tackled the complex questions of what it means to engage with research that speaks to undoing or undermining oppressive practices and structures. In addition, Swartz (2011) argues that ethical strategies should explicitly address vulnerability and emancipation in practice. Smith's (2008) notion of 'responsible advocacy' captures this imperative, the aim of which is 'to avoid coercion and exploitation of vulnerable individuals and groups in research, increase validity and reliability, and avoid pre-emptive exclusion of such groups in the research design' (p. 248).

Vulnerabilities can, of course, be created or exacerbated by research. In Section 3, for example, authors grapple with the question of anonymity, confidentiality, and voice. Harms may accrue to participants if anonymity is not maintained in research under certain circumstances. These harms need to be balanced, however, with the harms of lack of voice, as well as the potential harms of unrealistic promises of anonymity and confidentiality. Thus, while critical researchers need to question how notions of 'vulnerabilities' and 'harms' are understood and deployed in research, they equally need to inspect very thoroughly the procedures they implement, the interactions that they have with participants, and how the outcomes of the research may impact not only on individuals, but also on their families and communities.

The Vulnerabilities of Researchers

Vulnerability extends not only to participants but also to researchers who may experience their encounters in the field as distressing, especially in circumstances in which there is in-depth engagement in the field (e.g., Akhurst et al., Section 2). During in-depth encounters, such as interviews about personal and sensitive issues, researchers may select to reveal, or want to reveal, their own experiences of such issues (e.g., Edelman, Section 1). Whilst sensitive encounters and revelations may be beneficial to the research, they also may be distressing for the researcher. Generally, researchers can attempt to overcome such distressing effects through engaging in debriefing sessions, self-care, counselling, and reflexive writing. Unfortunately, these kinds of activities are rarely factored into research grants or support structures, despite the fact that:

> [r]esearch institutions have a duty of care to ensure that researchers are not in undue danger, and this includes access to counselling support when it is known to be likely that they have spent time interviewing people about […] traumatic stories (Pittaway et al., 2010, p. 235).

If we see vulnerability as relational, then the vulnerable positioning of researchers in the research encounter can act as a key focus of analysis and insight. What do the vulnerabilities experienced by the researcher suggest about the interactional space and power relations set up in this research? These kinds of questions have generally been discussed under the rubric of reflexivity in critical research. Reflexivity refers in this context to deep reflection not only on the social categories within which the researcher is located vis-à-vis the participants, but also to the unfolding dynamics that take place in research spaces. Researchers have argued that this kind of reflexivity should not appear as a brief confession but should be integrated throughout the report, including in the analysis (Etherington, 2007).

This connection, between researcher subject positions in the research encounter and the interpretation of the data, is what lifts discussions on reflexivity from a methodological concern to an ethical one. In reflecting on the vulnerabilities invoked in the self in the research encounter, the researcher is able not only to encapsulate power relations in situ, but also to be productive in exposing the self and participants in particular ways. As argued by Etherington (2007):

> Reflexivity, although enabling the conduct of ethical relational research, also requires researchers to come from behind the protective barriers of objectivity and invite others to join with us in our learning about being a researcher as well as remaining human in our research relationships. (p. 599)

In other words, in writing up the results of the research in reflexive ways, the researcher joins the participants in the potential learning that can arise from the sharing of sensitive and intimate details of their lives.

Social Justice Through Participation

If the public circulation and acknowledgement of gross violence in research in the twentieth century were foundational in concretising codes of ethical research conduct, in the twenty-first century, researchers are compelled to take into serious consideration large-scale inequalities as well as insidious circuits of power in which research may take place. What emerges strongly in a number of chapters throughout this handbook is the centrality of social justice as a paradigm through which ethical dilemmas are negotiated.

Institutions of research are far from neutral in the seemingly divergent spaces of administrative bureaucratic committees and critically driven theoretical research as well as the spaces in between. The elevated ground where members of universities were once located is increasingly shaky. Researchers are being called upon to locate their research in local contexts and realities, to produce applied research that can be used by communities, and to acknowledge their entanglement with fractured ideological, political, and social power relations.

Not by coincidence then, in different formulations, the chapters in this handbook attend to the question of social justice as a foundation that features in the doing of critical research and ethics. Research communities have often been accused of being extractive, generating knowledge of benefit primarily to the researcher, and reinforcing particular power relations. For example, critical disability researchers remain cognisant of the way the bodies of people with disabilities have been used in instrumentalist ways by researchers resulting in further reinforcing ableism (see, e.g., Rice et al., Section 3). Intellectual work is deeply embedded in, indeed constituted by, such relationships of power. There is therefore the suggestion that research relationships that build trust and reciprocity should be taken seriously in order to re-think the model of research as a bracketed and isolated act or an event with an ending. Chapters in the handbook refer to the importance of building relationships in varying contexts. Transdisciplinary and participatory research intends to minimise that distance by actively involving participants who identify what is felt to be important enough to be addressed (see, e.g., Cockburn & Cundill, Section 1).

Taking reciprocal relationships seriously means acknowledging the systems in which all stakeholders are embedded, marked as they are, in legacies of inequality. For scholars committed to advocacy and activist work, traversing spaces outside formal institutions is essential. Participatory action is often an important component of activist-driven research. Having members of communities (however defined) as partners in deciding on research questions, formulating how data will be collected and what methodologies are used, collecting and analysing data, and deciding on dissemination is a process that attempts (even as it fails) to undermine particular power relations, depending on the research question.

Guta, Nixon, and Wilson (2013) ask whether what they call ethics creep (the dominance of the formal ethics review assemblage) has become a moral panic that may restrict the uptake of community-based models of ethics review which would limit engagement with participatory methods. In other words, the imbrication of ethics review processes as the sole or most important aspect of assessments of the ethical conduct of research may serve to mask the lack of ethics in failing to engage in community-based participatory approaches.

Nevertheless, the ethics of critical research requires that researchers who do deploy processes that create reciprocal and respectful relationships must simultaneously be cognisant of the potential for these very processes to re-inscribe particular power relations (Cornwall, 2003). Cooke and Kothari (2001) draw attention to these potential difficulties in their book entitled *Participation: The new tyranny?* They argue that people in marginalised positions may be subtly coerced, in the name of empowerment, into activities and decisions for which they are ill-prepared and from which they gain little. The 'tyranny of the group' emerges when participatory approaches fail to take account of complex power relations and inequalities *within* communities. As such, they may reinforce or strengthen already existing relations of power in these communities. Cornwall and Brock (2005) argue that 'participation' has become a buzzword that robs participatory research of its potency. Politicised versions of participatory research cognisant of the complexities involved in conducting ethically responsive research that contributes to social justice are increasingly called for (Hickey & Mohan, 2004).

In addition, epistemological access cannot be overlooked; access to knowledge production resources reinforce traditional Western institutions as bastions of knowledge. This can create conditions of 'trusteeship' if it is the researcher who is seen as having 'granted' a space for participation. Yet, even when researchers clearly aim to do no more than generate knowledge, this does not prevent their positioning from being capable of effecting social and economic change, compelling them to face growing forms of disenfranchisement that exist alongside growing knowledge about the world. This raises many questions about the future of ethics review as applied to critical research.

Reimagining Ethics Review

Throughout this handbook, authors have illustrated how certain conventions in the interpretation and application of standard ethics principles have undermined the ethical conduct of critical research. Chapter authors have called for ethics review processes that are more responsive to the specificities of different types of research, to the fluid and unpredictable nature of flexible methodologies, and to the contextual power relations within which the research is conducted. In the light of the critiques and narratives of ethical conundrums as they played themselves out in the deliberations and decisions of ethics committees, in unanticipated but ethically important moments in the field, and in those often lonely spaces in which we sit down to write this all up, it is pertinent to ask: what does the future hold for ethics review of critical research?

As intimated by the stories from the field shared in the handbook, there are multiple complexities associated with conducting critical social and health research, and potential solutions to ethical conundrums in critical research must be nuanced and responsive to the various critiques these encounters occasion. At the same time, these responses cannot become overly convoluted. They must be honed to speak directly to key issues specific to critical social and health research and the context in which this research is undertaken. In the opening introduction chapter we suggested ethics review processes that are informed by basic ethics principles must be responsive to situated and relational dynamics. Adopting a critical and pragmatic approach has implications for how ethics review of critical social and health research is conducted. This raises a number of questions addressed in this section which members of ethics committees as well as researchers need to ask themselves: How can critical research be better accommodated in the ethics review process? How might the ethics review forms that researchers have to complete be fashioned to encourage both principlist[1] and contextual ethics responses? How might ethics committees provide support to researchers who attempt to navigate the complexities of conducting ethical critical research? How might ethics committees accommodate participatory research that requires researchers to engage with communities prior to formulating research questions and methods?

Accommodating Critical Research in the Ethics Review Process

It is well established that medical experts have been over-represented on research ethics committees (de Vries & Forsberg, 2002). In recent years, growing concerns about litigation have resulted in a parallel growth in research ethics committee members with legal training (de Ville & Hassler, 2001). It is also established that even when ethics committees are not dominated by members from medical or legal professions, they still tend to be unfamiliar with the aims and methods of critical research and are inclined inappropriately to apply ethics principles (Gallant & Bliss, 2006; Louw & Delport, 2006). That said, recent research findings indicate that there is a growing awareness among members of ethics committees of the need to be accommodating of emergent and unconventional methodologies (Guta et al., 2013).

Concern about the training and competencies of ethics committee members is not new (Israel & Hay, 2006), but has been brought to the fore in the context of the review of critical research where a cursory introduction to bioethics is clearly inadequate to the task. Critical researchers have been quick to critique ethics committees, believing that 'their work is being constrained and distorted by regulators of ethical practice who do not necessarily understand social science research' (Israel & Hay, 2006, p. 1). Curiously, however, critical researchers have made limited contributions to challenging the composition of research ethics committees or in lobbying for the greater involvement of critical researchers, even though our involvement could help to shape new approaches in ethics review.

Many countries now have national guidelines regarding the composition of ethics committees to ensure diversity in terms of gender, ethnicity, ability, and the inclusion of community members. This is to ensure that reviewers of proposed research are not limited to individuals socially and culturally removed from the communities or groups being researched, but these guidelines only set out the minimum requirements and certainly do not foreclose on opportunities to include members representing a broad range of research interests. The findings of recent research indicate that ethics committees experience high workloads (Caligiuri et al., 2017; Guta et al., 2013; Kotsis & Chung, 2014) so the involvement of a greater number of critical researchers is likely to be appreciated. With a greater representation of critical researchers on ethics committees, some of the common pitfalls in the review of critical research may be averted.

Some universities are experimenting with a system of devolved ethics committees, for example, Queen's University in Northern Ireland, Rhodes University in South Africa, and University of Waikato in Aotearoa/New Zealand. In these instances a central research ethics committee provides secondary support to school- or faculty-level committees to ensure the promotion, review, and monitoring of ethical practice in research (see Queen's University Belfast, 2017; Rhodes University, 2017; University of Waikato, 2017). This often includes facilitating university-wide conversations to support the development of ethics committee members and researchers and is a form of professional development around ethics review and responsiveness to ethical concerns. As the members of school- or faculty-level ethics committees are likely to be familiar with the methodologies under review, there is a greater opportunity for researchers and reviewers to engage in appropriate dialogue about ethics issues rather than merely aiming to achieve tick-box approval. If frustrations with inflexible, unresponsive, and slow ethics review processes are at least partly as a result of the centralisation of ethics review (Tolich et al., 2016), then the outcomes of experimentation in devolved ethics committees are going to be interesting to observe over the coming decades.

Regarding the ethical responsibilities of ethics reviewers and researchers, Bond (2012) argues that, while these responsibilities can be antagonistic, this need not be the case if reviewers understand their role as being in support of researchers in being ethical. In addition to time, effective ethical engagement in the development of a research protocol requires significant 'investment of personal values, energy and agency by the researcher which can be supported or undermined by the research process' (Bond, 2012, p. 108). The literature on ethics review suggests that these processes most often occur behind closed doors (Ashcroft & Pfeffer, 2001; Stark, 2012). And as few researchers have gained access to the inner workings of ethics committees, researchers are often in the dark as to precisely what is required of ethics committee members (Fitzgerald, Phillips, & Yule, 2006; see van den Hoonaard, 2011, for exceptions).

Tolich et al. (2016) argue that researchers become better aware of the process of ethics when they are invited to attend the ethics committee meetings at which their proposed research will be discussed. By doing this, ethics committee deliberations and decisions become subject to external scrutiny. If the attendance of researchers at ethics committee meetings is used as an opportunity to engage researchers in the constructive dialogue of the ethics issues occasioned by their proposed research, then that discussion might have a positive impact on the review outcome as initial questions or concerns can shift as a result of new information about the research that emerges during discussion. The input of critical researchers in ethics review discussions may also offer rich learning opportunities for both researchers and ethics committee members as debate helps to develop understandings of the ethics issues under discussion. In fact, it is for these reasons that increased availability of research committee members for consultation outside formal ethics committee meetings has been shown to have a positive impact on review outcomes (Guta, Nixon, Gahagan, & Fielden, 2012; Stewart-Withers, 2016; Tolich et al., 2016).

Related to the issue of evaluating the benefits of critical research, there is a need for critical researchers to think critically about claims regarding the impact of research that is only accessible to others in our echo chamber, for example, because of the language we use and/or where we choose to publish. Critically evaluating the ethics of, for example, 'research tourism' (Mistry, Berardi, & Simpson, 2009) would increase the responsiveness of the ethics review process to concerns related to critical research; however, it would be naïve to assume that methodological responsiveness would necessarily make the ethics review process easier to navigate because more pertinent questions are sometimes also more difficult to answer.

Encouraging Both Principlist and Contextual Ethics Responses and Support

A key message of many of the chapters in this handbook is that ethics committees need to be prepared to acknowledge that some ethics principles should be interpreted in relation to the specificities of the research context. How do ethics committees navigate conflicts in particular principles that may be foregrounded in critical research as when harm to individual participants may accrue in research that aims to contribute to social justice? Do committee members simply revert to traditional interpretations of ethics principles, or are they able to accommodate interpretations of ethics principles informed by epistemologies applied in critical research? There are no straightforward answers to these kinds of questions, but ethics committees are perhaps the ideal location for the deliberation of these very issues.

How do ethics committees navigate the difference between what is legal and what is ethical? Legal and ethical concerns about research often overlap, but typically the impetus behind these concerns is primarily to protect universities rather than individual participants, communities, researchers, or ethics committee members. For example, confidentiality and respect for privacy are ethical imperatives (see Section 3), but they are also constitutionally protected rights in many countries, and failure to uphold confidentiality or respect for privacy can be punishable under law and/or under the regulatory powers of professional practice bodies. In contrast, legal and ethical questions are also raised when researchers are made privy to information about crimes that have been committed or the intention of individuals to harm themselves or another; should such information be considered confidential, or might failure to report such information be considered unethical, or even aiding and abetting under some circumstances? For example, Marzano (Section 4) and van den Hoonaard (Section 4 and 2011) discuss research on legally complex issues such as trade in human organs. The question then becomes whether ethics committees and institutions are willing to stand by researchers who are able to make a good case for conducting ethical research that contributes to social justice but which raises legal concerns.

A strategy that has shown promise in terms of making the ethics review process more responsive to the types of research undertaken by critical researchers is for ethics committees to facilitate proportional ethical review. This generally involves tying ‘the amount of paperwork, the rigour of the review, and the processing time to a smart assessment of the risks and ethical issues associated with the proposed work’ (Allen, 2008, p. 112). There is no reason why this should not include tailoring which questions are posed and the way in which they are posed so as to be responsive to the kinds of research being proposed. This approach is already applied by some ethics committees but usually works on the presumption that researchers are able to choose adequately from tick-boxes describing a range of possible methods. This does not mean that very careful consideration is not required in assessing both the direct and indirect benefits of critical research (see, e.g., Carter et al., Section 1). It is often the case that critical researchers experience ‘a real sense of impotence and inadequacy at not being able to do much, if anything, of immediate material benefit’ (Cloke, Cooke, Cursons, Milbourne, & Widdowfield, 2000, p. 139) for participants in vulnerable or precarious circumstances. In these instances we tend to reason that our research includes the prospect of improving the quality of life of the broader community or social group from which our research participants are drawn. While this is sometimes the case, however, it is certainly not guaranteed.

Formative feedback received during researcher consultations with ethics committee members prior to the submission of their ethics protocols for review has a positive impact on both the experience of the review process and the outcome of the review process (de Jong, van Zwieten, & Willems, 2013; Hedgecoe, 2012; Tolich et al., 2016). The availability of ethics committee members to engage with researchers can be constrained by their workload (Allen, 2008; O’Neill, 2010; Tolich et al., 2016). Comparing ethics review structures and processes across five universities in Aotearoa/New Zealand, Tolich et al. (2016) argue that the volume of ethics applications requiring ethics review in some universities is preventing them from implementing the open-door approach adopted by others. Consequently, it appears that institutional support for ethics committees is required in order to provide the sort of assistance that researchers need in order to navigate successfully the ethics review processes.

When institutional support *is* provided, then previously 'dysfunctional' ethics committees can become responsive. For example, Griffith University in Australia implemented an intervention to address long-standing frustrations with the ethics review process (Allen, 2008). One aspect of the intervention involved establishing a research ethics advisor network. The purpose of the network was to ensure that every discipline had an academic member of staff as a research ethics advisor to undertake support, which included providing judgement-free and discipline-relevant advice to researchers, delivering ethics workshops relevant to their discipline, participating in the expedited review system, and facilitating communication to and from the ethics committee. Two years after the intervention was implemented, a comprehensive external review found 'universally strong endorsement' for the university's research ethics system which was described as 'effective and responsive' (Allen, 2008, p. 113). It would appear, therefore, that critical researchers wanting more out of their ethics committees have a responsibility to demand that their institutions provide the resources that ethics committees need to enable them to deliver appropriate and optimal support (Pearce, 2002).

Accommodating Participatory Research in Ethics Review

In most countries, all research with human participants must undergo ethics review, and this includes community-based participatory research. However, practitioners of community-based participatory research have reported an ambiguous positioning of these methods as 'research' in countries including Aotearoa/New Zealand (Marlowe & Tolich, 2015), Canada (van den Hoonaard, 2002), and the United States (Malone, Yerger, McGruder, & Froelicher, 2006). Conservative notions about what does and does not constitute scientific inquiry means that practitioners of community-based participatory research are not always clear about when ethics approval to conduct 'research' is or is not required. Researchers report being excluded from ethical review processes even when they were conducting health and disability research that clearly should have been eligible for ethics review (Marlowe & Tolich, 2015), and this seems particularly likely when the people conducting research are not employed by a university nor collaborating with academics. In these instances, opportunities to obtain ethics guidance are missed, and this is unfortunate given the kinds of ethics issues to which community-based participatory research gives rise.

Practitioners of community-engaged participatory research have highlighted the difficulties of drafting a detailed research proposal for ethics review prior to the commencement of research. This is largely because community-engaged participatory research is a form of emergent inquiry in which the research process is shaped by an iterative interchange among research questions, data collection, and analysis (e.g., Cockburn & Cundill, Section 1). Attempts should still be made to describe the intended process as fully as possible. For Wassenaar and Mamotte (2012), the difficulty in describing emergent forms of inquiry for ethics review 'is not a sound reason for not persisting in finding a way of doing it. Researchers should address ethical issues in their research with the same intellectual and creative vigour that they use to develop methodologies and analytic methods' (p. 273).

There are many issues that ethics committees might assist community-based participatory research practitioners to consider before entering the field. Critical researchers may appreciate feedback about ways of involving communities in defining what constitutes ethical research. Some members of ethics committees might be ideally placed to offer advice about the kinds of interpersonal skills needed to foster and maintain community collaboration, develop trust and transparency, and how to respond in the event that this is compromised. Ethics committees might also be ideally placed to advise about the importance of negotiating mutually agreed-upon aims and objectives in participatory research and how to develop and implement methods that enhance democratic engagement (see, e.g., Lovell & Akhurst, Section 4). Likewise, critical researchers may wish for advice about attending to power differentials in the community and negotiating how communities and individual members will be represented, for example when considering naming willing participants (see, e.g., Ashdown et al., Section 3). Negotiating a clear understanding of who has ownership of the 'data' is also a potentially predictable issue or one about which an ethics committee might offer advice when it arises unexpectedly (see, e.g., Mayeza, Section 4).

Persistent engagement in ethics considerations in community-based participatory research is important. Tatebe (2015) argues that the necessity to 'get through' (p. 233) the ethics review and approval process places greater emphasis on ethics as a static process over conducting ethical research. According to Tolich (2016), this is possibly because ethics committees ask only three questions—'what is the research about, what are the ethical issues raised by that research, and how will the researcher address those issues?'—when they should ask a fourth as well: 'how will the researcher address the ethical issues that arise in the field that neither the researcher nor the ethics committee can predict during ethics review?' (pp. 46–47). Thus, ethics committees supportive of community-based participatory research and all critical research could help researchers to think through the kinds of issues that may arise in the process of the research and to put in place appropriate support mechanisms.

Conclusion

For every ethical imperative that is constructed within health and social fields of research, critical research as a collective presents challenges and critical researchers face challenges that resonate personally. In sharing stories of these challenges, the authors of chapters in this handbook have demonstrated ways of traversing ethical imperatives that exist in the dominant forms of ethics review across the many varied international contexts. The tools of narrative and reflexivity prove powerful in deconstructing ethical imperatives and re-envisioning a future for critical research subjects to a more inclusive and responsive process of ethics review.

This chapter has concluded the handbook with a re-analysis of four overarching issues across the sections of the handbook: (1) learning how to apply process ethics in critical research through researcher education, communities of practice, and researcher reflexivity; (2) constructions of vulnerability in critical research that apply both to potential participants and researchers; (3) seeking social justice through participation in critical research; and (4) reimagining ethics review by considering the limitations and possibilities of ethics committees in reviewing research applying critical methodologies and epistemologies. In combination with the richness of the worked examples of critical research in each of the chapters, these overarching issues provide recommendations and questions for critical researchers to take forward as we engage in ethical, transformative health and social research.

Notes

1. See the main introduction chapter for more background on principlism.

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