Deep thinking is attainable only by a man of deep feeling,
and all truth is a species of revelation

Samuel Taylor Coleridge

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Participants' Perspectives of Risk Inherent in Unstructured
Qualitative Interviews

by

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A thesis submitted to the Faculty of Graduate Studies and Research
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For my mother and grandmother,

Dorothy Marilyn Thompson

Lila Mae Pickard

Abstract

The purpose of my dissertation research was to ascertain participants'
perspectives regarding perceived risk inherent in unstructured qualitative interviews. The
impetus for my research was the current crisis in research ethics governance; namely, its
lack of evidence with respect to research participants' perspectives and experiences and
to the appropriateness of the current normative context of research ethics oversight to
qualitative research. My hope was the actual experiences of participants would inform the
moral conduct of interviews and their ethical review.

Research Ethics Boards and some researchers regard emotional distress as a
predominant risk to participants in interview research. My first paper, "Research Ethics
Boards and the Ethics of Emotion," is a conceptual analysis of this phenomenon.
Contemporarily, emotion has been conceptualized in terms of valence and polarity; that
is, either negative or positive and one opposite to another. Thus, emotional distress is
regarded as negative and harmful and the opposite of benefit. However, this
conceptualization is too simplistic to capture the complexity of emotion. My paper
contributes to the literature an explication of emotion as well as an elucidation of the
factors of ethics oversight that perplex the proportionate review of emotional distress and
confound the presumptions of emotional distress as harm.

In my second paper, "The Diversification, Utilization and Construction of the
Semi-structured Interview" I elucidate various types of semi-structured interviews that I
discerned within the literature. The descriptive/corrective type of semi-structured
interview is selected for my study because of its unique capacity to describe, compare
and correct dominant conceptualizations of risk that reflect non-participants' perspectives
with the actual experiences of participants themselves.

In my final paper, "Participants' Perspectives of Risk Inherent in Unstructured
Qualitative Interviews" I describe participants' paradoxical responses to interview

participation. They experience distress but report benefit, not harm. Participants believe

unstructured interviews provide a unique and profound opportunity to tell their stories.

Most find interview experiences to be revelatory and transformative. Despite REB

presumptions of risk to participants in unstructured interviews, participants report no

experience of harm. I discuss the implications for ethical conduct and oversight of

interview research.

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Table of Contents

INTEGRATING CHAPTER: INTRODUCTION AND OVERVIEW

The overall purpose of this dissertation is to determine if participants' perceive that qualitative unstructured interviews cause harm. This question has implications for the ongoing debates concerning contemporary research-ethics governance of qualitative inquiry.

Little is known about the experience of participating in unstructured interview research—in particular, any risk inherent in it—and researchers have made few attempts to solicit this information from research participants themselves. McDonald (2001) and Hirtle (2003) have argued that the absence of such evidence is a critical gap in the literature with important ramifications for ethical and effective research ethics governance. Research ethics oversight, which is not based on evidence, assumes risk despite the absence of verified harm. For many researchers and Research Ethics Boards (REBs), unstructured interviews—with their unique constellation of emergent design, sensitive topics, vulnerable participants, and evocation of emotional distress—is a method that could potentially pose significant risk to participants. Currently, however, there is no evidence to verify the risk predicted.

In this research, I will explore participants' perspectives of risk inherent in unstructured qualitative research interviews. The results will help to resolve the evidentiary gap created by the absence of such knowledge. Furthermore, these findings have implications for research-ethics oversight of interview research. This goal entailed three research projects: (a) a conceptual analysis of emotional distress, (b) a methodological exploration of the semi-structured interview, and (c) the conduct of a descriptive-corrective semi-structured interview study to explore participants' experiences of participating in qualitative health research in which data were collected using unstructured interviews. Results are presented as three papers in publication format.

Impetus for the Research

As nurses we acknowledge our patients to be our best teachers for eliciting information about care and the experience of illness. Therefore, in qualitative inquiry, patients figure prominently as interview participants. Their lay perspectives and experiences of personal and sensitive health-related concerns are used to inform our professional practice and advance our disciplinary knowledge. Beyond nursing, such knowledge is more broadly socially beneficial. Indeed, the three Canadian granting agencies have acknowledged that: "research subjects contribute enormously to the progress and promise of research in advancing the human condition" (Tri-Council Policy Statement [TCPS]; Canadian Institutes of Health Research (CIHR), Natural Sciences and Engineering Research Council of Canada [NSERC], and Social Sciences and Humanities Research Council of Canada [SSHRC], 2005, section i.7).

Concomitantly, one needs to acknowledge the particular social value of sensitive research. Dramatic substantiation of this acknowledgement may be found in the landmark legal case of Russel Ogden (Palys & Lowman, 2000). Ogden was a graduate student investigating the assisted suicide of people with AIDS when he was subpoenaed to disclose the identities of his informants, people who had been present at and/or assisted these suicides. Ogden refused to breach the confidentiality he promised his participants. During the proceedings the Court granted Ogden a rare legal privilege to protect the identities of his informants. The protection of the privacy of Ogden's participants prevailed, in part, because of the social value of his research. In delivering his *obiter dictum* (remarks, distinct from his legal findings), the judge upheld the "great social value" of sensitive research: its contribution to topics wherein there is a "dearth of empirical data" and its "vital" and timely role in "informing social and parliamentary debates" (such as the debate surrounding Sue Rodriguez who appealed to the Supreme Court of Canada for her right-do-die and Robert Latimer who was convicted of second-

degree murder for euthanising his severely disabled daughter) (Steinberg, 1998, p. 16). Furthermore, the judge cited s. 46 (c) of the University Act and the duty the university has to protect academic freedom to pursue original, including controversial, research.

Sensitive research, of course, definitively encompasses more than the risk of criminal prosecution: It encompasses sensitive topics, emergent designs (that undermine *a priori* informed consent), allegedly vulnerable people, the potential harm to participants of becoming emotionally distressed, and so forth. Nurses gave compelling testimony in the Ogden case (Palys & Lowman, 2000) that substantiated the importance of his research. They have contributed valuable research of their own in such sensitive topical areas as domestic violence (Wuest & Meritt-Gray, 2008), eating disorders (Weaver, 2008), workplace bullying (MacIntosh, 2006), palliative care (Steele & Davies, 2006), suffering (Morse, 2001, 2003), and with vulnerable persons such as dying children, women who have experienced abuse, homeless persons, prison inmates, and those who nearly died and were resuscitated, among others.

Sensitive research and those who participate in it warrant protection. There is concern, however, about whether the protection afforded to qualitative researchers and interview participants by the current context of research-ethics oversight is appropriate, effective, and adequate—or even necessary at all. Because REBs' concerns may impede or interrupt this important inquiry, exploration of this topic must be given priority.

Background

Governing bodies and experts assert that the ethics governance of research involving human participants is in crisis in Canada, the United States and internationally (Centre on Governance, 2000; Deschamps, Vinay & Cruess, 1995; Expert Committee for Human Research Participant Protection in Canada, 2007; McDonald, 2001; National Council in bioethics in Human Research, 1995; Hirtle, 2003). The Expert Committee for Human Research Participation Protection in Canada states "Current systems of human

research participation protection face increasing pressures related to governance, consistency, transparency and public accountability" (2007, p. 2). Several reports were commissioned to identify the most salient issues underlying this crisis. Reports authored by McDonald (2001) and Hirtle (2003) identified the key issue underpinning this crisis as the lack of evidence-based ethics with particular emphasis on the lack of evidence concerning (a) research participant perspectives and (b) the current context of governance for social science and humanities research involving human participants (McDonald, 2001; Hirtle, 2003).

Other experts argue that research-ethics review is a moral panic (van den Hoonaard, 2001) defined as a "threat to societal values and interests" (Cohen, 1972, p. 9). "A moral panic is indicated by hostility and sudden eruption of measured concern shared by a significant segment of the population, with disproportional claims about the potential harm moral deviants are able to wrought" (van den Hoonaard, 2000, p. 25). Within the context of this moral panic, qualitative research is conceptualized as deviant and becomes particularly vulnerable within the research-ethics review process.

Moral panic or not, research-ethics governance constitutes a crisis for qualitative research that is unlikely to dissipate. The lack of evidence with which to underpin research-ethics oversight augments this crisis. Evidence is required in order to address, revise and dismantle this crisis cum moral panic.

The Current Context of Ethics Governance for Qualitative Research

Good research ethics governance requires good ethical standards, among others. Ethics guidelines constitute the standard to which ethics of proposed research must conform and by which it is reviewed. Recently, disparate disciplinary ethics standards (Canada) or departmental regulations (United States) governing the diverse domains of biomedicine, social science and humanities, and the natural sciences have been

amalgamated into one normative ethics. In Canada, the normative standard is the TCPS (CIHR et al., 1998).

Social science and humanities researchers have asserted that "one size does not fit all" (Social Sciences and Humanities Research Ethics Special Working Committee, 2004, p. 10) and that normative ethics standards failed to accomplish the full integration of multidisciplinary approaches to ethics governance but, rather, amalgamated several disciplines under the unitary governance of biomedical research. In Canada and internationally, governing bodies concede the "real or apparent biomedical focus" of current standards and acknowledge that the perspectives and approaches of social scientists and humanities researchers have not been adequately represented in the formulation of common ethics guidelines (Expert Committee, 2007).

Furthermore, qualitative researchers have alleged that the biomedical hegemony inherent in normative standards, the positivist epistemology and the presumed research context of the biomedical experiment, is incongruent with qualitative methodologies (SSHWC, 2004). The literature makes the case that research, risk, human subject are defined in terms of clinical research not field research. Qualitative research is not generalizable, risk may not be statistically calculated a priori, and human 'subject' implies a hierarchical relationship in which the researcher has the power and the subject is relatively powerless —none of these are reflective of qualitative inquiry in which more equitable relationships exist between researcher and participants, risk is emergent and could include risk to the researcher. Privacy and confidentiality issues have conflicted with populations' desire to have their identities known e.g. Aboriginal elders; informed consent represents another complication in which an unnecessary layer of bureaucracy is inserted into human relationships and compromises research with no gain of participant protection in which consent as process is more appropriate. In Canada, the Experts Committee (2007), a group in support of normative ethics oversight, itself acknowledged

the "real or apparent biomedical hegemony" of the TCPS and that the guidelines needed amendment in order to better reflect qualitative methodologies. Indeed, to their credit, the latest iteration of the TCPS, though still in process, has redefined human subject to human participant and included a greater section devoted to qualitative research. They have asserted that the failure of standards to reflect methodological diversity has had a "chilling effect" on qualitative research (Church, 2002, p. 2), that it has threatened the ability of social science and humanities researchers to carry out their traditional social and cultural mandate (Lincoln, 2005; Social Sciences and Humanities Research Ethics Special Working Committee, 2004, 2006; van den Hoonaard, 2002).

Risk in Qualitative Inquiry

Qualitative researchers have alleged that this lack of sensitivity to the spectrum of research methodologies affects ethics governance by blunting the consideration of ethical issues specific to diverse methods (Adler & Adler, 2002). Indeed, the definition of minimal risk and its proportionate review have been specifically cited as problematic within this context (Expert Committee, 2007). In sum, many social scientists allege that current ethics governance of qualitative research involving human participants by normative ethics standards is ineffective and unethical (van den Hoonaard, 2002; Haggerty, 2004; St. Pierre, 2004; Gunsalus, Bruner, Burbules et al., 2007; SSHSWC, 2004; McDonald, 2001).

Risk, the definition of minimal risk and its proportionate review is an ethical issue that must be considered within the context of its methodological specificity. Qualitative researchers have asserted that risk in qualitative research is unique and distinct from risk in experimental research. Although qualitative researchers agree that all research poses risk to participants, they consider that risk posed to human subjects in a clinical trial is different from and greater than that posed to human participants in ethnographic research, in which the control of the interaction is balanced or in the control

6

of the participant rather than the researcher (Abbott, 1983; Adler & Adler, 2002; Cassell, 1978, 1980; Chaitin, 2003; Coffey, 1999; Cowles, 1988; Hammersley, 1992; Kelman, 1982; Mead, 1969; Murphy & Dingwall, 2002; O'Neill, 2002; Tang, 2002; Wax & Cassell, 1981; Wong, 1998).

Furthermore, normative guidelines conceptualize risk in monolithic, positivist terms, that risk is objective, statistically calculable, predictable, and generalizable (CIHR et al., 2005; Expert Committee, 2007; Social Sciences and Humanities Research Ethics Special Working Committee, 2004). The nature of risk in qualitative research, however, is subjective as well as objective, contextual, relational, emotional and emergent (Morse, Niehaus, Austin, Varnhagen, & McIntosh, 2008). For example, the risk of interview participants becoming re-traumatized by recounting a traumatic experience is not absolute. How one person will react may not be how all people will similarly respond. Hence, this risk is, in part, subjective. This defies an a priori proportionate review. Current guidelines therefore constitute a crude calculus for the assessment of risk in qualitative research. As Haggerty (2004) has pointed out questions of value are not rationally resolvable; similarly, trauma, which is notoriously subjective, cannot be rationally assessed (McNally, 2003). The epistemological incongruence between normative ethics standards and many qualitative research methodologies is borne out in the problematic implementation of the TCPS with respect to social sciences and humanities research. There is consensus that an evidence-based approach to research ethics requires an interdisciplinary research effort (McDonald, 2001; Social Sciences and Humanities Research Ethics Special Working Committee, 2004; Social Sciences and Humanities Research Ethics Special Working Committee, 2006).

It behooves qualitative researchers, therefore, to contribute empirical evidence of the uniqueness of risk within their methodologies. If risk is specific to method, what is its nature in unstructured interview research, for example? The unstructured interview,

characterized by sensitive topics, vulnerable persons, emotional evocation, and an emergent design, is a challenging method for the ethics-review process to assess. Research ethics boards, as well as researchers themselves, worry about risk to participants by this method (Cowles, 1988; Guillemin & Gillam, 2004; LaRossa, Bennett, & Geles, 1981; Lee & Renzetti, 1990; Lincoln & Tierney, 2004; Munhall, 1991; Ramos, 1989; Rew, Bechtel, & Sap, 1993; Smith, 1990). Researchers' primary concerns are the "implications of the emergent design" (Ramos, 1989, p. 57), presumably the unintended or coerced disclosure of very sensitive details and the evocation of "strong emotional responses and sometimes pursuing thoughts that might otherwise never be revealed" (Cowles, 1988, p. 163).

This review has already established that there is a paucity of empirical evidence regarding research ethics and qualitative inquiry with which to inform the ethics review and ethical conduct of qualitative and interpretive research. In particular, researchers have particularly neglected the perspectives and experiences of research participation in unstructured interviews. The ramifications of this empirical gap include the overestimation of both the magnitude and probability of risk to human participants in social sciences and humanities research (Social Sciences and Humanities Research Ethics Special Working Committee, 2004) and the "over-reaching of REBs due to uncertainty about the interpretation of guidelines and regulations" (Expert Committee, 2007, p. 24). Such ramifications might negatively affect the approval, design, and conduct of qualitative research, and without considering what these mean for the protection of research participants.

Lack of Evidence Concerning Research Participants' Perspectives

In his commissioned report on ethics governance, Michael McDonald (2001) described a "dearth of useful information about what happens to research subjects in the conduct of research, but also a general failure to systematically and rigorously seek such

information" (p. 12) and declared "an urgent need for research on what happens to humans in research" (p. 11). Hirtle (2003), in her commissioned report, concurred:

> Little is known about the effects of research on participants . . . We are equally
> ignorant about the effect of research on communities or groups or about the
> effect of regulations on the health of participants or the patients. (p. 5)

Standard setters

> ought to be intensely concerned about the effects of the research they sponsor on
> research subjects and in particular for ensuring that appropriate and effective
> standards are in place . . .To ask for this information and to act upon it would
> seem a basic and essential part of governance. (p. 5)

According to McDonald (2001),

> Ultimately, some of the most important evidence would likely come from those
> most affected by research—namely, research subjects, their families and
> communities. That is, an evidence-based approach should in my view also be a
> subject-centered approach—taking the lives and testimony of research subjects as
> central. (pp. 13-14)

The ascertainment of participant perspectives and engagement of their active involvement is crucial for effective and ethical governance:

> The final desideratum for effective and ethical governance is the active
> involvement of the general public and particularly research participants in
> governance – not only in its implementation of policy but also in its design. (p.
> 11)

Statement of the Research Problem

Contemporary research ethics governance of qualitative research is not evidence based. The lack of empirical evidence regarding participants' perspectives and experiences of risk inherent in their participation in unstructured qualitative interviews constitutes a significant evidentiary gap. In the absence of such evidence normative research-ethics oversight governs from assumptions and principles that are wrought from positivist epistemology and are more congruent with the quantitative research paradigm. These two factors, the lack of evidence and the incongruity of ethics guidelines with qualitative inquiry make the proportionate review of risk in unstructured interview research particularly problematic. The literature evidences researchers' experiences with their REBs who have assumed unstructured interviews to be harmful, that participants are vulnerable i.e. incapable of protecting themselves, and that they will be harmed if they become emotionally distressed (Holland, 2007; Gunsalas, 2004; Shea, 2000). Holland (2007) asserts the epistemological bias of the current ethics review framework "serves to constrain qualitative inquiry and first-person perspectives in mental health research" (p. 895). Gunsalas (2004) states "adverse effects of [emotionally distressing] interviews are grossly overestimated; and IRBs should not focus on whether some participants might become distressed but rather on whether the final outcome of the interview is a positive one for participants" (p. 378). The absence of evidence precludes a feedback loop with which to inform the veracity of these assumptions or the appropriateness of current normative standards to govern ethics in interview research. Above all the lack of evidence based research-ethics governance precludes any certainty that human participants or the qualitative research enterprise are adequately, appropriately, or effectively protected. In sum, the empirical gap constituted by the lack of participants' own perspectives regarding their unstructured interview experience is antithetical to an

evidence-based approach to research ethics that thwarts its ethical and effective governance.

Philosophical Basis of this Research

The philosophical basis of this dissertation research is standpoint epistemology (Stanford Encyclopedia of Philosophy, 2009; Wylie, 2003; Smith, 1974, 1987, 1990a, 1990b). As a type of feminist epistemology, the purpose of this perspective is to elucidate the actual, material experiences of women and demonstrate how these exist in disjuncture with the abstracted perspectives of the relations of ruling that governs them. In this dissertation the participants are interpellated as possessing the culturally ascribed feminine traits of vulnerability (incompetency) and tendency to emotionally distress (irrationality) within a ('soft') science such as unstructured interviews that are associated with a feminine cognitive style and mode of knowledge acquisition as opposed to more masculinist cognitive styles and research methods such as experimentation. Thus, as with all feminist perspectives, this approach may be extended to other non-dominant groups though not women per se. Other researchers have, in fact, used this approach in a study of research ethics committees (Truman, 2003).

The tenets of standpoint theories that are applicable to this research are: 1) the privileged epistemic authority of first person or direct knowledge of people (de se knowedge) about themselves and the phenomenon they experience versus the third party knowledge of a particular social situation, in this case, the perspectives of participants regarding risk inherent in unstructured qualitative interviews versus the perspectives of non-participants. Only participants can claim deep knowledge of risk posed by interview research; non-participants, despite their privilege as researchers or ethicists can claim only superficial knowledge. First person knowledge may only be ascertained by third parties by imaginative projection or by ascertaining the testimony of the first persons; 2)

11

By virtue of this privileged perspective, participants claim superior knowledge of the human potentialities with respect to risk in interview research. The standpoint of some researchers and some REBs may be that participants are vulnerable and incompetent to protect themselves. Participants perspectives may assert this conceptualization to be socially contingent and how this notion can be corrected or overcome; 3) Standpoint epistemology asserts that the standpoint of the privileged offers a representation of the social world as co-incident with universal human interests but that is really only in relation to their own interests. In the case of this research, some researchers and REBs may conceptualize unstructured interviews as posing high risk of harm to vulnerable participants. This may be justified by their mandate to protect human participants from risk inherent in research. However, this conceptualization of risk may be self-serving. Unstructured interview research may pose risk but the risk of harm may be less to participants and more to the status quo (Harding, 1991). Participants' perspectives may better coincide with universal human interests in particular the role the knowledge produced by interview research may have in social transformation and justice (Hartsock, 1987). In sum, standpoint epistemology acknowledges research participants as knowers.

In addition, standpoint epistemology asserts alternative modes of knowledge and methods of knowledge acquisition. Risk assessments are knowledge claims. Positivist philosophy of science regards knowledge as abstract, theoretical, disembodied, emotionally detached, analytical, deductive, quantitative, atomistic, and oriented toward values of control or domination. Standpoint epistemology posits knowledge as concrete, practical, embodied, emotionally engaged, synthetic, intuitive, qualitative, relational, and oriented towards values of care (Flax, 1983; Hartsock, 1987; Rose, 1987, Smith 1974). Risk assessments of notoriously subjective phenomenon such as emotional distress are problematic when adjudicated from a positivist perspective. Standpoint epistemology allows knowledge claims regarding risk to be alternatively considered.

Finally, standpoint epistemology acknowledges the androgenicity of mainstream scientific methodologies (Bordo, 1987; Code, 1991; Flax, 1983; Rooney, 1991). Qualitative inquiry has been considered "soft" science. This dissertation research will consider whether interview research is a strong scientific method.

Standpoint epistemology asserts emotion as knowledge, qualitative research methods as strong modes of inquiry and the epistemic authority of first person accounts (Duran, 1991; Rose, 1987; Smith, 1974). The following research questions are therefore underpinned by this philosophical foundation. This perspective is sustained throughout this dissertation in that each paper that addressed the research questions represents a specific tenet of standpoint epistemology i.e. emotion as essential to research and as knowledge; rigour of qualitative science; epistemic authority of standpoint of people.

Research Questions

   The following research questions emerged from this problematic and guided this dissertation research. These questions were addressed in the papers as follows and the interrelationship among them is illustrated on Figure 1.0:

1. Using the literature, I explore participants' emotional distress as a predominant risk factor posed by unstructured interview research, and consider: Does emotional distress constitute harm?

2. Given the abundance of discourse from the perspectives of non-participants about risk to participants, as well as the under-represented voice of the participants themselves, I explore: What method is best employed to ascertain participants' perspectives?

3. What are participants' perspectives of risk inherent in unstructured qualitative interviews?

Contextual Factors Regarding Risk to Participants in Unstructured Qualitative Interviews

- non-evidence based research ethics governance characterized by prediction of risk without verification of harm
- paucity of evidence regarding participants' perspectives has been identified as a critical gap

Research Question 1

Do unstructured qualitative interviews cause emotional distress?
Does emotional distress constitute harm?
Are unstructured interviews that evoke emotional distress unethical?
Should unstructured interview participants be protected?

Research Question 2

How best to ascertain participants' own perspectives of risk within the context of the preponderance of researcher and research ethics governance discourse about risk to participants, such that the former may support, elaborate upon, or refute the latter.

Paper 1: REBs (IRBs) and the Ethics of Emotion

A conceptual paper exploring the nature of emotion, its essential role in qualitative inquiry, and the adequacy of current research ethics guidelines to review the risk of emotional distress in unstructured interviews.

Paper 2: The Semi-structured interview as a stand-alone method

An exploration of the methodological options and issues implicit in the collection and analysis of data in research that aims to describe participant perspectives and correct dominant discursive conceptualizations of risk to participants inherent in unstructured interviews.

Research Question 3

How do participants describe their experience of participation in unstructured interviews?
What are their perspectives regarding risk, harm and benefit inherent in such participation?
Is there a disjuncture between dominant discursive conceptualizations of risk to participants and participants' own actual experience of harm?
Are research ethics boards' predictions of risk to participants inherent in unstructured qualitative interviews validated by participants' experiences of harm?

Paper 3: Participants' Perspectives of Risk Inherent in Unstructured Qualitative Interviews.

Exploration of results from a descriptive/corrective semi-structured interview study designed to ascertain and analyze participants' perspectives of risk arising from their participation in interview research.
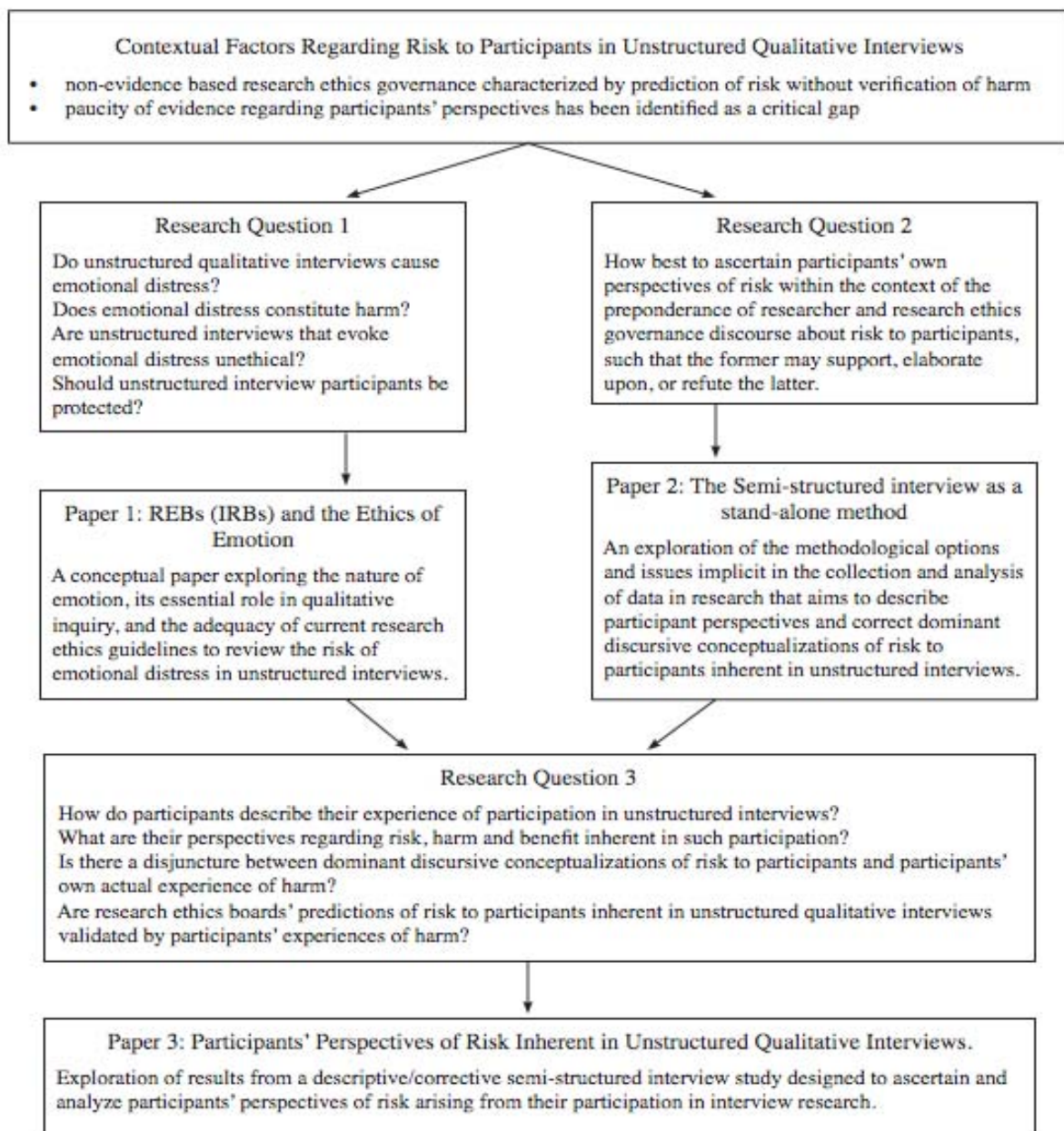
Figure 1.0 Overview of Dissertation Research

The Papers

Paper 1: Research Ethics Boards and the Ethics of Emotion.[1]

Purpose

The purpose of this paper was to explore the concept of emotional distress. In particular, I was interested in whether unstructured interviews caused emotional distress, whether emotional distress constituted harm, whether interviews that evoked emotional distress were unethical, and whether interview participants should be protected.

Method

The method employed in this conceptual analysis was the review of relevant literature that encompassed emotion, culture, risk and qualitative research, philosophy, ethics, ethics guidelines, and the limited literature that exists regarding participants' perspectives on research participation.

Results

The results were as follows.

Do unstructured interviews cause emotional distress? Unstructured interviews do not cause emotional distress. Emotion is integral to qualitative inquiry, not an adverse effect of it. Unstructured interviews provide a context in which participants tell stories of enduring meaning using their emotional voices. The circumstance of the life event must not be conflated with its telling.

Does emotional distress constitute harm? Participants' interview experience is paradoxical. Participants describe their interview experience as painful yet positive and beneficial. Emotional distress is not a simple, one-dimensional negative valence such as

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[1] A version of this paper has been published. McIntosh, M. J. & Morse, J. M. (2009). Institutional Review Boards and the Ethics of Emotion. In N. K. Denzin & M. D. Giardina (Eds.), *Qualitative inquiry and social justice* (pp. 81–107). Walnut Creek, CA: Left Coast Press.

harm, nor is it the opposite of a benefit. Conceptualizations of emotion in terms of valence and polarity are too simplistic to capture the complexity of emotion.

Are unstructured interviews that evoke emotional distress unethical? No. However, the research-ethics review process that draws from ethical theories such as utilitarianism might come to that conclusion. Utilitarianism requires a single valence, polar opposite conceptualization of emotion in order to plot distress on a risk-versus-benefit scale. Such simplistic conceptualizations of emotion lead to unethical reviews. Moral reviews must be underpinned by good knowledge that includes a variety of ethical perspectives and theories that include the complexity of emotion with moral reasoning.

Should interview research participants be protected? Ethical oversight of interview research must encompass a wide terrain of ethical perspectives. Emotion is a critical (but historically absent) component of moral reasoning and must be included within ethical perspectives that govern interview research. Emotion is a critical component of the ethical conduct of interviews. Emotional, relational engagement between the researcher and the participant helps ensure the ethical conduct of interviews. REBs must take this local aspect of governance into consideration when conducting reviews.

Conclusion

Stories told in unstructured interviews cultivate our collective moral imagination such that we "understand ourselves well enough to talk good sense in ethics" (Nussbaum, 2001). Life stories have an essential role in just, human societies. It behooves REBs to protect participants who tell these stories as well as the moral imperative to hear them.

Link to Other Research Questions

This conceptual analysis provided an important foundation for the ascertainment of participants' perspectives of risk in unstructured interview research. First, the elucidation of this conceptual construct informs the design of the interview guide, and

second, this conceptualization of emotional distress may be compared with participants'

actual experiences.

Paper 2: The Diversification, Utilization and Construction of the Semi-structured Interview.

Purpose

The purpose is to methodologically explore the semi-structured interview as a stand-alone research method for the collection and analysis of participants' perspectives of risk inherent in unstructured qualitative interviews. I explored the development of the semi-structured interview, and descriptions of its construction and utilization.

Methods

I conducted a literature review in order to explore the semi-structured interview as a stand-alone method. This literature review included methods texts (that instructed how to conduct interviews), qualitative research texts (that included discourse regarding trends and issues in interview research), and published research studies that used semi-structured interviews. Using semi-structured interview as the subject heading and keyword, I searched the major databases to illustrate the increased use of the semi-structured interview by decade since 1960. I then described the process of constructing the semi-structured interview questionnaire.

Results

The semi-structured interview has proliferated, diversified and evolved from a research strategy into a stand-alone method. A search of the frequency of published studies that used the semi-structured interview per decade since 1960 demonstrated a significant proliferation of this method beginning in 1990 and continuing to today. This search also revealed the increasing diversity of the disciplines that are using this method. However, the health professions, especially nursing, use this method the most. The paper provides a graph that visually depicts the frequency of use of the semi-structured interview per decade and the databases in which they appeared.

The literature review also revealed a diversification in the semi-structured interview method over time. Indeed, four types of semi-structured interviews were discerned in the literature: descriptive/confirmative, descriptive/interpretive, descriptive/corrective and descriptive/discerning. The semi-structured interview is useful to research with neo-positivist, critical and feminist and parsimonious phenomenological aims.

The unique construction of this type of interview makes it chameleon-like, amenable to qualitative, quantitative, and mixed methods research design to be used as a strategy in an overall research design, or a sequential or simultaneous supplement to the core in mixed method research. Its unique construction enables it to stand alone or as a single data-set mixed method research design. I conclude the paper by providing an overview of method used for constructing the semi-structured interview.

Conclusion

The semi-structured interview is an appropriate method to collect and analyze participants' perspectives of risk inherent in unstructured qualitative interviews.

Link to Other Research

The descriptive/corrective type of semi-structured interview identified in this paper was critically important to the design, implementation, and analysis of the data collected in the semi-structured interview study that followed.

Paper 3: Participants' Perspectives of Risk Inherent in Unstructured Qualitative Interviews.

Purpose

The purpose of the project is to ascertain participants' perspectives of risk inherent in unstructured qualitative interviews.

Methods

North American English-speaking adults who had previously participated in an unstructured qualitative interview regarding a sensitive or personal health-related topic constituted the participants for this study. Recruitment strategies comprised snowball sampling and direct recruitment. I invited qualitative health researchers to assist with the recruitment of participants in this study. In particular, researchers were invited to inform their former unstructured interview participants of my study. Interested participants could then contact me to indicate their willingness to participate in my study. Researchers were informed about the study electronically via online discussion groups and in person at conferences. I directly recruited participants by advertising my study e.g. in newspapers. (see Appendixes A-G). In total, 15 persons were willing to participate and 9 of these met the eligibility criteria. Participants were excluded because they had not actually participated in unstructured interviews but rather experimental studies, focus groups and structured interviews.

I used the semi-structured interview method to ascertain participants' perspectives and experiences of their research participation. I used an interview schedule to guide my interviews. I conducted all of the recorded interviews by telephone. The audiofiles were anonymized and transcribed verbatim. Data per item were amalgamated into separate data sets to facilitate content analysis. Unfortunately, the sample size for this study was too small to employ nonparametric statistical analysis to discover and verify patterns discerned in the content analysis.

Results

The preliminary findings of this dissertation research suggest that there are disjunctures between the dominant discursive conceptualization of risk to participants and participants' actual interview experiences. Foremost among these disjunctures is that predictions of harm to participants inherent in their participation in unstructured qualitative interviews are not borne out in participants' actual experiences. Furthermore, absolutist conceptualizations that participants are vulnerable, i.e. don't know enough to protect themselves, is an inaccurate and harmful maxim. Indeed, assumptions regarding the vulnerability of participants and their exemption from clinical research may themselves do harm: historically women have been excluded from clinical trials because of the complication of their menstrual cycles and/or their risk of pregnancy. This has resulted in androcentric research and implications e.g. knowledge regarding symptoms of myocardial infarction or risk of HIV transmission. The literature attests to the agency of other populations historically considered most vulnerable e.g. dying patients including children (Steele & Davies, 2006; Terry et al, 2006). This does not mean that there are no vulnerable people, but that these determinations ought be made not from the perspective of universal moral codes, but ethics committees should look at them from the perspectives of those being studied (van den Hoonaard, 2001). My tentative findings suggest that participants *are* capable of making decisions regarding interview participation that consider the potential risks to them; in addition, they mediate their risk throughout the interview by refusing to answer questions, withholding information they do not wish to share, and refusing to delve into deep reflection to avoid going to the "sore part" if they decide against it.

In addition, there are no topics so sensitive that they pose high risk of harm. Indeed, there is benefit to people in being able to share their experiences with someone bound by confidentiality. Otherwise, the sensitive nature of their experiences precludes

opportunities for sharing and therefore relegates participants to inhibit talking about their experience. For some this feels like "crumbling on the inside." Finally, the emergent design of the unstructured interview seems to confer protection upon participants rather than constituting risk to them. conceptualized as risky protective. It uniquely provides the participant with the freedom and control over the content and the process of telling their story.

Although participants experience emotional "upheavals of thought" during unstructured interviews, they seize the unique opportunity for participants to tell their story. The verbalization of their experience forces them to face or acknowledge their situation as well as their feelings about it. Most participants become emotionally distressed during the interview. One significant, albeit tentative, finding is the attribution of this distress: It is the talking about the situation and not the interview per se that evokes emotion. In addition, emotional distress is not a unitary negative-valence phenomenon but is a complex constellation; one participant described a "whole gamut of emotions." Crying was therefore only part of the emotions of distress concomitant with joy, relief, hope, and unburdening. Thus, emotional distress is not simply synonymous with harm, nor is it the opposite of benefit. Indeed, most participants experience the interviews as profoundly affecting, with emotion accompanying revelation and even transformation.

These preliminary findings corroborate as well as correct researchers' and REBs' conceptualization of risk to participants inherent in unstructured qualitative interviews. They might tentatively inform the current context of normative ethics oversight regarding social science research, in particular the definition of minimal risk and the utility of the proportionate review of risk regarding interviews. This tentative evidence might remedy "ethics creep" (Haggerty, 2004) and its deleterious impact on the production of qualitative research. In sum, these tentative findings might contribute to the assurance of

23

participant protection in unstructured interview research as well as the protection of

qualitative interview research in general.

Conclusion

The most significant finding, despite the small sample, is that although

participants reported distress, none reported actual harm. The implication of this for

research ethics governance is that the predictions of harm to participants in unstructured

qualitative interviews were not verified in actuality. In fact, these tentative results

indicate that the unstructured interview might be protective against harm by virtue of its

granting the freedom and control of the telling of the story to the participant.

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Research Ethics Boards and the Ethics of Emotion

by

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RESEARCH ETHICS BOARDS AND THE ETHICS OF EMOTION

In the research arena, research ethics boards (REBs) have accepted the responsibility to ensure that researchers "do no harm" to participants. Although this mandate is clear in the prevention of physical harm, for social science research that poses no physical risk but the possibility of psychological harm, the issues are less clear. Here, I consider what harm might result from interview research: the talking and listening that occurs in qualitative research interviews and is similar to that which occurs in everyday life. Regardless of researchers' statements about the benefits of qualitative inquiry, REBs consider that research requires oversight and participants need protection when participating in qualitative unstructured interviews.

I have selected unstructured interviews as the discussion point for this paper for several reasons: (a) it is a commonly used method of qualitative data collection, (b) it is a strategy that allows the participants the freedom to tell their stories without the researcher's control of a framework of questions to guide the interview, and (c) because of the emergent nature of these interviews, the research protocol is unspecified. Participants are free to delve into their innermost emotional lives to the level they choose and do so using their emotional voice. Here, I examine the ethics of this research method that evokes strong emotional responses from its participants. I consider if such emotions or manifestations of distress are detrimental to the participants and are caused by the researcher and/or the research context, and whether they are harmful. I consider the ethical frameworks within which REBs consider these issues.

REB's Mandate

REBs are mandated to ensure the protection of participants from harm while ensuring the production of socially beneficial research. This mandate is achieved by the development of a risk-benefit ratio, considering the risks to participants against the benefits to participants and society. This proportionate review must normally reveal

benefit, if not to the individual participant then to society, and should outweigh the risks to the individual.

Such a weighing of risk to benefit is problematic for social science research and in particular for qualitative inquiry. Although risks and benefits in biomedical research are believed to be quantifiable, this is not true for the cost of emotions such as psychological distress. REBs are further handicapped in risk assessments of participants' distress by an ethics-review process governed by guidelines that do not account for emotion. REB guidelines are dominated by positivistic assumptions that (a) are designed for the evaluation of experimental designs and standardized research; (b) consider that emotion, although worthy of investigation per se, is otherwise abjured within research. So emotional distress in interviews therefore is as an adverse side effect necessitating postinterview counselling; and (c) considers that the lay public as subjects are unable to protect themselves from risk (Kopelman, 2004) and that the REB alone is authorized to determine the level of risk to which a person should be exposed.

REB members are presumably humane, empathetic, and well intentioned; the proposed topics of inquiry, particularly those explored in nursing research, are heart rending. To review proposals that aim to ascertain participants' experiences and perspectives of such difficult issues as the death of their loved ones to drunk drivers, coping with the withdrawal of life support from loved ones declared brain dead, or the right of small children dying from cancer to die at home, vicariously exposes REB members to these circumstances and undoubtedly engages their sympathy towards the people who have experienced them. REB members worry that people who have already suffered will be retraumatized within the interview (Corbin & Morse, 2003). When

31

considering the possibility of harm, they use their moral imaginations[2] to place themselves in the shoes of the participants and make decisions "as if" they were the participants themselves. But REB members are not the participants, nor are they in a relational context with them. Such moral imaginings, therefore, might be inaccurate, unrestrained, and unverifiable.

In this situation, ethical theory provides insufficient guidance. Traditional ethical theory has not yet incorporated a well-developed theory of emotion (Nussbaum, 2001; Coecklebergh, 2007; Norvedt, 2004). Treatment-based counselling theory is inappropriate. Furthermore, there is scant literature on actual participants' experiences and outcomes from qualitative inquiry (Haggerty, 2004; Boothroyd, 2000; Brannen, 1993; NatCen, 2006; Carter, 2007; Lowes & Gill, 2006; McDonald, 2001). Although some qualitative researchers have documented benefits, including those to the participants, REBs relatively ignore these benefits and predominantly focus on the risk of harm (van den Hoonaard, 2001). Indeed, some REBs are so concerned about the risks of psychological harm to participants "that they require researchers to develop a priori strategies as a contingency should untoward effects occur, such as identifying counsellors for participant referral should the need arise" (Corbin & Morse, 2003, p. 336). They are concerned that the interview compounds suffering by increasing distress. Beyond REBs concern for the participant is their concern for institutional liability. REBs evidence a corporate perspective "in calculations of risk and in elimination of culpability and of potential legal 'exposure' " (Johnson & Altheide, 2002, p. 62). These issues might account for the fact that qualitative researchers proposing socially sensitive research are twice as likely as others to have their proposals rejected by REBs and that the foremost reason given for non-approval was the protection of human subjects (Ceci, Peters, &

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[2] Moral imagination means "an ability to imaginatively discern various possibilities for acting in a given situation and to envision the potential help and harm that are likely to result from a given act" (Johnson, 1993, p. 16).

Plotkin, 1985). Other researchers concur that the ethics review of sensitive research is problematic (Church, Shopes & Blanchard, 2002; Haggerty, 2004; Lincoln & Cannella, 2004; Shea, 2000; van den Hoonaard, 2001, 2002; Gunsalus, 2004; Gunsalus, Bruner, Burbules et al., 2007; St. Pierre, 2004). In 1985 Ceci, Peters and Plotlin found that sensitive topic research was twice as likely to be rejected by REBs on the basis of sociopolitical consequences).

<center>Unstructured Interviews and Emotional Distress</center>

Unstructured in-depth or narrative interviews are shared experiences in which researchers and interviewees come together to create an intimate context in which participants feel comfortable telling their story (Ramos, 1989). The unstructured interview begins with what Spradley (1979) referred to as a grand tour question: "Tell me. . ." Participants are provided with the freedom to tell their stories, beginning wherever they choose, selecting the topics they wish, describing as much detail as they want, and taking as long as they desire. Corbin and Morse (2003) identified the phases of the unstructured interview as: pre-interview, tentative, immersion, and emergence. During the pre-interview phase the researcher accomplishes such instrumental tasks as explaining the study to the participant, reviewing the consent form with him and arranging a time for the interview. In addition, the researcher and participants have an opportunity to assess each other and "begin to establish a degree of comfort and trust. Most importantly, it establishes the groundwork for reciprocity: the researcher and the participant agree to exchange information for bearing witness to the participants' story (Corbin & Morse, p. 341). The next phase, the tentative phase, marks the transition from the pre-interview to the interview itself. During this phase, the participant begins to tell their story, typically starting with background information before moving to more intimate disclosures. Corbin & Morse (2003) describe this process as the peeling back of layers of the persons' lives and events leading up to the event of interest. Participants

typically experience emotional distress during the phase of immersion, at which point "the telling might become distressful to the participant, the story provoking feelings of deep loss and grief, anger, or despair. An interviewee might cry or become too overwhelmed to go on" (p. 343). Indeed, many researchers have noted that becoming emotionally distressed is a characteristic feature of the unstructured interview (Boothroyd, 2000; Boothroyd & Best, 2003; Carter, Jordens, McGrath, & Little, 2008; Cook & Bosley, 1995; deMarrais & Tisdale, 2002; Dyregrov, 2004; Dyregrov, Dyregrov, & Raundalen, 2000; Lowes & Gill, 2006; Rager, 2005). Participants emerge from this phase and enter the emergence phase, which is characterized by less emotional intensity. Participants are not distressed throughout the entirety of the interview, nor do they leave the interview in a distressed state, but often leave feeling elated and relieved (Corbin & Morse, 2003). Furthermore, they do not experience emotional distress during other kinds of qualitative interviews, in particular focus groups or semistructured interviews, because in these forms the researcher has control of the interview agenda, and this prevents the person from entering a level of intimacy that enables the expression of distress.

Unstructured Interviews Evoke Emotional Distress

The unique characteristics of the unstructured interview elicit participants' emotional distress. Lee & Renzetti (1990) emphasize that the sensitive character of a piece of research seemingly inheres less in the topic itself and more in the relationship between that topic and the social context within which the research is conducted." (p. 5). Interviewers cultivate a high degree of trust and rapport with their participants. According to Harris and Huntington, (2001, p. 140). "Creating space for interviewees to discuss what is important for them, taking their concerns seriously into account, attending to nonverbal as well as verbal cues in interactions or ensuring that respondents understand the boundaries of the interaction may all facilitate the collection of high-quality information as they have an impact on the emotional tenor of the interaction." The

emergent nature of the interview may allow for the possibility of topics of discussion that induce negative mood states (Hadjistavropoulos & Smythe, 2001). Furthermore, unstructured interviews typically last an hour or more and this relatively long duration fosters intense focus upon the experience under study. The socio-spatial aspects of data collection including the face-to-face and private conditions established further contribute to the cultivation of an atmosphere conducive to participants' emotional disclosure of past traumatic and negative experiences (Sin, 2003). Unstructured qualitative interviews uniquely create a social context in which participants emotionally relive the experiences they are narrating.

Many of these features may be deliberately manipulated by the researcher to produce rich data (e.g., through the establishment of trust) despite the researcher's knowing that such conditions are likely to evoke distress This is the researcher's "culpability" (deMarrais & Tisdale, 2002) in a "Machiavellian" aim (Homan, 1992). Without a doubt, unstructured interviews establish conditions that are emotionally evocative, yet the question remains: Do unstructured interviews cause emotional distress?

Do Unstructured Interviews Cause Emotional Distress?

The problem with the question of whether interviews cause emotional distress is that implicit in the question is the dichotomization, or severance, of emotion from research. Although unstructured interviews can provide a context for emotional distress to occur, this does not mean that they cause emotional distress. Unstructured interviews invite people to tell stories of events from which they have suffered and are suffering. When participants are invited to tell these stories, they are aware that telling their stories will be emotionally distressing. Yet despite this knowledge, they accept these invitations. As one participant expressed it, "I was concerned about sharing such an emotional topic experience with a stranger—but in my heart knew that it was the right thing to do" (Cook

& Bosley, 1995, p. 166). Emotional distress is not a by-product of interview research, nor even an adverse side-effect or sequela of it. Rather, it is a part of the phenomenon.

Emotion Is Integral to Unstructured Interviews

Qualitative research is intimacy work, and as such, affect, emotion, and the senses are critical components. Indeed, some have asserted that emotion is the essence of qualitative research (Gilbert, 2001). Emotion, including distress, must therefore be ontologically and ethically understood within the context of the data collection; that is, the unstructured interview. Recently, Carter et al., (2008) identified three dimensions of their participants' experience of participation in their interview research: purposive/relational, epistemological/ontological, and emotional. Using these dimensions, I will explicate how the original event and emotion are integral to unstructured interview research.

Interviews Are Purposive

The first domain of participants' perspectives of participating in qualitative research was purposive and relational. "Participating made sense if by participating one helped people with whom one had a relationship" (Carter et al., 2008, p. 1273). Many participants report altruistic motives to explain their rationale in participating in interviews. Perhaps most poignantly, persons who were dying stated, "Not everyone gets the chance to know when they are dying, so I say yes let me help" and "It would be a way to give something back now before I die, I would have done something good for the future" (Terry, Olson, Ravenscroft, Wilss, & Boulton-Lewis, 2006, p. 408). Conversely, participants refuse to contribute to research whose substance or funding is aversive to them (Graham, Lewis, & Nicolaas, 2006).

There are numerous examples of participants hoping to help the researcher by participating in the study. Carter et al., (2008) quoted "Colin" (one of their participants) as saying, "I hope it helped *you* a great deal" (p. 1268). However, participants also

intended to help others they did not know personally but with whom they shared similar circumstances or who belonged to their community. For instance, injection drug users wanted to benefit the drug user community and improve drug-related policies and practices (Barratt, Norman, & Fry, 2007), parents of children with diabetes hoped their participation would "help future parents cope with it" (Lowes & Gill, 2006, p. 590), mothers who returned to the labour market after maternity leave associated the research project with the need to improve the situation for employed mothers and their children (Brannen, 1993), and Bosnian refugees living in Norway "felt a very strong solidarity with all refugees around the world and felt responsible for helping others" (Dyregrov et al., 2000, p. 418). Other participants intended to raise public awareness or educate those who were outside of their own community or circumstances to "provide real or true information about drug use" (Barratt, 2007, p. 236) or about what it was like to be a woman living with HIV/AIDS (Lather & Smithies, 1997). Dying persons wanted to share their intimate knowledge of pain: "I do feel I'm a bit of an expert in pain, in a way that someone who is not dying might not be" (Terry et al., 2006, p. 408).

In summary, participants are motivated to participate in interview research because they care about others they feel akin to and want to assist or do good for them. Because altruism emerged as a theme particularly in those interviews that addressed a difficult or traumatic situation, Graham et al., (2006) noted that emotional distress seemed to inspire altruism.

Purposiveness and relationality capture dimensions of research that likewise engage the emotional life of the researcher. Behar (1996) stated that it is only worthwhile doing research that "breaks your heart" (p. 161). Emotion provides the impetus to embark upon a research topic, but it drives it as well, from participant recruitment to conducting the interviews, to transcription, analysis, publication, and living with the results (DeMarrais & Tisdale, 2002; Ellis, 1995; Lather & Smithies, 1997; Rager, 2005).

Interviews Are Relational

Similar to a health care encounter, the interview brings into focus a particular kind of relation that connects strangers together in meaningful and even intimate ways (Bergum & Dossetor, 2005). Carter et al., (2008) noted that the relationship, built over time between interviewer and interviewee, clearly had emotional content and importance. Indeed, this emotional connection is an essential component of qualitative interview research. The literature provides some evidence of the importance of this relationship to interview participants: Participants stated that they wanted to be recruited by people they already knew, or they wanted the researcher to be someone with whom they already had an established clinical relationship, and, if there were to be repeat interviews in a study, the majority of participants preferred to have the same researcher conduct all interviews (Terry et al., 2006). For example, in Brannen's (1993) study, 56% of participants would have liked to have been interviewed each time by the same researcher; repeated encounters with the same researcher made the experience more personal, helped them to relax, or made it easier to talk. Participants did not want to have to reveal themselves or their circumstances to someone new, so the research would, in effect, be a product of an already established understanding or rapport.

The basis of this emotional connection is mutual respect. The etymology of the word *interview* is to see the other. Maykut and Morehouse (1994) have called on the researcher to understand the participant's point of view; other researchers have confirmed that qualitative inquiry is not a purely intellectual exercise but, rather, one for which researchers enter the world of their participants and, at least for a time, see life through their eyes (Rager, 2005). Gilbert (2001) advised researchers to connect with participants cognitively and emotionally.

The literature provides participants' testimonies of such relational engagement during interviews. Researchers were informed, knowledgeable, open, interested, and

understanding about the participants and their circumstances. In addition, participants appreciated researchers who were empathic, warm, caring, kind, gentle, human, sincere, and nonjudgmental (Cook & Bosley, 1995; Dyregrov et al., 2000); who were "not embarrassed by emotion" (Cook & Bosley, 1995, p. 166); "did not withdraw from our pain"; who were patient ("gave room for our sadness and crying"); and who inspired confidence and were skillful and professional ("posed the right questions") (Dyregrov, 2004, p. 6). Cook and Bosley wrote that the "empathic, open-ended style was very hopeful, including the researcher's ability to follow feelings and ideas which emerged through the interview process" (p. 166). Participants appreciate researchers who anticipate the potential for their emotional distress. Similarly, participants appreciate researchers who are flexible during the interview and offer further help and information (Dyregrov, 2004; Dyregrov et al., 2000; Lowes & Gill, 2006; Scott, Valery, Boyle, & Bain, 2002; Terry et al., 2006).

Researchers reciprocally experienced care and respect from their informants. Lather recalled the ameliorating effect her informants had on the emotional distress she experienced during her research investigating women with HIV/AIDS: "Two bad cries in such a project testifies to the work the angels did for me, their cooling comfort that let me get on with the book" (Lather & Smithies, 1997, p. 222).

Interviews Are Epistemological/Ontological

Through narrative we come into contact with our participants as people engaged in the process of interpreting themselves and seeking meaning in the events that are being suffered. The interviewer and the interviewee are connected, and intimacy is experienced through dialogue and intense listening. The interview becomes a particular kind of social relationship wherein both interviewer and participants engage in the co-construction of meaning (Mishler, 1986).

Unstructured interviews are sites of active, reflexive, and reconstitutive practice. The reconstruction of one's extreme experiences and one's self was inescapably emotional (Carter et al., 2008). Hiller and DiLuzio (2004) suggested that people are more likely to take part in research on a topic in which they have some ego involvement, where participation allows for reflection and articulation of their personal experiences, and where they have thoughts or feelings that have few outlets or little legitimacy in current communities of interaction. Dyregrov et al. (2000) similarly reported that before the interview two respondents thought that participation might help them to rethink and analyze their situation. Palliative care patients interviewed by Terry et al., (2006) wrote that research participation actively maintained their self-image: "Participating in research allowed patients to see themselves and to be seen by others as more than 'a dying person'" (p. 408). The participants stated, "If I'm part of a research I am still real, and if you doctors are doing research I know you think of me as real too" (p. 408). Other studies have corroborated the importance of interest or involvement in the research topic as an important dimension of interview participation (Brannen, 1993; Dyregrov et al., 2000). This dimension of research participation, in Carter et al.'s (2008) observation, was the richest and most compelling domain.

Researchers, too, have experienced the epistemological/ontological dimension of interviews. Lather and Smithies (1997) described the emergence of their "very personal need to negotiate a relationship to loss" during the course of their research project with women with HIV/AIDS (p. 221). Remarking on Lather's epistemological growth throughout the research project, Amber, one of Lather's informants, remarked "You've grown so much and gotten a lot smarter than when I first met you at the AIDS retreat" (p. vi). Finch (1984), as a result of conducting interviews with women, came to see her researcher-self as potentially dangerous to informants who put their trust in her and her motives.

Interviews Are Emotional

      Interview research invites participants to tell life stories, especially those that have deep and enduring meaning (Chase, 1995). It is theorized that this telling forces the respondent to relive the painful emotions associated with the original experience (Gordon, 1956; Morse 2002). Life stories are told through the dialogue of emotion as well as words, tears, silences, utterances, and facial expressions. According to de Marrais and Tisdale (2002),

> We found that in most of our interviews the troubling emotions of anger, frustration and anxiety were relived by the participants during the process of describing the anger incident. This reliving was expressed by participants in a variety of ways including direct references to "feeling or experiencing the anger again" as well as physical exhibitions in the form of flushed face and neck, shortness of breath, sweaty palms, and facial expressions indicating discomfort, frustration or anger. (p. 118)

Painful life circumstances are painfully recalled and retold. Life stories are not, like reports, disconnected from life circumstances but remain embedded in them (Chase, 1995).

      Researchers hear, see, feel, and bear witness to the life stories participants tell. Rager (2005), discussing her interviews with women who had breast cancer, reported how emotionally drained she was after each interview and how she experienced physical ailments, including pain in her right breast. Similarly, a colleague, in reading her dissertation draft, reported that she, too, was emotionally and similarly physically affected. Lather recalled, "Over the course of this project, I broke down badly twice . . . broke down, crying" (Lather & Smithies, 1997, p. 221). The researcher, too, is an embodied subjectivity: "I remember reaching out to touch Linda's hand as she spoke. I

also remember the tears running down my own cheeks as I listened with both my head and my heart to what she was sharing" (Rager, 2005, p. 23).

This emotional distress is but part of an emotional repertoire that are evoked during unstructured interviews. Although participants experienced interviews as significant emotional events, they did not regard their emotional distress as the most significant aspect of their research participation (Carter et al., 2008).

Emotional Distress Is Integral to Participants' Experience of Participation in Interviews

Within the context of relational engagement during the interview, participants are invited to tell "life stories" defined as "narratives about some life experience that is of deep and abiding interest to the interviewee" (Chase, 1995, p. 2). Participants who accept this invitation also assume responsibility for the import of its meaning (Chase, 1995). Participants tell their story and communicate its import with their emotional voice. The telling of these experiences requires the participant to relive them; this includes the re-experiencing of the emotion originally felt (Morse, 2002). Emotional distress is integral to emotionally distressing circumstances; emotional distress is likewise integral to the telling of these circumstances in interviews that invite them. More than this, however, emotional distress is integral to participants' responses to interview participation; it underpins and interconnects all of the dimensions of participants' participation in interviews. Emotional distress motivates purposive participation, creates relational connections, facilitates self-knowledge of participants' and their experiences, and expresses its voice in the emotional space afforded by the interview (Carter et al., 2008). It is a gross simplification, therefore, to conceptualize emotional distress as a mere component, by-product or adverse effect of unstructured interviews. Emotional distress is central to unstructured interview research (Gilbert, 2001). If the cardinal sign of

worthwhile research is that "it breaks your heart" (Behar, 1996, p. 161), then emotional

distress is the cardinal sign of worthwhile interview research.

Is Emotional Distress Harm?

A paradox is consistently identified in the emerging literature exploring

participants' perspectives of their participation in interview research (Carter, et al., 2008;

Graham et al., 2006). Emotional distress, described by participants as hard, painful, sad,

nervous, angry, and upsetting (Boothroyd & Best, 2003; Cook & Bosley, 1995;

Dyregrov, 2004; Dyregrov et al., 2000; Parslow, Jorn, O'Toole, Marshall, & Grayson,

2000; Scott et al., 2002), was not experienced as adverse or harmful. Furthermore,

emotional distress coexisted with positive, beneficial experiences of interview

participation. Most participants who experienced emotional distress as a response to their

participation in interviews evaluate their interview experience as "positive" and

"beneficial" (Bruzy, Ault, & Segal, 1997; Cook & Bosley, 1995; Corbin & Morse, 2003;

Cowles, 1988; Dyregrov, 2004; Dyregrov et al., 2000; Honeycutt, 1995; Kavanaugh &

Ayers, 1998; Lee & Renzetti, 1990; Lowes & Gill, 2006; Wong, 1998). For example, a

participant in Dyregrov et al.'s study stated, "It hurts to talk, but it also feels good and we

need to talk" (p. 415); other participants concurred: "Through the interview I could go

through all the details again. That felt good. At the same time, it was painful in many

ways" (Dyregrov, 2004, p. 6). How can emotional distress not be considered harmful?

Furthermore, how can it coexist with evaluations of interview experiences as positive and

beneficial?

This paradox exists only within a conceptualization of emotions as distinctly

positive or negative. Contemporary Western scholars have inherited valence and polarity

as predominant notions of emotions (Solomon & Stone, 2002). Researchers have

suggested a complex relationship between emotional distress and positive benefits of

participation (Hutchinson, Wilson, & Wilson, 1994).

In the section that follows, I will argue that valence and polarity conceptualizations of emotion are too simplistic to account for the complexity of emotion. Emotional distress is not a simple negatively valenced emotion. Emotional distress is a "mixed feeling," not only in the sense of one emotion coupled with another; within the constellation of emotions that constitute distress, there are polyvalences. Pain and pleasure are too complex, multidimensional, contextually determined, and qualitative than one-dimensional valences can allow (Solomon & Stone, 2002). Emotional distress therefore cannot be understood simply in terms of negative emotion or, indeed, as harm. Ethical approaches that require seeing emotion in these ways are inadequate to make ethical decisions about emotional distress in interview research

Emotional Valence and Polarity

"The distinction between 'positive' and 'negative' emotions is as ancient as talk about emotions, and it was, under the rubric of virtue and vice, the hallmark of medieval theories of emotion" (Solomon & Stone, 2002, p. 417). Today the distinction is evident in everyday speech as well as in such sophisticated discussions as professional social science and nursing research publications and the ethics review of scientific research. It enters into these discussions through the concept of valence.

> From a global perspective, it seems that past research on emotion converges on only two generalizations. One is that emotion consists of arousal and appraisal. The other, emerging from the scaling literature, is that any dimensional characterization of emotions is likely to include at least the two dimensions of *activation* and *valence* . . . [But] the valence dimension [is] the dimension of appraisal. (Ortony, Clore, & Collins, 1988, p. 6)

Thus, valence refers to the appraisal of an emotion as positive or negative, possessing a net positive or net negative charge. Although this positive-negative polarity

has its origins in Aristotelian ethics and not in the scientific study of emotion, it has taken on the vernacular of chemistry to serve its purposes, which might include an attempt to enhance the concept scientifically (Solomon & Stone, 2002).

Related to the notion of valence is that of emotional polarity, or opposites. Emotions with positive valences are good, pleasure, happy, conducive to happiness, positive attitude to self, healthy, and so on. Negatively valenced emotions are bad, pain, sad, "upset," conducive to unhappiness, and negative attitude to self. Furthermore, pleasure is the emotional opposite of pain. These conceptualizations of emotion, valence, and polarity are evident in discussions of participants' responses to research participation; that is, benefits are "positive," and harms are "negative" (Boothroyd & Best, 2003; Cook & Bosley, 1995; Dyregrov, 2004; Dyregrov et al., 2000). Emotional distress, as described by participants as pain, sadness, anxiety, anger, and upset, is clearly regarded by REBs to possess a negative valence and thus must be the polar opposite of positively valenced emotions such as those constituting benefit.

This brings us back to the paradox. Clearly there is a problem with such conceptualizations of emotion and participants' experiences of them. Indeed, valence and polarity notions of emotion are too simplistic and superficial to account for the complexity of emotion. This is not, however, to dispute "that there is no such thing as valence or no such polarity or contrasts, but rather that there are *many* such polarities and contrasts" (Solomon & Stone, 2002, p. 418).

Context and Consequences of Emotional Distress

The context and circumstances of the emotion are too often confused with the emotion itself. I have already argued that unstructured interviews typically invite participants to tell a life story of human suffering and participants become emotionally distressed in the telling of these stories. How can such a clear example of distress be ambiguous?

45

Suppose the circumstances of the narration involve the tragic diagnosis of a child with a terminal illness. The participant, the child's mother, is clearly grief stricken. However, is grief, in this context, a negative emotion? Many theorists would argue that it is a negative emotion, a "bad" emotion, on the grounds that the circumstances provoking it tend to be threatening to one's well-being, but it does not follow from the fact that the circumstances that provoke grief might be bad for us that the emotion of grief itself is bad for us. The emotion of grief might even be perceived as a good emotion if it propels us toward healing or is cathartic. Aristotle (1985), in his *Ethics*, used the example of fear in the same way: Although the circumstances that incite it might be life threatening, the emotion itself enables one to escape such circumstances. Furthermore, he posited catharsis as an explanation for why Greek citizens would willingly attend terrifying plays; that is, because it was good for them. The same cathartic incentive might explain why people who experience adverse circumstances agree to be interviewed to talk about them. The circumstances that provoke emotions may be bad, but the emotion might not be. Emotional distress, therefore, cannot be conceptualized as negative simply in view of the bad circumstances that caused it.

Good and bad emotions can also refer to their various consequences: that they are good or bad for us. Consider the emotion of being upset. Much social science, as well as clinical research, fosters the notion that negative emotions make us upset whereas the positive emotions do not (Solomon & Stone, 2002), but upset is also highly ambiguous. Does it refer to the state of being agitated or excited (in which case, it may be incited by joy or irritation or anxiety), or does upset refer to the object of emotion that is upsetting? In the latter case, Solomon and Stone noted, this upset is a matter of appraisal, not arousal. This implies that the "evaluational baggage" (p. 421) of REBs when considering participants' emotional upset reduces the complexity of emotional distress to one simplistic, superficial feature.

Distinguishing positive-negative emotions by their consequences does not consider subjective relativism. Emotion that makes a "person well or happy or ill and unhappy is a very individual matter depending on context and upbringing and history and culture and religion and all sorts of things" (Solomon & Stone, 2002, p. 422). Terry et al. (2006), investigating hospice patients' views on research in palliative care, starkly contrasted how palliative patients regarded harm and benefit of research participation with the views of ethicists. Some ethicists asserted that terminally ill patients with fewer than 6 months to live should be disqualified from human subjects research because they are too desperate to be able to distinguish research from treatment (Annas, 1996). In essence, such ethicists believe that terminally ill persons are vulnerable to false hope, that is, hope for the prolongation of life. Terry et al.'s (2006) surprising finding was that "our patients regarded the possibility of an unexpected prolongation of life as an adverse event rather than as a benefit" (p. 412). Thus, the experience of emotional distress is relative to the person experiencing it. Does emotional distress constitute harm? It depends on whom you ask.

Is Emotional Distress Intrinsically "Painful"?

Can emotional distress be conceptualized in terms other than circumstances and consequences? Can emotional distress be intrinsically negative? If emotional distress is intrinsically negative, where is this negativity located? Early philosophers, in particular Spinoza (1985) and David Hume (1955), located goodness or badness of emotion in the intrinsic sensations (or "impressions") of pleasure and pain. Thus Frijda (1986) insisted that there are just two experiential emotional qualia, pleasure and pain. Others similarly have taken the pleasure-pain polarity as primary in theorizing basic emotions (Solomon & Stone, 2002).

Solomon and Stone (2002) posed the question whether pleasure and pain are true polarities and in what sense can they be compared as well as contrasted:

The technical notion of "valence" makes it quite clear that pleasure and pain are

quantifiable features of an emotion, very much along the lines of the old

"happiness calculus" invented by Jeremy Bentham and the English Utilitarians.

Pleasure is positive and pain is negative, both come in degrees or quantities and

pleasures and pains can be juxtaposed and compared on a single measuring scale.

(p. 423)

Certainly, utilitarianism is a central ethical perspective in REB guidelines; REBs regard

emotional distress in such one-dimensional terms: Their proportionate review of risk

compares the pain of participant emotional distress with the pleasure of socially

beneficial knowledge. Furthermore,

Bentham ingeniously laid out a list of dimensions of pleasure and pain such as

intensity, duration, certainty, proximity, fecundity, and purity, and insisted that

the number of people whose interests are involved be included, but the result was

a single value on a single scale with the most pleasure at the top end and pure

pain at the bottom. (Solomon & Stone, 2002, p. 423)

Bentham's dimensions of pain are still used in REBs' proportionate review of

participants' emotional distress; that is, how painful was the emotional distress? Does it

persist after the interview and for how long? How certain is it that participants will

experience this in unstructured interviews? Does the timing of the interview to the

adverse event make a difference in participants' experience of distress? Thus, pleasure

and pain are conceptualized in one-dimensional terms.

Consider the benefits or pleasures of interview participation. Participants have

reported experiencing interviews as beneficial (Carter et al., 2008; Graham et al., 2006).

The various benefits include catharsis ("the expression of which provides a sense of

relief"), self-acknowledgement ("validation as an individual with integrity and worth"), a sense of purpose ("feeling good about sharing information with researchers that may in turn by shared with other professionals or lay people through publication and presentations"), and facilitating ("movement and change") (Hutchinson et al., 1994, p. 161-4). These benefits or pleasures are qualitatively different and therefore cannot be quantitatively calculated.

Moreover, these pleasures are not simple positive valences. For example, the benefit (pleasure) of self-understanding is multi-valenced. Participants have acknowledged that interviews were thought provoking and catalyzed insight and self-realization, providing an altered perspective (Carter et al., 2008). The experience of being interviewed enabled participants (new mothers re-entering the labour market) to reflect on their return to work after childbirth and reassess their roles as mothers, workers, and partners. As one woman said, it had made her realize which parent spent most time with the child, whereas another noted a number of changes. Reflection enabled participants to articulate issues of worry and concern for them (Brannen, 1993). Nevertheless, such realization is not entirely positive as the worries and concern were highlighted. Solomon and Stone (2002) argued "pleasure and pain are often far more complex, multi-dimensional, contextually determined, and 'qualitative' than the Benthamite calculus would suggest" (p. 424).

Emotional pain or suffering is interpretive: "We compare pains and measure suffering not just by gauging how much they 'hurt,' but by bringing in all sorts of contextual considerations and cultural expectations" (Solomon & Stone, 2002, p. 425). A review of the literature exploring participants' perspectives of interviews (Graham et al., 2006) noted, "Feelings of altruism can outweigh anxieties or anticipated pain involved in participation and lead people to participate in research even though they suspect it will be personally distressing" (pp. 9–10). For example, Dyregrov et al.'s (2000) study among

refugees in Norway found that most participants reported being "anxious, tense and curious" (p. 420) about the interviews before participating but still rated the potential benefits for others as an important motivation. In Scott et al.'s (2002) study, 47% reported anticipating that research interviews would be painful. However, 94% said they felt eager to participate, and 98% that their participation would be beneficial to others. Thus, emotional pain is measured within the context of altruism.

Despite the dominant view that all positive and negative emotions are reduced to the polarity of pleasure and pain, Solomon and Stone (2002) have cogently argued that pleasure and pain do not form a simple polarity and are in no singular sense "opposites." Nor does the rich texture of most emotions allow the assigning of a single valence on the basis of pleasures and pains.

> It is an essential datum in the study of emotions, this phenomenon of "mixed feelings," but this does not just mean one emotion coupled with another. Within the emotions, there can be a number of different "valences," even in terms of pleasure and pain. (p. 425).

Participants' responses to interview participation bear out this argument. Emotional distress is hard, pain, sad, nervous, anxious, and angry, yet none of these emotions are singularly painful valences, nor are they in any singular sense opposite to pleasure. Indeed, the paradox of participants' responses to interview participation is that emotional distress coexists with benefits. Emotional distress is a richly textured, polyvalent emotion that defies simplistic assignments of negativity and harm.

Are Unstructured Interviews Unethical?

Institutional review boards are concerned about the emotional distress that participants typically experience in unstructured qualitative interviews. This concern for the human protection of participants has caused REBs to refuse approval for sensitive

research (Ceci et al., 1985). Clearly, in these cases, REBs regarded emotional distress as harmful and proportionately greater than the benefits to the participants and to society through the knowledge that might have been produced from such research. However, how was this proportionate review of the risk of harm portended by emotional distress conducted?

Utilitarianism is a dominant ethical perspective in ethics guidelines; it underpins the proportionate review of risk. Utilitarianism assesses the morality of actions or policies based on their effects or consequences (Beauchamp & Childress, 2001). REBs employ utilitarianism to review the risk of harm posed to participants by emotional distress in unstructured interviews. All of the potential good (benefits) outcomes to all concerned are compared to all of the bad (harms) that could ensue to all concerned, in particular to the participants. The morally required or "ethical" action or policy is that which produces the best outcomes. Some utilitarians use the standards of happiness and unhappiness to assess whether consequences are good or bad, whereas others judge consequences in terms of whether they produce pleasure or pain. In any case, utilitarianism works with such standards conceptualized as one-dimensional constructs that can be plotted on a risk-benefit valence scale. Such ethical reasoning that includes the conceptualization of emotional distress as one-dimensional may conclude that unstructured interviews are unethical if they evoke emotional distress. However, as our earlier argument has shown that emotional distress is complex, multidimensional, contextually determined, and "qualitative," a utilitarian calculus is too crude to be employed for such ethical decisions regarding it. Flawed moral reasoning can lead to unethical decisions.

Traditional ethical theories, perspectives, and principles are insufficient for making ethical decisions regarding emotional distress in interview contexts. These perspectives are too acontextual, objective, absolute, rational, and universal to inform the emotional context of the research interview. Rather, an ethical perspective that is

inclusive of emotion and context is required. Emotion is integral to interview research; therefore, emotions may, in themselves, be drawn on to ensure participant protection within moral interviews. Furthermore, as emotion is subjective, contextual, and interpretive, this "upheaval of thought" (Nussbaum, 2001, p. 1) must be included in moral reasoning about emotional distress in interview research. Indeed,

> If emotions are suffused with intelligence and discernment, and if they contain in themselves an awareness of value or importance, they cannot, for example, easily be sidelined in accounts of ethical judgment, as so often they have been in the history of philosophy. Instead of viewing morality as a system of principles to be grasped by the detached intellect, and emotions as motivations that either support or subvert our choice to act according to principle, we will have to consider emotions as part and parcel of the system of ethical reasoning. We cannot plausibly omit them . . . We will have to grapple with the messy material of grief and love, anger and fear and the role these tumultuous experiences play in thought about the good and the just. (pp. 1–2)

Emotion is a crucial component to moral reasoning about participants' distress in unstructured interviews as well as the moral conduct of the interviews themselves.

Despite the painful aspects of the interview, participants appraise the emotional experience of interview participation positively. This is in large part, I suspect, because interviews were emotionally informed e.g. participants' emotionally conveyed their suffering and researchers empathically responded to it. This perspective, the ethics of emotion, may both augment REBs moral reasoning regarding such ethical issues as participants' distress and assuage REBs compassionate concern for the vulnerability of participants in sensitive research.

Toward an Ethics of Emotion

Emotion enhances the moral performance of the interview. They enable the researcher to perceive, judge, and act with a moral attitude (Vetlesen, 1994). Acting morally, however, presupposes moral sensitivity; that is, the morally relevant features of a situation are properly recognized. "In short, moral excellence is based on *perceiving* the salient features of the situation so that *moral judgments* can be sufficiently reliable and so that the *action* itself can display proper respect for the person's dignity" (Nortvedt, 2001, p. 448, emphasis added). Thus, moral sensitivity is the basis for moral judgment and action: how we care for the other. Emotions are an essential component of moral sensitivity and must augment the role of the intellect in moral sensitivity and judgment. The cognitive, affective, and moral dimensions of emotion enable the researcher to comprehend the situation of the participant, to emotionally engage with their emotional distress, and be morally responsive to the participant, thereby ensuring their protection.

Emotions uniquely capture the human import of a situation, which is the true personal significance of human experience (Taylor, 1985). Emotion contributes to moral sensitivity by facilitating the understanding of the significance of an experience to an individual and also because it motivates genuine personal human involvement in another person's situation. The external manifestations of the participants' emotional distress signify and communicate the importance of the experience to them. Their emotional distress engages the altruistic emotions of the researcher, their compassion, empathy, and concern (Blum, 1980). The researchers' emotional engagement enables them to appreciate the other's situation and the degree of significance the pain has to the person who experienced it. Compassion reflects the ordeal and painfulness of human suffering (Nortvedt, 2001). This moral understanding could not be achieved without the researcher's emotional engagement with the participant. Recently moral philosophy has conceptualized ethics in terms of reasoning and justification of actions, thereby missing

an important aspect of morality (Blum 1994; Vetlesen, 1994). Although knowledge, thinking, reflection, and cognitive imagination are important, they are not sufficient. To reason about difficult moral cases and also to perceive what is morally at stake in situations of caring for others, emotion is needed to engage one personally (Nortvedt, 2001).

Human beings are able to respond emotionally to another person's distress because we are relationally and emotionally attached to them. Empathy is defined as an affective response to the human condition of others and a cognitive way of understanding other people's experiences (Hoffman, 2000). Empathy as an affective dimension of emotional sensitivity is sensory, impulse based, and immediate. "This impulse is what works when we feel the hurt of someone else as an aching in our own body" (Nortvedt, 2001, p. 456). Researchers on empathy often describe this affective moral impulse as an empathic distress response—the involuntary and forceful experiencing of another's emotion—the distress is often contingent not on our own but someone else's painful experience (Hoffman, 2000). Our capacity to be moved by the emotional distress of another is critical to moral agency. "Emotions anchor us to the ethically relevant aspects of a situation so that our rational judgments can be fully informed" (Nortvedt, 2001, p. 456).

Sometimes, researchers' emotional responses indicate an ethical dilemma (deMarrais and Tisdale, 2000). deMarrais and Tisdale stated, "Emotions shown within the interview itself can be a signal to researchers to examine their practices as researchers and attend to the human needs of participants" (p. 120). Empathically informed judgment is exemplified in Carter et al.'s (2008) decision to allow a participant the freedom to continue with the interviews despite the acuity of his suffering heightened by the death of his wife that was so intense it upset the research team. "We *felt* it was important to respect Henry by allowing him to make his own decisions about continuing participation,

while repeatedly emphasizing non-obligation and the ability to discontinue at any time"
(p. 1271, emphasis added). In a similar way, emotions facilitate participants' self-
protection. In a study investigating children's experiences of participating in interviews
regarding their history of sexual abuse, a young female participant described how
emotions helped her to discern danger in a given question. She said that when she felt
like she was going to faint, she knew not to answer (Heltne, 2007).

Emotion has an important role in moral action and motivation. "Emotional
motivation is significant both because it makes us care for a person's well being and also
because emotion helps us care with the proper attitude" (Nortvedt, 2001, p. 461).
Aristotle (1985) stated that having virtue is virtue of character. A morally virtuous person
acts for the right reason and with the right emotion. The virtuous researcher is well
motivated to commit to caring behaviour toward the participant. The researcher's
emotional attitude shapes the tone, atmosphere, and attitude of interviews, creating the
necessary respect and attentiveness that allow the participants' needs to be addressed.
Indeed, when asked what researchers had done or said that was most helpful during the
interview the participants indicated, "empathy, warmth, kindness, humanity, knowledge,
understanding, and a nonjudgmental and interested *attitude*" (Dyregrov et al., 2000, p.
418, emphasis added).

Do Participants' in Unstructured Interviews Need Protection?

All people who volunteer to participate in scientific research require protection
from harm, including participants in interview-based research. Qualitative researchers
have been criticized for wielding a moral superiority (Kvale, 1996). Although they
asserted that the harms participants risk by participation in interview research are no
greater than those in everyday life (and are of lesser risk than clinical research), risks to
participants exist. For example, betrayal or exploitation or lack of reciprocity can ensue
from the lack of moral respect for research participants (Ellis, 1995).

Ethical oversight of interview research must encompass a wide terrain of ethical perspectives, principles such as informed consent (autonomy) and nonmaleficence remain critical; traditional theories such as deontology also have a role, but these must be augmented by the ethic of emotions. The protection of participants who participate in unstructured interviews is optimized when they and their stories are attended to both cognitively and emotionally, with minds and hearts.

The development of an adequate ethical theory hinges on the development of an adequate theory of emotions, including "their sometimes unpredictable and disorderly operation in the daily life of human beings" (Nussbaum, 2001, p. 2). Nussbaum advised turning toward such texts as literature and music to be able to imagine such emotional upheavals of thought in our own lives to "understand ourselves well enough to talk good sense in ethics" (p. 2). Yet the stories of human suffering told in unstructured interviews in qualitative inquiry provide other such texts to inform the role "tumultuous experiences play in thought about the good and the just" (p. 2). Moreover, the people who share their stories are also instructive: They remind us that stories have an essential role in a just, human society.

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The Diversification, Utilization and Construction of the Semi-structured Interview

by

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THE DIVERSIFICATION, UTILIZATION AND CONSTRUCTION OF THE

SEMI-STRUCTURED INTERVIEW

Beginning in the 1990's semi-structured interview research has proliferated, diversified and evolved from a research strategy to an independent research method. In addition, semi-structured interviews have become increasingly utilized by a multiplicity of disciplines. Its unique semi-structure affords it an affinity with qualitative, quantitative and mixed method research. Unfettered by any foundational philosophical commitments, the semi-structured interview can accommodate a multiplicity of philosophical assumptions reflecting feminist, critical, phenomenological and neo-positivist aims. The purpose of semi-structured interviews is to ascertain participants' perspectives regarding an experience that is the topic of the research. Beyond that common denominator, however, semi-structured interviews have diversified into different types, each uniquely oriented to assessing, confirming, validating, refuting or elaborating upon existing knowledge and the discovery of new knowledge. Furthermore, the contemporary semi-structured interview is empathetic and politically engaged. The diverse types of semi-structured interviews produce knowledge that is politically active, taking the stance of the participants and committed to improving their lives. Given the increasing popularity of this method and the potential for it to produce knowledge congruent with the social justice aims that characterizes qualitative inquiry overall, it is essential that this method is conducted well so that its results are strong.

Paradoxically, despite the frequency of its use and the significance of its contribution, the method itself and the explication of the method, lack description in the literature. In this article, as background, I first explore the evolution, proliferation and diversification and utilization of the semi-structured interview as a research method.

Finally, I address this current gap in the literature by discussing procedures for constructing a semi-structured interview.

What is the semi-structured interview?

The semi-structured interview is designed to ascertain subjective responses from persons regarding a particular situation or phenomenon they have experienced. They are used when there is sufficient 'objective' knowledge about an experience or phenomenon, but the 'subjective' knowledge is lacking (Merton & Kendall, 1946; Morse & Field, 1995; Richards & Morse, 2007). The semi-structured interview employs an interview guide or schedule. Analysis of the objective knowledge constitutes the framework for the development of this guide and foci for the development of the interview questions. The interview questions focus the responses of each participant and constitute the *structure* of the semi-structured interview. Participants are free to respond to these questions as they wish and the researcher is free to probe these responses; this flexibility constitutes the *semi-structured* aspect of this method. The semi-structured interview is unique amongst interview methods in the degree of relevancy it provides to the topic under investigation while remaining responsive to the participant (Bartholomew, Henderson & Marcia, 2000).

Analytically the semi-structured interview is characterized by comparison, usually by comparing participant responses by item. Since all participants are asked the same questions, data collected are comparable, and may be quantified.

The type of data derived from semi-structured interviews cannot be obtained using structured questionnaires, participant observation or analysis of the literature, although semi-structured interviews may be combined with these other data collection strategies. Neither can these data be obtained through unstructured interviews as the semi-structured interview participants' responses are directed to specific areas of inquiry.

Evolution of the semi-structured interview

The historical antecedent of the contemporary semi-structured interview is the "focused interview" conceived of, and procedurally advanced by Robert Merton and Patricia Kendall in 1946. The focused interview arose out of studies of the social and psychological effects of mass communications—radio, print and film (Merton & Kendall, 1946, p. 541). Its initial purpose was to provide some basis for interpreting statistically significant effects of mass communications.

Merton and Kendall (1946) outline the character of such applications by examining the role of the focused interview at four distinct points: 1) specifying the effective stimulus; 2) interpreting discrepancies between anticipated and actual effects; 3) interpreting discrepancies between prevailing effects and effects among subgroups—(i.e. "deviant cases"); and 4) interpreting processes involved in experimentally induced effects. These original roles of the focused interview constitute the antecedents for the contemporary types of semi-structured interviews that are described later.

The empathetic turn of the interview

The "empathetic" turn of the interview refers to a shift in the interview from a neutral stance to one of political involvement (Fontana & Frey, 2005, p. 696). "Empathetic interviewing takes an ethical stance in favor of the individual or group being studied. The interviewer becomes an advocate and partner in the study, hoping to be able to use the results to advocate social policies and ameliorate the conditions of the interviewee" (Fontana & Frey, 2005, p. 696). This empathetic turn became a key catalyst in the diversification of semi-structured interviews.

Philosophical foundation for the semi-structured interview

Traditionally, a required component for a mature method was that it be underpinned by a philosophical foundation, as, for instance, cultural theory underpins ethnography (Richards & Morse, 2007). This requirement now appears to be changing.

For instance, Charmaz (2009) suggests that grounded theory strategies may be used with other theoretical starting points and states that "few subscribe to symbolic inter-actionist theoretical orthodoxy" (p. 134). Similarly, Kvale (1996) observed that a "phenomenological approach in a general non-philosophical sense" is prevalent in qualitative research (p. 52). This non-adherence of qualitative research methods to a unitary and explicit philosophical foundation, however, does not mean that research practice is uninformed or not influenced by a variety of philosophical perspectives—or that it is underdeveloped (Avis, 2003).

Semi-structured interviews, like all qualitative research methods, involve practices that develop, are molded and mature with use. The emergence of various typologies of semi-structured interviews are, in part, distinguished by their unique philosophical influences derived from quantitative and qualitative paradigms—neo-positivism, dialectics and phenomenology in particular. Semi-structured interviews involve principles-in-practice (Seale, Gobo, Gubrium & Silverman, 2004). Such principles are not de-contextualized nor abstracted from the research itself but appear as assumptions, and are reflected in the methodological strategies used. As research practice expands so too do the philosophical principles it draws from to guide it. Philosophical issues are similarly informed by research practice. In this way, both method and philosophy advance and mature. Therefore, semi-structured interviews as present day practice are informed by assumptions but at this stage do not adhere to a unitary, explicit philosophical foundation.

Affinity of semi-structured interviews to the quantitative paradigm

The focused interview was originally conjoined with experimental science, constituting the interpretive component to the statistical analysis. Contemporarily, the semi-structured interview maintains this affinity to the quantitative paradigm—it has the structure, sample size, and suitability for quantification that appeals to quantitative

researchers and it is the most frequent qualitative method included in mixed method research (Bryman, 2006). Similarly, the semi-structured interview method is more compatible with research ethics review that itself privileges quantitative research and is incongruent with the unpredictability of the emergent designs of in-depth interviews. Thus the semi-structured interview has been able to accommodate the current political conditions that threaten other types of qualitative research.

The Diversification of the Semi-structured Interview

The semi-structured interview has both proliferated and diversified over that past few decades[1]. Figure 2.0 demonstrates that there has been a rapid increase in semi-structured interview research beginning in 1960 and continuing to today.

Figure 2.0: Frequency of semi-structured interviews

	1960-69	1970-79	1980-89	1990-99	2000-09
CINAHL	29	99	34	2519	14040
Sage	6	18	47	208	1370
PsychInfo	2	17	39	448	1410
Web of Science	0	0	0	90	424
Eric	0	11	11	29	142
Sociological Abstracts	5	5	2	2	70

Decade

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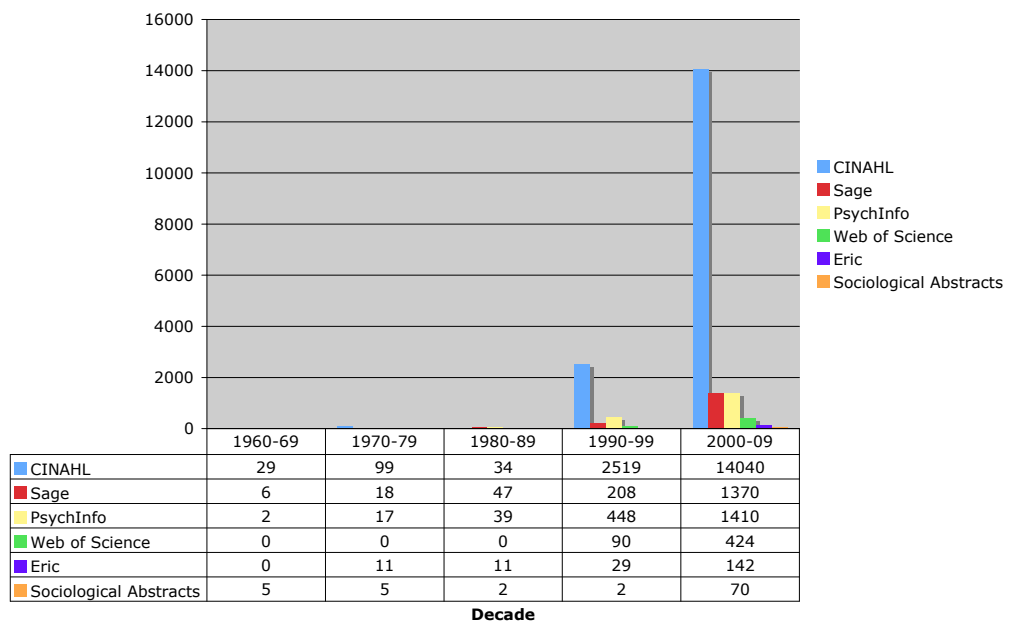
[1] I asked: 1) How many semi-structured interview studies were reported per decade since 1960. To illustrate the historical trend in the use of this research method I searched the following databases: Eric, PsychInfo, Sociological Abstracts, Sage, Web of Science, CINAHL. Semi-structured interview was the main subject heading and key word. Searches were run per decade from 1960 to 2009 (see Figure 2.0).

While reviewing the literature in which semi-structured interviews are used, I observed the apparent confusion among researchers regarding what constitutes a semi-structured interview and its distinction from other types of interviews such as the guided interview. The semi-structured interview is defined by its construction and use of an interview guide. The interview guide reflects the foci of the content analysis of the experience that is the domain of the research inquiry and lists the questions that will be asked of each participant. A guided interview, on the other hand, does not use an interview guide but has a loosely organized list of questions or topics it intends to cover. A guided interview often begins with a grand tour question and then, depending upon the participants' response, those questions may or may not be asked. This is different than for a semi-structured interview where it is critical to the analysis that its data is comparable. All data must be aggregated by item, hence it is vital that each item is posed to each participant to ascertain their response.

The hybrid terms "in-depth, face-to-face, semi-structured interviews" also cause confusion. Since semi-structured interviews do provide the participants with the freedom to answer the open-ended questions as they wish, their responses are often in-depth. Semi-structured interviews may take as much time as in-depth interviews. In-depth interviews, however, do not focus the participants' responses to any particular aspect of their experience, the data is not collected by item and the analysis does not proceed by content analysis per item. In-depth, guided and semi-structured interviews are disparate interview types that must not be conflated.

Current types of semi-structured interviews

A diversification of semi-structured interviews has paralleled its proliferation. Examination of studies that used the semi-structured interview as method revealed the following typology. The different types of semi-structured interviews were differentiated according to their purposes, their epistemological privileging of the established

68

knowledge implicit in the interview guide or the knowledge of the participant(s), the role

of the participants and the outcome of the research.

These characteristics enabled me to construct a typology that may be used as a

heuristic device with which to communicate this diversity (Table 2.0). As I previously

mentioned, the historical antecedents of these types of semi-structured interviews seem to

be the focused interview.

Table 2.0: Heuristic Typology of Semi-structured Interviews

Interview type	Purpose	Epistemological privilege	Role of Participant	Outcome
Descriptive/ Confirmative	Assessment	Known	Respondent	Confirmation of fit
Descriptive/ Corrective	Evaluation	Knower and the known	Collaborator	Refutation, Elaboration, Correction
Descriptive/ Interpretative	Discovery	Knower	Informant	Understanding
Descriptive/ Divergent	Contrast	Groups of knowers	Informants	Discernment

Descriptive/Confirmative

Historically, the focused interview aimed to augment experimental findings with subjective responses; the analytic component of the findings was augmented by this interpretive component. The descriptive/confirmative contemporary type of semi-structured interview most closely approximates this original interview role. The purpose of this type of semi-structured interview is to obtain subjective responses to the objective knowledge of the interview guide in order to assess its hypothetical assumptions. Indeed, this type of interview epistemologically privileges the known rather than the knower. Although participants' perspectives and experiences are important, they are most relevant to the assessment of the frame. In the examples to follow, this frame is manifest as a theory or an instrument.

Descriptive/confirmative semi-structured interviews have been used to assess: the usefulness of a research impact framework to capture the impact of health services and policy research (Kuruvilla, Mays & Walt, 2007); the relevance of "uncertainty reduction" theory to the experience of homeless teen mothers (Scappaticci & Blay, 2009); the suitability of the disease-specific health-related quality of life instrument for use with patients after myocardial infarction (Roebuck, Furze & Thompson, 2001); and finally, the potential for the Osteoporotic pain program to increase patient's insight, skills and motivation to self help and possibly reduce pain (Jensen & Harder, 2004).

The outcome of the descriptive/confirmative type of semi-structured interviews is to confirm the objective knowledge of the interview frame. In the aforementioned examples, instruments or theories, themselves derived from prior scientific study, are confirmed by the subjective responses of interview participants. These theories or instruments, now confirmed, may themselves be used as modes of clinical or social assessment or program evaluation.

Descriptive/Corrective

Historically, a primary aim of the focused interview was to interpret discrepancies between anticipated and actual effects (Merton & Kendall, 1946, p. 541). Similarly, the purpose of the contemporary descriptive/corrective semi-structured interview is to evaluate the dominant discursive representation of an experience by comparing it with participants' actual experiences. This type of interview uniquely juxtaposes what is known about an experience (i.e. established knowledge in the literature), or known only from the privileged perspectives of others (e.g. those persons who represent others, such as researchers reporting on the vulnerable, invisible groups), with the perspectives of those whose views are typically absent or under-represented and who have actual material knowledge of this experience. The word disjuncture, coined by Dorothy Smith (1990), refers to the discrepancies between the conceptualization and textual mediation of an experience with the material actual experience of people.

The elucidation of disjuncture is not the intended outcome of this type of research but is, rather, the means to correction. The outcome of this interview research is to confirm, refute or elaborate upon the assumptions of the frame. The intention is that the participants' actual experiences of the phenomenon will act as a corrective to the assumptions in the dominant discourse and effect political action for change.

Evidencing a social constructivist approach, this type of interview epistemologically privileges both the knower and the known. Descriptive/corrective semi-structured interviews exemplify empathetic interviewing and hence are particularly useful to research with feminist and critical aims such as institutional ethnography, participatory action research and social movement research (Blee & Taylor, 2002). The researcher and the participant collaborate to produce knowledge with which to effect political change.

Descriptive/corrective semi-structured interviews have juxtaposed the perspectives of mothers addicted to crack cocaine regarding mothering, with popular assumptions of such mothers (Kearney, Murphy & Rosenbaum, 1994); general physician's explanatory models for Irritable Bowel Syndrome (IBS) with the explanatory models used by patients afflicted with the condition (Casiday, Hungin, Cornford, deWit & Blell, 2008a, 2008b); and media and scientific representations of the female orgasm with women's subjective thoughts and feelings regarding it (Lavie-Ajayi & Joffe, 2009). Disjunctures were revealed and pointed to dominant assumptions or practices in need of revision or correction: mothers addicted to crack uphold as strong commitments to mothering as mothers who are not addicted; physicians do not know the full impact of IBS on sufferers' lives; women graft the importance of relational and emotive aspects of orgasm onto the scientifically driven representations of it.

Corrective action indicated by these disjunctures included: greater sharing between physicians' and patients such that medical interventions are informed by patient perspectives; the need for woman-centered policies and programs including safe drug-free housing, health care, childcare, education and job assistance; and the laying bare of cultural and social norms associated with having orgasms such that the set of anxieties they produce might be reduced and this, in turn, may diminish women's experience of having problems with orgasms.

Descriptive/Interpretive

Historically, the aim of the focused interview was to elucidate the subjective response to the stimulus. The descriptive/interpretive contemporary type of semi-structured interview is exemplified by research with the aim of discovering the experiential world of the respondent within topical dimensions. Semi-structured interviews are a viable option for researchers with parsimonious yet phenomenological aims. This type of interview epistemologically privileges the participant as knower. From

72

the outset, the frame is acknowledged to be limited and subjective knowledge is critical to its expansion. Sometimes the limited knowledge of the frame is confirmed and expanded by participants' perspectives; sometimes the frame is refuted by participants' perspectives and gives rise to new categories, themes and hypothesis with which to understand the experience.

Descriptive/interpretive interviews have been used to investigate: the long-term impact of sudden infant death (Dyregrov & Dyregrov, 1999); next-of-kin's perceptions of end-of-life care (Williams, Woodby, Bailey & Burgio, 2007); maternal infanticides in Fiji (Adinkrah, 2000); and influences on parents' fever management: beliefs, experiences and information sources (Walsh, Edwards & Fraser, 2006).

Discoveries that emerged from these interviews included the discovery that parents who have experienced the sudden death of an infant still view the death of their child as affecting their daily life in important ways 12-15 years after it happened (Dyregrov & Dyregrov, 1999, p. 657). Second, a critical discovery that emerged from the study investigating maternal infanticides in Fiji (Adrinkrah, 2000) was that, contrary to the legal definition of infanticide that presupposes postpartum depression in infanticidal behaviour, unwanted pregnancies were the major precipitant for maternal neonaticides. Most 'offenders' were young, poor, unmarried Fijian women with minimal formal education. This discovery lead to the hypothesis that if unwanted pregnancies were curtailed, the incidence of infanticide would decrease.

Descriptive/Divergent

Historically another application of the focused interview was to "interpret discrepancies between prevailing effects and effects among subgroups—"deviant cases" (Merton & Kendall, 1946, p. 542). Contemporarily, the descriptive/divergent type of semi-structured interview applies the same interview guide to disparate groups of participants in order to discern differences and similarities in perspectives and

experiences among them with respect to the dominant discourse that underpins the interview guide. The purpose of this type of interview is to contrast perspectives of different groups of knowers. This type of interview epistemologically privileges the knowers and seeks to discern their contrasting perspectives and experiences.

Descriptive/divergent semi-structured interviews have been used to investigate such topics as: women's attitudes towards technology (resistant versus flexible) and their childbirth experiences (Kornelson, 2005); women's attitudes toward postmenopausal long-term hormone therapy (five different types of users were identified who differed from each other in terms of their reasons for using hormones, their expectations of this type of therapy, and their personal habits and circumstances) (Kolip, Hoefling-Engles & Schmacke, 2009); elite women wrestlers' muscles (senior wrestlers accepted the 'athletic body' and muscularity with its social costs; junior wrestlers were 'holding back' giving priority to the 'private body') (Sisjord & Kristiansen, 2009); lesbian versus gay activists attitudes towards transgender inclusion (Stone, 2009).

The elucidation of divergent perspectives, attitudes and experiences regarding phenomena enables deeper insight into various ways that people negotiate the personal and social contexts that shape human choices and experiences.

Constructing the Semi-Structured Interview

Preparing the Interview Schedule

Semi-structured interviews are semi-standardized, and characterized by the design and utilization of this schedule. They are conducted using an interview questionnaire or schedule comprised of pre-determined or scheduled primary questions or question stems, followed by probing sub-questions or 'probes'. It is important that these questions are open-ended and formulated to elicit unstructured responses and generate discussion. These questions are typically asked of each interviewee in the same way and in a systematic order, but the questions are *semi-structured* in that the interviewers are

74

allowed freedom to diverge slightly from the script. There is some variability granted the researcher within the limits of the intended replicability of the schedule to rephrase questions in order to elicit the pertinent information. More important than the exact phrasing of the question is conveying equivalence of meaning to all participants (Denzin, 1989). Furthermore, the interviewers are expected to probe within each participant's responses (Berg, 1989). These probes are intended to elaborate beyond the participant's initial response. For example, probes such as "In what way…?" or "Tell me..?" or "Such as. . ?" These dual qualities of replicability and flexibility yield pertinent as well as rich data.

Probes may be scheduled (scripted) appearing after the question stems on the questionnaire, or unscheduled arising from the dialogue. Unscheduled prompts are improvisational, and some researchers find that respondents more fully express their perspectives in response to the unscheduled prompts (Berg, 1989).

To prepare the interview schedule, the researcher must: 1) identify the domain of the topic under investigation including its boundaries; 2) identify the categories of the topic; 3) identify the question stems. Once the questionnaire is drafted, it is critiqued and tested. A previously mentioned descriptive/interpretive semi-structured interview study will be used to illustrate this process. The particular study, conducted by Dyregrov and Dyregrov (1999), sought to ascertain parents' perspectives and experiences of the sudden death of their infants after the passage of a significant amount of time.

Identifying the Domain of the Topic

Semi-structured interviews are used when the researcher knows enough about the topic to be able to identify the domain and the main components of the topics but is unable to anticipate all of the possible answers (Morse & Field, 1995). The more extensive the investigator's knowledge, the more precisely can the aspects to be covered

in the interview be outlined in advance and the more significant questions may be posed

(Kvale, 1996; Merton & Kendall, 1946).

Interviewers know in advance of constructing the interview, which topics they wish

to include and even some of questions they wish to ask. This knowledge of the

phenomenon may be variously acquired. Researchers may have initially observed or

experienced the phenomenon. Spradley (1979) and Patton (1980) suggest that researchers

prepare a preliminary outline listing all of the broad categories they feel may be relevant

to their study. Conducting a literature review is an essential component in ascertaining

what is known about the phenomenon, using the literature in an "informed, skeptical, or

comparative manner" (Morse, 2003, p. 891) to maintain an inductive approach to

questionnaire development. Knowledge about the phenomenon may also be derived from

the researcher's "conceptual baggage"—information acquired from clinical practice or

prior fieldwork (Kirby & McKenna, 1989, p. 21). Thus, familiarity with the phenomenon

is not exclusively derived from the literature but also from the researcher's intuition,

experience and observation. Further, the domain of the research topic is delimited by

boundaries so that a specific aspect to be investigated is tightly circumscribed.

> *Example: Long-Term Impact of Sudden Infant Death (Dyregrov & Dyregrov,*
>
> 1999)*: In this study, the domains of inquiry were first, parents' experiences and
>
> perspectives regarding the death of a child over time and second, gender
>
> differences in parental response to death over time. The following boundaries de-
>
> limited the topic i.e. indicated what would remain outside of the research domain:
>
> 1) Time. Parents' acute response to the recent death of infants. 2) Nature of
>
> death. Infant death due to accident or intent.

Identifying the Categories

Once the domain and its boundaries have been delineated, the researcher can focus within the domain to ascertain its categories. The domain is sub-divided into categories established by their particular shared characteristics.

Example: In the above mentioned study, the domain of parental response to infant death over time was sub-divided into categories: 1) the experience of the cot death; 2) parental communication about the lost child over the years; and 3) the subjective meaning regarding the effects the loss of their child had over the 12-15 years. These categories were amassed from a literature review that included studies pertaining to the acute crisis reactions following the loss of an infant child, to family responses over time to an older child who dies of cancer, and the different patterns of paternal versus maternal grief response (Dyregrov & Dyregrov, 1999, p. 635-639.

Identifying the Items

Items are then constructed from each of these conceptual categories. An item is defined as an individual article or unit that is part of a collection or set. These items form the main structure or question stems formulated for the interview schedule.

Example: The following items were derived from the category pertaining to parental communication about the lost child over the years. "The parents were asked about how they had talked about and memorialized the child over the years (i.e., pictures, the grave, and celebration of birthdays), and if anyone in the family needed or wanted to talk about the dead child more than others and how did the rest of the family meet these demands?" (Dyregrov & Dyregrov, 1999, p. 641).

When the domain, categories and question stems are determined, a chart can be constructed that depicts the domain, its categories, the question stems as well as the

literature from which they were derived. This chart or 'aide memoire' can be used as a resource interviewers may consult before or during the interview (depending upon whether the interviews are face-to-face or over the telephone) to remind them of the relevance of the question to the topic and its specific intent. This enables improvisational prompts that maintain congruency with the information intended by the question itself and can optimize the ascertainment of the information sought. This may be particularly useful to a novice researcher or to an experienced researcher in the early interviews of a new project. The chart used in the research example is shown in Table 2.1.

Table 2.1: Construction of Interview Schedule for Domain of Parental Responses to the Sudden Death of their Infant Over Time

Category	Item #	Scheduled Question Stem and Probe	Reference for Category Development
Parental experience of cot death	1	Can you share with me what the experience of losing your baby was like for you? *Probe: How did the people around you react?*	Martinson, Davies & McClowery (1991). Parental depression following the death of a child.
Parental communication regarding infant death	2	What was it like to talk to your partner about the death of your baby? *Probe: How did it feel to talk?*	Lang, Gottlieb & Amsel (1996). Predictors of husbands' and wives' grief reactions following infant death: The role of marital intimacy.
Subjective meaning regarding the effects the loss of their child had over 12-15 years	3	Did anything remain the same after the death of your child? *Probe: Did anything change?*	Martinson, McClowry, Davies & Kuhlenkamp (1994). Changes over time: A study of family bereavement following childhood cancer.

Writing the Question Stems

Lazarsfeld (1954) offered three principles to guide the construction of question stems: specification, division and tacit assumption. These principles have been re-named and elaborated upon but these original principles still constitute the basis of question design (Berg, 1989; Rubin & Rubin, 1995).

Specification refers to the focus of each question. This principle is easily achieved in the construction of question stems since they are derived from specific categories of the domain. The principle of *division* ensures that the questions stems are appropriately worded and sequenced. Questions need to be formulated to ensure they are adequately and clearly communicated. Many researchers choose zero order level of communication—that is, the wording of the questions and ideas conveyed are leveled to the least sophisticated of all potential respondents. Furthermore, affectively worded questions should be neutralized. Instead of asking "*Why* did you…?", ask "Can you tell

me how you decided to …?. Neutral questions, even when the content is sensitive, improve the likelihood of a full answer. Questions should be presented in a logical, possibly chronological, order. By logical order, I mean that the interview should move from mild, non-threatening questions to more complex and sensitive questions as the interview proceeds. Questions should not be double-barreled but should address only one aspect of a category (Berg, 1989). Finally, the principle of *tacit assumption* refers to the process of making explicit what is implicit in participants' responses. This principle is accomplished via scheduled and unscheduled probes.

Questions collect data in implicit and explicit ways. *Explicit* data collection is the responses obtained. *Implicit* data collection is how questions motivate these responses by giving an impression of the interviewer—for example, questions convey the extent of the interviewer's understanding of the topic area. This instills trust in the participant that they will be understood and may inspire fuller responses. The participant must always be kept in mind, therefore, when constructing the questions.

Piloting the Interview Schedule

Once the content and form of the questionnaire appear satisfactory, it should be subjected to critique or internal testing (Mann, 1985) to ensure its cogency. The following questions may guide this assessment (Chadwick, Bahr & Albrecht, 1984):

1. Has the researcher included all of the questions necessary?

2. Do the questions elicit the types of response that were anticipated?

3. Is the language of the research instrument meaningful to the respondents?

4. Are there other problems with the questions, such as double meaning or

    multiple issues embedded in a single question?

5. Are the questions in logical order?

6. Finally, does the interview guide, as developed, help to motivate respondents to

    participate in the study?

Testing

Testing allows the interview schedule to be rehearsed in mock conditions that closely approximate the actual in order to amend it before main data collection. Pre-testing also allows the prospective interviewers to rehearse their interview performance. How participants respond to questions, whether the questions elicit the intended information, and the interviewers' capacity to collect data are illuminated by this process such that amendments may be made in advance of actual interviews.

Data Collection

The interview schedule can be administered via written questionnaire, electronically (via chat rooms, virtual spaces, electronic mail), face-to-face, over the telephone and as a component of a quantitative questionnaire (Fontana & Prokos, 2007). The following section identifies the relative advantages and disadvantages of each of these modes of administration.

Face-to-Face

The face-to-face administration of the semi-structured interview has both advantages and disadvantages (Shuy, 2001). Among the advantages are: (1) the presence of the interviewer gives structure to the interview situation. Communication is optimized since both verbal and non-verbal communication is possible. More complex interview schedules are possible as the interviewer may clarify questions if the participant appears confused and unscheduled prompts that elicit clearer and more elaborate responses from participants may be improvised. In addition, visual aids may be presented to respondents to ascertain their perspectives; (2) the physical presence of the interviewer may allow him/her to discern any discomfort or unease on the part of the respondent and offer a break or emotional support, hence face-to-face may be a more ethical way to conduct the research.

Disadvantages may include: (1) participants feeling inhibited when asked to respond to sensitive questions face-to-face. More socially desirable answers and conventional answers may be given than when a self-administered questionnaire is utilized; (2) unwanted interviewer affect is maximized in this type of interview. For example, the physical presence such as the appearance of the interviewer, are known to affect respondents and their answers. The face-to-face interview maximizes the influence of the interviewer such that the responses from participants are very similar; (3) conducting this type of interview is costly in terms of time and money. Fewer face-to-face interviews can be completed in a given time period than via other modalities e.g. Internet or telephone (de Leeuw, 2008).

Telephone Interviews

The advantages of telephone administered semi-structured interviews include: (1) enhanced accessibility to hard to reach populations such as those who are elderly, infirm, live in geographically remote locations and those for who must participate surreptitiously e.g. women experiencing abuse; (2) exclusive auditory communication i.e. absence of visual cues means that any barriers are removed, e.g. pre-conceived ideas about the interviewer caused by their appearance that may impede participants from fully expressing their perspectives; (3) telephone interviews may encompass a large geographic area including countries and continents; (4) they are less costly in terms of time and labor and are therefore more efficient. Furthermore, more interviews may be conducted in a given time period than might not be feasible with face-to-face interviews. Disadvantages include: (1) recruitment may be compromised if prospective participants must pay long distance telephone charges to enroll or find out more information about a study; (2) recruitment may be compromised if only participants who have access to a telephone or telephone coverage may participate (Liamputtong, 2007).

Internet Administration

The Internet is a medium for self-administered semi-structured questionnaires as well as conducting the interviews themselves (Fontana & Frey, 2005). The advantages of electronic modes of administration include: (1) privacy: Some sensitive topic research suggests that people prefer the anonymity of the computer, than disclosing face-to-face (DiLillo, DeGue, Kras, Loreto-Colgan & Nash, 2006). Although electronic mail makes identity difficult to protect, participants (including the interviewer) in interviews in virtual worlds such as Second Life may assume an avatar identity; (2) recruitment: The Internet allows for fast collection of large numbers of questionnaires at low cost, and exploding the potential for global recruitment. The disadvantages may include: (1) distress: Although participants may disclose more information in a self-administered questionnaire, some report feeling more distressed than when answering questions face-to-face with an interviewer (Halek, Murdoch & Fortier, 2005). As the participant is not immediately accessible, the researcher cannot immediately respond therapeutically; (2) recruitment: Not all prospective participants have access to the internet. On the other hand, electronic administration provides an opportunity to those participants precluded from more typical modes of participation because of disability, age or geographic isolation; (3) data collection: Many people may "lurk" or not give the questionnaire adequate time Internet questionnaires must be short, with less than 10-15 minutes to complete (de Leeuw, 2008, p. 320); (4) design of questionnaire: The design and implementation of Internet semi-structured questionnaires require highly skilled personnel who combine technical knowledge as well as knowledge on usability and visual design. This increases the cost of this mode of administration (de Leeuw, 2008).

As Components of a Quantitative Questionnaire

Semi-structured interviews may also be administered as a component of a quantitative questionnaire. This mixed design may combine the advantages of two

administration strategies. The quantitative questionnaire serves as an objective instrument the findings of which may be triangulated with the perspectives of the respondent in response to the open-ended questions of the interview. The timing of the administration of the questionnaire with respect to the interview may be critical—closed-ended questions posed first may inhibit more complete responses to those posed during the interview.

The data from semi-structured interviews has also been used in the creation of quantitative instruments. For example, the content analysis of data derived from qualitative studies yields categories that are useful to the construction of a questionnaire. For example, Morse and Doan (1987) conducted a qualitative study to ascertain adolescent girls' perspectives regarding menarche. Researchers used the data derived from that study in the construction of the likert scale items for an adolescent menstrual attitude questionnaire (Morse, Kieren & Bottorff, 1993).

<div align="center">Sampling</div>

Sample Size for Data Adequacy

Sampling for semi-structured interview research must be guided by the following principle to ensure the data collected is adequate. 1) A minimum of 30 participants is recommended for initial recruitment to ensure adequate data collection. Adequacy of data in this type of research is defined in both qualitative (i.e. the depth of data collected) as well as quantitative terms (i.e. the number of datum collected). Semi-structured interview data may be thin[2]. Although participants know they are free to respond to questions as they wish, they are also aware that they are to respond to scheduled questions. Hence, participants may respond to categorical questions in kind. The

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[2] To illustrate this concern, a set of responses to a single semi-structured interview question (n=135) was obtained. A sample of 20 responses gave very thin data, non-responses were problematic and invalid responses further reduced the usefulness of these data (Morse & Doan, 1987).

complexity or simplicity of responses is also related to the topic of investigation, the mode of administration of the interview schedule (face-to-face may facilitate more elaborate responses than on-line or self-completed questionnaires), the participants (whether they are willing, reflective, articulate), the ability of the interviewer to draw people out and how motivating the questions are for participants' responses.

The second aspect of adequacy, however, is the sufficiency of the data for quantitative analysis. Since semi-structured interview data is collected with an interview schedule in which each participant is asked the same questions, data analysis proceeds by item. Such analysis is amenable to non-parametric statistical analysis (Morse, 1992). A sample size of 30 is the minimum number recommended for such statistical analysis to be meaningful. Finally, in addition to qualitative and quantitative analysis, data derived from semi-structured interviews may be used in a mixed-methods study, for example, a QUAL-quan sequential mixed method design in which the qualitative data are transformed for quantitative analysis. In this case, the QUAL sample size needs to be minimally 30 for adequacy of the quantitative analysis (Morse & Niehaus, 2009).

Sampling for Appropriate Data

The second principle to guide semi-structured interview sampling ensures the collection of appropriate data, i.e. data that are representative of the phenomenon under investigation. Sampling for semi-structured interview research is purposive, therefore participants for semi-structured interviews are selected because of their particular experiences, perspectives or expertise, and not because they are demographically representative of the larger population (Blee & Taylor, 2002; Rubin & Rubin, 1995). Purposive sampling is essential to semi-structured interview research to optimize valid findings that may be extended to other arenas. This is contrary to the literature that cites conscious bias as a constant danger with purposive sampling and advises that findings from studies that employ it be regarded with caution (Lo-Biondo-Wood & Haber, 2005).

There are various strategies to purposively sample: convenient (eligibility criteria are posted and the first volunteers who meet it comprise the sample); snowball (people with inside knowledge of eligible participants connect them with the research project); homogenous (people who are very similar) and variable (participants who represent the full scope of the domain).

Example. In the study that investigated the long-term impact of sudden infant death (Dyregrov & Dyregrov, 1999), the purposive sample was comprised of participants who had lost a child to SIDS between 1981 and 1984. The participants were people who were married couples at the time of the death of their child and who had previously been interviewed approximately 1 year after their loss. The couples were heterosexual in order to meet the dimension of gender important to the analysis of grief response.

Data analysis

As noted, the objective of semi-structured interview research is to elicit and ascertain participants' perspectives in order to confirm, correct or discover new knowledge pertaining to the focus of inquiry. Therefore, the analysis of semi-structured interview data is designed to provide a comprehensive and accurate descriptive summary of participants' perspectives. Unlike other research methods such as grounded theory or phenomenology, semi-structured interview data are not usually abstracted into theory, nor are they mined to discern the essence of participants' experience. Analysis remains close to the data.

Data analysis proceeds by: 1) preparing the data for analysis; 2) conducting content analysis; and, 3) if desired and the sample size is adequate, transforming the textual data into numerical data.

1) Preparation of the data for analysis

Preparing the interview data for content analysis involves the transcription of audio-files to text, and importing transcripts into Computer Assisted Qualitative Data Analysis (CAQDA) software (Lewins, 2007).

Transcription: When having an audiotape transcribed, it is crucial that the tape be transcribed exactly (word-for-word) from the tape and not paraphrased. Identifying information that may compromise the privacy of the participants and/or those to whom they refer during the interview can be removed at this time to maintain confidentiality. If the researcher requires, symbols may be utilized to indicate the tone of the voice (e.g. tears, laughter, expletives), with pauses or gaps indicated by dashes or ellipses and emotion indicated by square brackets e.g. [fearfully]. All pages of the transcript are numbered and the participant number is placed before each item number (Morse & Field, 1995). Once the transcript is returned from the typist, the content is checked against the audio tape to ensure accuracy of the data.

If CAQDA software is to be used, a program is selected that is capable of categorizing data by item, and then sorting/categorizing according to the research codes.

2) Conducting content analysis

The purpose of content analysis is to sort and summarize the informational content of the data, by item and by common characteristics within the data.

Qualitative Content Analysis. The first task is to derive codes from the data. The researcher works by item, first reading all participants' responses to the same question. The researcher then uses standard coding procedure, highlighting important words or phrases, and making notes in the margin that emphasize important features in each response.

Once the researcher grasps the commonalities appearing in each response, the sorting process begins. Initially, keeping the categories broad, data is sorted according to

similar characteristics and, once these categories become "cluttered" and lengthy, they are subdivided into smaller categories. A definition is developed and assigned to each category and a synthesizing statement about each category and subcategory is written.

Quantitative Content Analysis.. Quantification or counting is not incongruous with, but integral to, qualitative research (Sandelowski, 2000; Morgan, 1993; Richards & Morse, 2002). Because every participant has been asked the same question in the same order, semi-structured interviews are amenable to counting *by participant*. (Morse & Niehaus, 2009). The different types of responses to each categorical question stem may be tabulated and the responses expressed as percentages, frequencies etc. with the *n* (the sample size, the total number of participants. Quantification, or displaying information numerically, allows patterns to emerge from the data with greater clarity (Sandelowski, 2000). Descriptive statistics such as calculating frequencies, relative frequencies and means may be employed to discern, describe and summarize such patterns—analytically and ideographically— if they exist, in the qualitative data.

Mixed Method Design. Semi-structured interviews are the most common qualitative research method to be used in mixed method designs— those that integrate qualitative and quantitative research (Bryman, 2006). Indeed, every semi-structured interview study, therefore, may itself constitute a qualitatively-driven, mixed method design through the internal transformation of its data set from qualitatively analyzed textual data into numerical data for quantitative analysis (Morse & Niehaus, 2009).

> *Example:* The study by Dyregrov and Dyregrov (1999) could have been a
> QUAL-quan mixed method design. The interviews were conducted to ascertain
> participants' perspectives and experiences regarding the death of their infants
> over time. Once the content of these responses have been qualitatively analyzed
> (i.e. coded and sorted for the purpose of describing and summarizing the
> responses), they could have been transformed from textual data to numerical data

for the purpose of supplementary quasi-statistical analysis by non-parametric statistics.

Transforming Textual Data to Numerical Data

If researchers want to supplement the core qualitative analysis of the interview data with a quantitative component they must transform the textual interview data into numerical data. This transformation of data occurs after the qualitative content analysis is completed—that is, the supplemental component is conducted as a sequel.

First, however, a codebook must be created. This is accomplished by re-visiting the categories that have emerged from the coding of data for each question. These categories as well as the inclusion and exclusion criteria and an example (from the data) of a code that belongs to it are entered as headers in the codebook. These categories are then tested against all of the data that belongs to each item. The categories must be discrete and comprehensive—all of the data must fit into one of the categories. Different coders complete the process of tabulating data within the categories. Inter-rater reliability refers to the degree of confluence that exists among independent raters. Once the codebook is satisfactory, tabulation occurs—this results in frequency of categorical responses per participant. It is the establishment of frequencies that transforms the data from text to numbers. From these frequencies, other descriptive statistics such as relative frequencies may be calculated. With these numbers, non-parametric statistics such as Chi-square may be used. The Chi-square independence test is useful in determining whether there is an association or statistical dependence between two characteristics of a population.

> *Example:* While investigating parental responses to the death of their infants over time (Dyregrov & Dyregrov, 1999), a pattern was discerned—marital communication about the death of their infant appeared to be correlated with less intense grieving; conversely, couples who did not communicate about their

infant's death experienced more intense grief. Tabulating the frequencies of

categories pertaining to communication as well as those associated with grief

reactions would make the data amenable to chi-square statistical analysis to

discern whether or not a statistically significant relationship exists between these

experiences.

Once the results of the quantitative supplementary component have been calculated they

serve to augment the results of the core component.

Results

Results of semi-structured interview research constitute descriptive summaries

that are valuable primarily as end-products and, secondarily, as entry points for future

study. The end-product is knowledge—either confirmation or correction of that which

already exists or discovery of new knowledge. Results of semi-structured interview

research may seem simple, that is, 'mere' concrete description rather than abstract and

theoretical. But this is deceptive—such research results are key pivots to the

advancement of knowledge. This advancement of knowledge is far-reaching, influencing

multiple disciplines and typologies of knowledge. Semi-structured interviews advance

critical, feminist, phenomenological and mixed methodological aims.

Summary

In this article, I have discussed how the semi-structured interview has developed

from a research strategy to a prevalent and diversified research method. I traced the

historical development of the semi-structured interview from its inception as a focused

interview through its advancement via significant social, cultural and historical moments.

Such moments included the empathetic turn in interviewing, the contemporary

privileging of quantitative research and concomitantly the norming of research ethics

review. Contemporary research methods adopt various philosophical assumptions rather

than maintaining a tight theory-method commitment to a solitary philosophical

foundation. Semi-structured interview research is epistemologically versatile and compatible with quantitative, qualitative and mixed method approaches. I advanced a typology of semi-structured interviews that may be used as a strategy in an overall research design, a sequential or simultaneous supplement to the core in mixed or multiple method research, or it can constitute a single data-set mixed method design and it can stand-alone.

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Participants' Perspectives of Risk Inherent in Unstructured Qualitative
Interviews

by

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PARTICIPANTS' PERSPECTIVES OF RISK INHERENT IN UNSTRUCTURED

QUALITATIVE INTERVIEWS

What constitutes sensitive research is highly subjective (Sieber, 1993). Nonetheless, sensitive research is generally considered to be that which poses some risk or threat to participants such as the invasion of privacy, the evocation of emotional distress, the disclosure of stigmatizing behaviour and the "dissemination of invalid conclusions that might lead to harmful policy decisions" (Sieber, 1993, p. 18). At the same time, the social value of sensitive research is undisputed. Sensitive health-related research has contributed to our understanding of such issues as euthanasia (Young & Ogden, 2000), domestic violence (Wuest & Meritt-Grey, 2008), eating disorders (Weaver, 2008), workplace bullying (MacIntosh, 2006), pediatric palliative care (Steele & Davies, 2006), and suffering (Morse, 2001, 2003). Sensitive research contributes to subjects about which there is often a dearth of empirical data and informs social and public debates about controversial issues. Of course, what constitutes a sensitive topic to a researcher is, to a participant, a personal experience. Sensitive research is made possible by the participation of persons who are willing to share their personal experiences. Sensitive research is beneficial to society, but what is it like for the participants upon whom it depends? The purpose of this study is to ascertain participants' perspectives of risk inherent in unstructured qualitative interviews investigating sensitive health-related experiences.

Background

Are Interviews Risky?

Kvale (2006) made strong assertions of the propensity and extent of risk that is possible in qualitative research. He coined the term "qualitative progressivity myth" (p. 481) to refer to the "tyranny of intimacy" (p. 495) that underpins the ostensible goodness

and emancipatory intentions of the "warm, caring, and empowering dialogues" (p. 481) otherwise known as qualitative interviews. Reinharz (1983) employed the metaphor of rape to describe the nature of the harm posed by interview research: "Interview research takes, hits and runs. It invades privacy, disrupts perception, utilizes false pretenses, manipulates the relationship, gives little or nothing in return, and once the researchers' needs are satisfied, contact is broken off" (p. 80).

Unstructured qualitative interviews epitomize sensitive research methods that aim to ascertain people's in-depth experiences, and the interpretations, and meaning of such experiences. However, the sensitive nature of their inquiry, the vulnerability of their participants, and the emotional distress typically manifested during such interviews have prompted researchers' as well as REBs' concern regarding their impact on participants. Participants' contributions to sensitive research are socially beneficial, but is this benefit reciprocated to participants? Worse, are participants harmed by their participation in unstructured interviews? Currently although our REBs assume harm, there is no evidence with which to resolve these concerns.

Lack of Evidence-Based Research Oversight

Concurrent with a lack of evidence with which to inform risk posed by interview research, there is also a lack of evidence with which to consider the appropriateness of the current normative context of research ethics governance of interview research. A key component to the issue of normative ethics oversight is the definition of minimal risk and whether risk is methodologically specific. The current context of research ethics governance of qualitative research is characterized by a distinct lack of evidence pertaining to risk to participants in interview research, as well as evidence to substantiate or refute the appropriateness of the contemporary normative research ethics oversight to ensure participant protection. This study, in which I seek to ascertain participants'

perspectives of risk inherent in unstructured qualitative interviews, aspires to contribute to the resolution of these empirical gaps.

Implications of Non–Evidence-Based Research Ethics Oversight

Ethical and effective ethics governance, including the conduct of interviews themselves, requires an evidence-based approach that incorporates "virtuous learning loops" (McDonald, 2001, p. 11). In this case, predictions of risk may be either verified by actual incidence of harm or corrected by the absence of harm or other feedback. In addition, such feedback would inform whether the current normative standards are appropriate to govern ethics in interview research. Currently, ethics governance is uninformed by feedback from participants and, therefore, does not incorporate such loops. To compound this problem, lack of empirical evidence may result in what has been termed "ethics creep" (Haggerty, 2004, p. 402), an overreaching of ethics governance to compensate for this empirical gap (Expert Committee for Human Research Participant Protection in Canada, 2007).

Research Ethics Boards are mandated to protect research participants from harm as well as to protect research that may benefit society. In the absence of knowing participants' perspectives of risk, how can we be sure that participants, or the proposed research itself, have been appropriately, adequately, and effectively protected? Lack of knowledge regarding participants' perspectives and experiences of research participation constitutes a critical obstacle to the assurance of effective and ethical ethics governance. Thus, obtaining these perspectives is imperative to an evidence-based approach (Hirtle, 2003; McDonald, 2001).

Researchers' Conceptualization of Risk Inherent in Unstructured Interviews

Dominant discursive conceptualizations of risk to participants inherent in unstructured interviews represent the perspectives of researchers and REBs, not participants themselves. Indeed, there is a paucity of evidence representing the

perspectives of participants in this regard (Haggerty, 2004; Boothroyd, 2000; Brannen, 1993; NatCen 2006; Carter, 2007; Lowes & Gill, 2006; McDonald, 2001). In the following section, I describe researchers' and REBs' conceptualization of risk posed to participants by unstructured interview research. The evidence to substantiate these conceptualizations was derived via two strategies: first an analysis of a subset of survey questions posed electronically to qualitative researchers ($n = 512$) that asked them to define no, low, medium and high risk in qualitative interviews[1]. Some of this data was published and some remained unpublished (Morse, 2005, unpublished data; Morse, Niehaus, Varnhagen, Austin, & McIntosh, 2008); the references to unpublished data that follow pertain to this subset of survey data. The second strategy used to ascertain researchers' conceptualization of risk was a standard literature review. This literature review included the Tri-Council Policy Statement (TCPS; Canadian Institutes of Health Research [CIHR], Natural Sciences and Engineering Research Council of Canada [NSERC], Social Sciences and Humanities Research Council of Canada [SSHRC], 2005) to ascertain how risk was conceptualized within documents that governed REBs. This research yielded the following dimensions or categories of researcher and REB's conceptualization of risk: sensitivity of topic, vulnerability of participant, unexpected disclosures evoked by an emergent design, presence of emotional distress, attributes of the researcher, and the relationship between researcher and participant. Their conceptualization of benefit is also presented. I elaborate upon these categories in the next section.

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[1] This survey was Phase 1 of a multi-phase CIHR funded research project pertaining to risk to participants in unstructured qualitative interviews. This survey aimed to ascertain researchers' perspectives of risk to participants. I analyzed the data for a sub-set of four questions asking researchers to describe what constitutes no, low, medium and high risk to participants in unstructured interviews.

Topic

Researchers surveyed said, "Risk in qualitative research is highly determined by the nature of the topic being investigated" (Morse, 2005, unpublished data). Socially sensitive research is defined as: "studies in which there are potential consequences or implications, either directly for the participants in the research or for the class of individuals represented by the research" (Sieber & Stanley, 1988, p. 49). These potential consequences or implications are construed as negative or harmful. Lee and Renzetti (1990) refer to the potential "costs" to those participating in a study and considered the studies that pose greatest threat as the most sensitive:

> (a) research [that] intrudes into the private sphere or delves into some deeply personal experience (b) where the study is concerned with deviance and social control (c) where it impinges on the vested interests of powerful persons or the exercise of coercion or domination and (d) where it deals with things sacred to those being studied which they do not wish profaned. (p. 512)

Costs may be psychic, such as "guilt, shame or embarrassment" as well as "unwelcome consequences" (p. 512). An unwelcome consequence, for example, may refer to the mandatory reporting of abuse disclosed by a participant in an interview.

Research pertaining to violence against women exemplifies a sensitive topic. Fontes (2004) described the various kinds of harm that might befall participants including

> economic harm (e.g., if a woman separates from a batterer or sexual child abuser who is a wage earner after participating in a study), social harm (e.g., damage to a woman's or family's reputation), political harm (if cooperating with an interviewer is seen as conversing with the enemy), and physical harm (see World Health Organization, 2001). (p. 166)

101

In sum, researchers have conceptualized sensitive topic research as foreboding high risk to participants because of the harmful implications or consequences of their participation.

Other researchers refuted such definitive categorization of sensitive research and asserted that any revelation has risk; i.e., even the apparently safest topic can bring to light sensitive experiences that can be distressing in the moment of telling, or later (Morse et al., 2008).

Vulnerable Participants

According to researchers, risk is subjective. "It depends on whom you're asking". However, not all eventualities can be foreseen—"how one person reacts cannot predict how all will" (Morse, 2005, unpublished data). Still, researchers predict risk to be greater for participants who are vulnerable, such as those who are coerced, dangerous, unmanageable, unstable, currently in crisis or those who have not processed crisis, those who have experienced or perpetrated trauma and those in whom bad or repressed memories would be painfully recalled. According to this definition, many unstructured interview participants are vulnerable. Other researchers refuted this definition of vulnerability, however, and asserted that participants can mediate their own risk by refusing to participate in the first place or withdrawing their participation at some later point. For example, one interview participant said, "I don't know if I have resolved all of the issues. I think I have, but if it becomes too painful for me to talk about things, I will stop the interview" (Corbin & Morse, 2003, p. 337).

Research governance guidelines define vulnerability in terms of competency: "those whose diminished competence and/or decision making capacity make them vulnerable" (CIHR, NSERC, SSHRC, 2005, i.5). REBs worry that the emergent design of unstructured interviews precludes full disclosure of what might transpire during the interview, thereby undermining informed consent and increasing participant vulnerability. Others have questioned whether vulnerability is an absolute quality or a

dimension that can emerge during the interview such that the criteria for informed

consent met at the outset unravel as the interview is conducted (Fontes, 2004).

Effects of the Emergent Design on Unstructured Interview

Researchers surveyed said, "If we ask for stories, then we cannot predict what to

expect" (Morse, 2005, unpublished data). Unstructured interviews usually begin with a

"grand tour" question, and the participant is then given the opportunity, freedom, and

time to tell their experience to their satisfaction. "When an interviewer asks, 'Tell me

everything about when he raped you, from beginning to end,' might help a victim

remember details of the assault that she had never previously cared (or dared) to recall"

(Fontes, 2004, p. 158). The emergent design, therefore, might stimulate the recollection

of previously unexplored or repressed memories and provoke unintended disclosures.

Unintended disclosures might also occur because of other characteristic features of

unstructured interviews, namely "the seduction of the caring interview" (Clark & Sharf,

2007, p. 407). On the other hand, Ellsberg, Heise, Pena, Agurto, and Winkvist (2001)

found the lengthy duration of in-depth interviews have greater potential for therapeutic

effect.

Furthermore, reporting the experience is thought to "force [participants] to relive

the original emotions" (Gordon, 1956, p. 167). Morse (2002) referred to this as emotional

reenactment. Thus, unstructured interviews that invite the retelling of adverse

circumstances might evoke emotional distress, recovery of repressed memories, and

spontaneous disclosures.

Emotional Distress

Unstructured interviews predictably evoke strong emotional responses from

participants, and researchers worry that this emotional distress constitutes harm

(Hadjistavropoulos & Smythe, 2001). Indeed, Corbin and Morse (2003) classified the

unstructured interview as occurring in phases: the pre-interview phase, the tentative

phase, the immersion phase, and the phase of emergence. It is during the phase of immersion that participants typically become emotional:

> At certain points in the narration, depending on the nature of the interview, the telling might become distressful to the participants, the story provoking feelings of deep loss and grief, anger or despair. An interviewee might cry or become too overwhelmed to go on" (Corbin & Morse, 2003, p. 343).

Researchers are concerned about the potential for retraumatization (Campbell & Dienemann, 2001; Castor-Lewis, 1988). Research itself can be traumatic as it reawakens memories of prior traumas.

Paradoxical Participant Responses

The literature is replete with researchers' anecdotes attesting to participants' simultaneous experience of emotional distress and benefit derived from their participation. Researchers report that although participants cry and acknowledge the pain in telling their experience, participants evaluate their interview experience as positive and one from which they derived benefit (Bruzy, Ault, & Segal, 1997; Cook & Bosley, 1995; Corbin & Morse, 2003; Cowles, 1988; Kvale, 1996; Lee & Renzetti, 1990; Parslow, Jorn, O'Toole, Marshall, & Grayson, 2000; Wong, 1998). These paradoxical participant responses, however, are poorly understood, and the harm of distress overwhelms the merits of benefit in research ethics oversight.

Harm of Insight

Fontes (2004) stated that she "believe[s] all research is an intervention, but some have more impact than others" (p. 167).

> It is easy to think of examples in which questions asked may create in a woman the idea that something that she has accepted as part of her plight—for instance,

that her husband forces her to have sex at times or in ways that she does not want—actually is a problem, a crime or a form of violence. Especially if she is powerless to change her situation, is this raised consciousness beneficial or harmful? (pp. 167-168)

Indeed, alteration in perspective—realization, insight, reframing—might constitute a risk factor for participants in unstructured interviews.

Post-interview Sequelae

The conceptualization of risk to interview participants includes negative or harmful responses attributed to the interview that occur after the interview itself. According to some of the researchers surveyed, "High risk interviews pose greatest harm to the participant—lingering thoughts about the interview, prolonged and/or acute emotional distress requiring professional help, sleep disturbances, nightmares" (Morse, 2005, unpublished data). For example, Bergen (1993) reported that several of the women interviewed about their experiences of marital rape reported negative reactions after the interview such as flashbacks and nightmares. Yet, the same women claimed their interview experience was cathartic.

Attributes of the Researcher

Researchers stated, "Risk is related to how the researcher approaches the interview situation and can heighten or lower the risk involved" (Morse, 2005, unpublished data). Empathy is a "thoroughly double-edged phenomenon. The same sensitivity and skills that make beneficent empathy possible can be turned to manipulative and malevolent purposes" (Code, 1984, p. 81). Finch (1984) discussed her discovery of the easy rapport, hence easy disclosures that resulted from her making a good impression upon her participants, in particular their identification with her; that is, a woman like themselves, that they could relate to. Thus, the establishment of trust and

empathy can be used as techniques, as social lubricants with which to elicit unguarded confidences or to solicit a range of private information. Indeed,

> A quasi-therapeutic interviewer role, building on emotional rapport and therapeutic knowledge of defense mechanisms, can serve as a 'Trojan horse' to get behind defense wall of the interview subjects laying their private lives open and disclosing information to a stranger, which they may later regret. (Kvale, 2006, p. 482)

Finch recalls leaving an interview she had conducted, "with the feeling that interviewees need to know how to protect themselves from people like me" (p. 173). The risk posed to participants by empathy is exploitation.

Rapport

"All human relationships involve risk" (Morse, 2005, unpublished data); however, research relationships that pose high risk to participants are those characterized by "power imbalances favouring the researcher, a dependent relationship between them, attachment between them, mismatch of interviewer and target group" (Morse, 2005, unpublished data). Kvale (2006) asserted, "Close emotional relationships between interviewer and interviewee can open for more dangerous manipulation than the rather distanced relationships of an experimenter and experimental subjects" (p. 482). The risk to participants posed by rapport is betrayal (Ellis, 1995).

Benefits

Speaking from his own experience, one researcher said, "The benefits, not only to the wider population but to the participant himself, most often outweigh the risks" (Morse, 2005, unpublished data). Hutchinson, Wilson, and Wilson (1994, p. 161-164)) described the following benefits of participating in research interviews: catharsis ("the expression of which provides a sense of relief"), self acknowledgment ("person's feeling

106

of validation as an individual with integrity and worth"), a sense of purpose ("participants describe feeling good about sharing information with researchers that may in turn be shared with other professionals or lay people through publication and presentations"), insight ("a new perspective about their situation"), empowerment ("telling one's story and feeling heard"), transformation ("telling one's story can facilitate movement and change"), healing and providing a voice for the disenfranchised ("In depth research interviews can give a voice to the voiceless because researchers sometimes investigate questions that involve those who have never been allowed to tell their story"). Other researchers concur (Frank, 2000).

Method

Sample Selection and Recruitment

Eligibility criteria were designed to recruit those persons whose experiences would best maximize the phenomenon of risk to participants in interview research. Thus, recruitment focused on persons who had previously participated in unstructured qualitative interviews regarding a sensitive or personal health-related topic. Two recruitment strategies were used: First, snow-ball recruitment via qualitative researchers who had previously or were currently conducting unstructured interviews was employed. Researchers were electronically or physically provided with information about the study as well as recruitment materials (Appendixes A, B, C, D) and asked to consider forwarding these to their former participants as an invitation to also participate in this study. The recruitment efforts were extensive and North American in scope. To avoid the over-representation of a specific interviewer, a limitation of four recruits from any given study was stipulated. Given research that evidences gender differences in emotional responsiveness, it was also requested that the researcher forward recruitment materials to equal numbers of men and women where possible. The second strategy was direct recruitment of participants. Recruitment materials were disseminated electronically and

107

via newspaper advertisements, organizational websites, public postings, and distribution at conferences. (Appendixes E, F) Directly recruited participants were secondarily selected prior to the interview to ensure that they had participated in an unstructured interview and not another type of interview, such as a focus group.

The snowball recruitment strategy for this study was problematic and yielded few recruits. Direct recruitment of participants was more successful. Out of several respondents, nine eligible participants were successfully recruited and participated in this study. All were Canadian, five were male, four were female, and they ranged in age from 27 to 75 years, with a mean of 49 and a median of 45 years. They had previously participated in a single unstructured interview of between 1 and 1.5 hours' duration that had been conducted from 4 months to 3 years prior to this study. Their occupations included: graphic designer, physician, construction manager, bank manager, university student, volunteer for persons with disabilities, college professor, a former health professional and a retiree.

Data Collection

Construction of the Interview Schedule

The interview schedule was constructed from the categories that emerged from the previous conceptualization of risk (see Table 3.0). Each category underpinned the development of each question stem intended to ascertain participants' perspectives of that categorical component of risk.

Table 3.0: Construction of Interview Schedule for Domain of Risk to Participants

Category	Item #	Scheduled Question Stem and Probe	Reference for Category Development
Topic	1	Do you remember the topic of the research you were previously interviewed? *Prompt: What did you talk about?*	Lee & Renzetti (1990)
Mediation of risk	2	How did you come to participate in that study? *Prompt: How did you decide?*	Kavanaugh & Ayres (1998)
Location	3	Where was the interview held? *Prompt: Was this significant to you in any way?*	Corbin & Morse (2003), Cowles (1998)
Researcher	4	Who was present at the interview?	Terry, Olson, Ravenscroft, Wilss,, & Boulton-Lewis (2006)
Ethics— Exploitation	5	Did the interviewer tell you what would happen to your story? *Prompt: Have you seen the transcript? Did you make any changes?*	Finch (1984), Brinkman & Kvale (2005)
Benefit/harm	6	What was it like for you to tell your story?	Dyregrov (2004)
Disclosure	7	Did you really feel you had the opportunity to tell your whole story? *Prompt: What made that possible? Or, What would have needed to be different?*	deMarrais & Tisdale (2002)
Emotional distress	8	How did you feel after the interview?	Corbin & Morse (2003), Hoffman (2004), Josselson (1996)
People can mediate risk	9	Were there parts that you kept to yourself? *Prompt: Why? How?*	Corbin & Morse (2003), Dyregrov et al. (2000), Josselson (1996)
Ethics— disclosure	10	Did you say anything at the interview you later regretted? *Prompt: Was there anything you didn't tell but wish you had?*	Ellis (1995), Josselson (1996)
Emotional Distress	11	Tell me about your feelings during the interview? *Prompt: Did you cry? Get upset? Laugh?*	deMarrais & Tisdale (2002)
Emotional Distress	12	What was that like for you? *Prompt: Were you uncomfortable in that situation?*	Cook & Bosley, 1995
Ethics	13	What did the interviewer do? *Prompt: Did the interviewer offer to pause or stop the interview? Was it paused or stopped? If not, why not?*	Corbin & Morse (2003), Hadjistavropoulos & Smythe (2001)
Researcher	14	Tell me about the interviewer. *Prompt: What did you make of him/her?*	Tang (2002)
Rapport with researcher	15	What was it like to talk to him/her? *Prompt: How did you get along with him/her?*	Finch (1984), Wong (1998)
Exploitation	16	Do you think he/she understood your story?	Code (1984)
Insight as risk	17	Do you ever think about that interview now? *Prompt: How? Why? What?*	Brannen (1993), Josselson (1996)
Regret	18	Was the interview what you expected? *Prompt: Would you do it again?*	Kavanaugh & Ayres (1998)
Vulnerability	19	Did you ever feel insecure at all during the interview?	Lowes & Gill (2006)
Benefits	20	If there were benefits to being interviewed, what would those be? *Prompt: Were you paid?*	Newman, Willard, Sinclair, & Kaloupek (2001), Morecroft, Cantrill, & Tully (2004)
Harms	21	If there were disadvantages to being interviewed, what would those be?	Barratt, Norman, & Fry (2007), Josselson (1996)
Risk	22	How do you respond to the statement: Interviews are risky?	Carter, Jordens, McGrath, & Little (2008), Scott et al. (2002)

However, some individual categories, such as emotional distress, generated more than one question in order for the category to be sufficiently explored. An aide-mémoire was also constructed to help the interviewer recall the literature that informed each category and constituted the rationale for the individual questions being asked. Such recollection of the context of each question enabled the interviewer to better situate participants' responses within the literature or identify the information being given as new, and improvise prompts. The question stems and scheduled prompts and the order in which they were asked are provided in Appendix G.

Semi-structured Telephone Interviews

The descriptive/corrective semi-structured interview was selected for the method of data collection (McIntosh, 2009, forthcoming). This type of interview may be used to uniquely juxtapose what is known (i.e., established knowledge described in the literature) with the underrepresented perspectives of those who have experienced the phenomenon under study. In this case, the semi-structured interview schedule is predominantly designed from researchers' conceptualizations of risk to participants in unstructured interviews. Items are developed from the categories of this domain. Participants' perspectives and experiences pertaining to these categories were elicited to compare discursive conceptualizations of interview risk with actual experiences of it. The descriptive/correction type of semi-structured interview was selected in order to reveal if there is disjuncture between how risk is conceptualized and how it is experienced and allow for its correction by the privileging of participants' perspectives.

The semi-structured interviews were conducted over the telephone and audio-recorded with Phone Valet software. Interviews were assigned a numeric reference. Audio files were transcribed in preparation for analysis.

Content Analysis

Data for each item or item set were amalgamated within separate MS Word files. Each data set was coded and categorized. Participants' responses were then compared with the categories of established knowledge that underpinned each item or item set to confirm, refute, or elaborate on dominant discursive conceptualizations of risk to participants in interview research. The description of participants' responses appears in the next section as findings. How they compare with the dominant conceptualization of risk to participants follows in the discussion.

Rigour

Establishing reliability and validity is a major challenge when a qualitative research project is based upon a single semi-structured interview. In qualitative research these are indicated by the "judgments made by the researcher about collected information in relation to its truthful representation of the desired content, its comparability with known information, and its verifiability across subjects and across situations" (Brink, 1991, p. 167-168).

Reliability

In the absence of multiple methods I needed to establish the reliability of my study participants and must account for my own reliability in collecting and transcribing the data.

I asked all of my participants the same questions in the same order. I also used alternate form questions within the interviews (e.g. the category of emotional distress was informed via more than a single question). All participant accounts maintained internal consistency i.e. logical or explanatory rationale of ideas about the same topic with each interview. I audio-taped the interviews to produce an alternate form of the interview in order to establish equivalency. Verification of the truth of the data was achieved by the equivalency of their accounts with the published accounts of other participants from other studies.

Validity

Two concepts important to the validity of qualitative inquiry are error and measurement (comparability).

Error

I was deliberate in my attempts to reduce error to ensure the truthfulness of my results. The research questions had face validity. In constructing the interview schedule I ensured that the questions were representative of the content of each dimension or category of the domain. The interview schedule is graphically depicted so the reader may see an example of the research evidence that underpinned each question. The categories were mutually exclusive yet some categories wrought separate and numerous questions that were alternately worded. The wording of the questions avoided socially desirable or acquiescent responses. The choice of participants and the recruitment strategies were appropriate. The data were collected uniformly via the interview schedule, over the telephone and audio-taped. I compared the transcripts with the audio-tapes. I analyzed the data by item once all of the data were collected.

The data collected was an authentic representation of the participants' perspectives of risk, was comparable to other emergent findings regarding participants' perspectives, was verified among the participants in my study as well as participants from other researchers and other studies.

Ethics

Research Ethics Board approval was obtained from the University of Alberta. The consent form was read to participants at the beginning of the interview and their consent was audio-taped. (See Appendix H)

Findings

Sensitive Topics

All participants had previously participated in sensitive research. The topics of the unstructured interviews they had participated in were personal, sensitive, and health related. Participants had been asked to share their perspectives and experiences regarding: substance abuse, sexual orientation, trauma, diagnosis of a serious illness, gynecological and breast

examinations (as a woman with disabilities), worry, caring for chronically ill patients, and illicit romantic relationships. At first glance these topics seem to be vastly different in the intensity of their sensitivity, i.e., one would expect that worry would be less sensitive than trauma. However, as previously stated, sensitivity is subjective and relativist. Almost all of the participants in this study considered the research they participated in to be sensitive—deeply personal and private, emotionally distressing, and evoking insight. The sole exception was a man who had been diagnosed with a serious illness who stated he derived much pleasure and fun from his research participation, in particular, the relationship cultivated between him and the researcher.

Personal Experiences

For participants, research "topics" were personal experiences. Although all participants spoke at length about their previous interview experiences, when asked, "Do you remember the topic of the research you were previously interviewed about?" a few participants responded that they could not: "To be honest with you I can't remember what the actual research was for." Another participant's recollection was vague: "Yes, more or less." This is not to say that the participants did not recall the interview per se, they simply did not recall the topic or purpose of the study in which they had participated. The relevance of the topic to the participants was their personal experiences of it: "It was about drug use…*my* drug use."

Secrets

Five of the participants reported their concealment of these personal experiences. Participants hid these experiences from friends, family, colleagues, and even, as repressed memories, from themselves: "I kept it pretty much to myself"; "it is certainly not appropriate to discuss it at liberty anywhere"; "I did it in seclusion. And so, it was almost like I didn't really share it with anybody"; "I told her most of my friends don't even know I'm divorced." The impetus for the concealment of these experiences was social stigma, fear of censure, and shame.

Alienation From Others

For participants who did not hide their experiences per se, the nature of the experiences of which they spoke constituted boundaries between themselves and others. In some circumstances these boundaries were between life and death ("I lost my son"); in others, the alienation was between health professionals and recently diagnosed patients. For some the nature of the alienation was professional; for example, the inability of one profession to communicate effectively with another. In two cases, the traumatic experience the participants had was so rare and so harrowing it marked them as separate from most people who will probably never have such experiences ("I expect people to be curious but not necessarily understand"; "I wasn't looking to shock the woman [interviewer]").

Vulnerable Participants

Participants reported that their decision to participate in previous research was motivated by the relevance of the research to their lives. The topic or the purpose of the study was less important (and less memorable, as it turns out) than the characteristics of study participants that were being sought. A similar subject-centered approach was taken regarding their informed consent to participate: They conducted their own proportionate review weighing the relative helpfulness of their participation with the relative risks posed to themselves or others. Participants reported that they had previously refused to participate in some studies. Thus one strategy participants use to mediate their own risk is to refuse to participate in the first place. However, once they did consent to participate participants continued to mediate risk throughout the interview by withholding information they did not feel comfortable sharing or refusing to reflect deeply. One participant recalled a friend who had agreed to participate in a study investigating domestic violence. However, as soon as the informed consent was read and indicated mandatory reporting to police of any abuse that the participant may disclose during the interview, the participant decided against authentic participation. The interview was conducted but the participant did not actively engage in it in order to prevent exposing herself to the reporting risk.

114

Participants denied feeling insecure throughout the interviews and elsewhere emphasized the

degree of control they felt they possessed throughout. At the same time, however, those

participants who acknowledged experiencing emotional distress stated that they were surprised by

the intensity of their feelings as well as the insight that accompanied it.

Congruence of Research With Their Own Lives

A key factor in participants' decision to volunteer as research participants was their identification with the eligibility criterion profiled in recruitment materials; that is, their subjectivity matched the call for research subjects:

Whatever the ad said it seemed to very specific to me.

It was just like a perfect fit for me.

This recognition was frequently instantaneous.

I read it. I immediately took the number. And then, as soon as I got home, I called.

I pretty much immediately decided to participate—it was almost like she had designed it right around my parameters—I fit completely right into that so I totally wanted to participate.

Participants decided whether or not to participate in research through the consideration of its relevance within the context of their own lives.

Proportionate Review

Participants conducted their own subjective proportionate review, that is, they consider the risk versus benefit to themselves and others to decide whether to participate in research: "Certainly, I didn't think reliving it or retelling it was going to be so troubling that it would be a mistake." They weighed the benefits to themselves or others against prospective risk posed to themselves or others. Some indicated self-assessment of readiness for participation—"I have got to the point where I was able to discuss it"—suggesting that they might have opted against participation in other contexts, such as at an earlier period before they arrived at "this point."

Help. Just as "topic" is to researchers what personal "experience" is to participants, so, too, is "benefit" to researchers simply regarded as "help" by participants. Participants chose to

participate in studies to derive help ("At the end of it, they would offer any help that I would definitely need") or to provide help ("I like to help people out if I'm able to" and "I thought, you know what, even if it is in a different way, and it can help somebody else…I will certainly help"). Some participants want to help the research enterprise: "I think we have to help researchers." Participants volunteered for studies to help others in similar circumstances, especially when such perspectives were underrepresented: "It was a voice that wasn't really that heard from, so I was eager to give my two cents for that reason." Others were paid for their participation: "That helps, too."

Self-mediation of risk. Strategies employed by participants to mediate risk included refusing to participate in the first place, withholding information they considered "touchy," and refusing to reflect deeply. One would refuse to participate in research if she thought discussing the topic would cause her to "have nightmares." Another participant stated, "There was a lot of stuff I held back." One participant vetted out the researcher to ensure they were "understanding and compassionate" before referring other potential subjects in her community to them: "I had one researcher that was absolutely horrible. And I refused to pass her information on."

Security. When asked whether they felt insecure or uneasy during the interview, some participants said yes and some said no. The source of uneasiness was the same, however: talking about their experience ("I felt uneasy because I didn't really talk to anybody about that before," or "I almost want to say that I was at ease. Like I was okay sharing that information"). When probed directly whether they felt vulnerable, they all disagreed: "I didn't need any protection or anything like that because I felt safe." Others indicated they felt in control: "Given that I was in control I didn't feel my buttons were being pushed or I was being pushed into a corner…or an opinion was trying to be elicited from me." Elsewhere participants referred to the "relaxed atmosphere" of the interview as a "comfort zone."

Surprise

Most participants stated that their interview experience was what they expected it to be. In their responses they implicitly referred to their informed consent: "They reassured me that although it was a formal interview, it was going to be my story and they were going to be saying, 'and then what happened?'" Those who indicated that the interview was not what they expected indicated they were surprised by the depth of emotion and thinking they experienced during the interview: "I never thought it would be so draining for me . . . I never thought it would be sooo emotional for me . . . like I have to open my heart up for that interview . . . I never thought it would be so in-depth" and "It surprised me that it brought up the emotions it did." Others were surprised by what came up during the discussion: "I don't remember how I ended up talking about my son."

Unexpected Disclosure due to the Emergent Design of the Interview

Participants' Experience of Telling Their Story

Unique opportunity. Participants experienced the interview as a new and unique opportunity to share their experience with another person. The personal and sensitive nature of the participants' experiences precluded their everyday disclosure. Most respondents reported that their experiences were not shared with anyone previously, and one participant experienced the containment of her experience as internal disintegration.

Someone listened. Participants stated that their interviewer let them "talk and talk and talk" uninterruptedly while they listened. This interview experience, however, was distinguished from therapy in which people receive feedback. Having someone listen to them made participants feel cared about, that someone was interested in their situation and really wanted to hear what they have to say. In this regard, one participant distinguished unstructured qualitative interview research from what she referred to as "tick-box" studies.

Participants experience connection. In many cases the interview helped participants see that they were not alone. The interview itself fostered a feeling of connection, as a conduit for

vicarious connection both with others and with the interviewer. Participants found it meaningful that somebody cared to listen, was interested in their situation and what they had to say. As a result, some participants came to regard others from whom they had hid their personal circumstances as potential sources of support and friendship rather than fearing their scorn and admonishment. Some even experienced a reconnection with themselves.

Participants experience enhanced self-esteem. Participants' self-regard was also enhanced by their interview experiences. Many conceptualized their experiences of divorce, drug addiction, trauma, and relationships as socially stigmatizing or moral weaknesses or failings. For these individuals, having their experience as the focus of scholarly inquiry afforded them legitimacy and respect. Furthermore, participants felt that the interview validated their side of the story, a side that was otherwise generally underrepresented.

Participants can tell their whole story[2]. Participants felt that unstructured interviews provided a unique opportunity to tell their whole story. Participants defined "whole story" as the freedom to tell their story unconstrained by time limits, concerns about giving right or wrong answers, and the inquisition by others: "Women have to go tell their stories ten million times to different people. And they never get a chance to tell the whole story to one person." The absence of time limits meant that participants could "recount as many details as they could remember," such that "by the time we'd got to the end I'd said pretty much everything, start to finish." Participants felt they had told their whole story in its entirety to the extent that they did not have to hang on to any "bits and pieces."

Participants have power and control. Participants perceived that the emergent design of the unstructured interview gave them the power and control over the content and the process of telling of their story. The story was their "interpretation," and they could reveal or conceal the "minutiae of detail" according to their level of comfort. Prior to the interview some participants

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[2] "Whole story" is not intended to claim an objective notion of story but to capture what participants felt was a unique opportunity to tell their story in their own time and in their own terms.

119

were anxious about "what was going to be asked of me" even "taken aback" by the grand tour question, but once they realized that they had the control over the content and the process of the interview, participants were able to tell their story at their own pace and without interruption.

Telling their story is emotional. Unstructured interviews required participants to verbalize an experience ("By verbalizing it, you are acknowledging that that situation exists"), as well as how you felt about it. Talking evoked emotion: "I'm always *moved* when I *talk* about him," or "Immediately after the interview, I felt *sad.* You know, *because I was talking* about it," or "It was the first time I was able to *talk* about it without the *anguish.*" Interviews that require participation on a "lesser level" "probably wouldn't have caused me to cry"; for example, "answer the tick box." Hence, one participant notes that the "emotional cost of participating" in interviews must be acknowledged.

Participants experience insight, revelation. The experience of telling their experience meant hearing themselves talk. Verbalizing an experience forces participants to acknowledge the reality of their situation: "There is no way to hide from it . . . you just have to face it." Formal acknowledgement was often painful and depressing. For example, a participant struggling with drug addiction recalled how talking about his circumstances forced him to confront his reality: "You know I'm in a bad situation here. And I'm ruining my life." Other revelations, however, were positive and self-affirming: "I do have a heart of my own." Moreover, the interview shifted a participant's perspective about their situation, others, and themselves, providing an opportunity to reframe their experience. For example, during the interview a participant who had previously regarded substance abuse as a moral weakness might come to see it as a disease.

It is important to note that what participants concealed in the interview also catalyzed insight. One male participant who revealed his substance abuse in the interview, but concealed his homosexuality, stated that this caused him to later reflect not only on why he had not disclosed that during the interview, but also on the barriers that had existed in his life that prevented him from revealing his sexual orientation. His experience of disclosing his substance abuse in the

interview enabled him to reflect upon the possibility of disclosing his sexual orientation as well: "It gave me the realization that I should have talked about it." Subsequently, he did reveal that he was gay and was able to access specific programs for gay men with addictions.

Participants experienced transformation. Verbalizing an experience and acknowledging it allowed participants to move forward. Many participants regarded the interviews as "awakenings" to new possibilities, and many saw their interview experience as "the starting point." For some it provided "an open door" through which to access help for recovery. For others it marked a reorientation to their life, one in which they considered themselves: "I think about myself now." Ultimately, participants were transformed by their interview experiences.

Emotional Distress

Participants Become Emotionally Distressed

For most participants, unstructured interviews were emotional experiences that evoked deep feelings and deep thinking. Interviews were pleasurable for some: "a pleasant way to spend some time with a very pleasant lady." Another "looked forward" to connecting with the "very pleasant" interviewer again. Most other respondents, however, acknowledged some degree of emotional distress during the interview. Two female participants found the interview to be "really emotional" and admitted crying during the interview ("You know it landed me up in tears and so forth, to actually acknowledge how I felt about things"). The word "moved" was used by two participants to describe a shift in their emotional state during the interview: "Well, let's say that I felt well until. . . . I entered in the talking about my son's death and it's true that at that time, well let's say I felt a bit unhappy, I mean a bit moved." Another respondent recalled, "I was moved at certain times but not full of anguish or despair." When asked, "Did you cry?" he said, "Well, I would be lying if I wasn't—you know, close to, but no, I didn't cry, no." Another male respondent said he felt "nervous" and "sad" during the interview and admitted crying afterward.

Some participants denied feeling distressed during the interview. ("I wasn't emotionally upset. I guess I'm a little resigned to the fact that I've got [cancer] and I'm hoping for some cures

in the future") although one of these participants stated feeling tired after the interview; another participant stated that she felt "neutral" during the interview but acknowledged feeling "heightened senses" after the interview. Only one respondent was unsure of his emotional state during the interview ("I don't know if I had any particular feelings"). When asked, "Did you cry?" he replied "No, no, no, no."

Interviews do not cause distress

Participants were clear that their emotional response was associated with the situation they were talking about and not the interview per se. This particular attribution of their emotional distress is evident in the following four quotations from four separate participants:

> I mean, I guess the upset part would be more that I had *this disease* rather than upset that she would be asking me about it

> And the reason for my crying was that, this is a bad *situation.*

> Just the frustration of the *situation* that I was in, either in that, you know, nothing is going to rid of the RSD or nothing is going to stop my husband from stalking me. Just the hopelessness and the frustration of not being able to do anything about it…and a bit at peace that I have managed so much, facing these *horrible realities.*

> *Did you cry?*
> No. I cried enough at *that time,* I think I've cried all what I could cry and I don't cry anymore.

Emotional Distress is Complex

Emotional distress, as described by the participants, was neither positive nor negative but complex and encompassed a wide range of emotions. Interviews evoked a range of feelings: "just a whole gamut of feelings, like a whole bunch of feelings coming together." In addition,

emotional responses were "mixed," with participants feeling sorrow, hope, and joy at the same time, as captured in the following response:

> Number one, being able to say what it was like for me *was a good thing.* Recognizing how I felt about the various issues from the interview surprised me. That *wasn't a good thing.* You know, it landed me up in tears.

Crying was, therefore, also associated with relief, contentment, and hope as well as distress: "And I guess that is part of the crying, too, was that, you know, like it might have been joy, as well."

Emotional distress is contextual. Participants indicated that emotional distress is contextual; for example, dependent upon the state of the participant ("I got to the point where I could talk about it without the anguish") as well as the timing of the interview ("It depends on the day").

Emotional distress is interpretive. Participants felt it was important to help researchers. They were also aware of the emotional commitment that would be required of them to participate: "In order to give a true, realistic discussion you have to delve into those feelings which is what I do." Still, they decided to volunteer and connect with feelings of distress.

Emotional distress is subjective and relativist. One respondent offered a significant insight into the subjective relativism of emotional distress. When asked if interviews were emotionally distressing, he said,

> Like, using drugs is emotionally distressing. In comparison, no. You know, I think for the average person, possibly. But because of what I went through, not really. It was but it wasn't. Like sure it was emotionally distressing. But it wasn't like *hard* emotionally distressing. You know, because I felt good as well.

Emotional Distress Is Transformative

Participants experienced emotion as transformative. It was remarkable how frequently participants referred to both emotion and insight in statements describing the impact of the interview experience. Indeed, emotion accompanied "upheavals of thought." Realization and emotion seemed conjoined.

> It was too emotional for me . . . and plus it gave me a lot of insight about myself . . . I never thought about how *I* feel . . . I'm thinking about myself now . . . like a content type of thing now.

Such upheavals of thought facilitated transformation. It was as if seeing something differently mobilized changed. Such transformation was poignantly expressed by one participant:

> I remember leaving. And I remember feeling completely different than I have ever felt. I felt like almost—almost, like, there was a weight being lifted off me. You know, I felt there was hope . . . I'm doing the right thing, putting my foot in the right direction. I'm going to get some help.

Emotional Distress Is the Hallmark of Authentic Research

One participant said,

The subject of the interview and my acknowledging it made me cry . . . if I would have participated in the interview on a lesser level rather than so personally, then it wouldn't have caused me to cry. Or if it had been, answer the tick box that probably wouldn't have made me cry. But it also wouldn't have gotten out the real story which is what I think interviewers are looking for, the actual reality of whatever the subject is.

Post-interview Reactions

Interviews Have Impact

There was some consensus that after the interview participants felt that they had experienced a significant event. With one exception, a participant who was unaffected after the interview, all other participants referred to a change in emotional and intellectual state:

> My thoughts had been stimulated by recalling everything all at one time . . . It was just like a heightened senses—not negative . . . not necessarily positive either, just unsettled. Another participant recalled, "Immediately after the interview, I felt sad . . . but at the same time, I sort of felt hopeful.

Fatigue

No participants reported that they experienced harm as a result of their participation in unstructured interviews, either during or after the interview itself. None reported any negative responses or feeling "troubled" after the interview, regretful, or remorseful. Several reported feeling "tired, fatigued"; one distinguished feeling tired from therapy sessions, "where I was just drained . . . it was sort of like that. But this was just fatigue."

Positive Feelings

For some participants the experience had been cathartic: "I felt very relieved—I guess I just thought that the burden was gone out of my head and chest." Similarly, others felt "serene after the interview." Others felt "happy to have participated . . . I think research is important." They felt they had done their part in attempting to change things, "but you know I felt that I will have said what I feel about it. And maybe this will be helpful, maybe this will be not." Some felt "a sort of a sense of accomplishment."

Benign Afterthoughts

In response to the question, "Do you ever think about that interview now?" one participant said,

> Sure I do . . . because it was the first step . . . And I think back, you know, like, I just did that one thing, and I got paid for it, and look what happened . . . I'm clean and sober today. And special thanks to, you know, the people at [institution] and for that interview.

Most participants denied thinking about the interview afterward and reported a feeling of completion: "No, because I did it, told my whole story. Now, I'm finished. It is over. It is done. It is now up to [the researcher] to do something with it." As one participant distinguished, "I didn't think about the interview or the interviewer as much as the subject matter." Indeed, a few participants recalled what was learned in the interview: "She was always repeating that worries never feed you . . . so that is one of the things that has stuck in my mind," and "I just think about how relieved I felt when I cried."

Researcher Attributes

Participants Felt Cared About as People, Not Data

Participants thought "very highly" of the interviewers who they felt were "really interested" in what they (participants) had to say—rather than exclusively "interested in the research itself." Participants stated they "felt" or "sensed" the interviewer cared about them. The interviewers expressed their care in various ways. One participant recalled that the interviewer was " pleasant, calm, not abrupt, very open, had a soft, pleasant voice"; another commented that their interviewer was authentic ("She's not just talking words, she's interested in the way I'm answering"); another participant commended the interviewer for being "trustworthy and non-judgmental" ("There are no right or wrong answers"). According to the participants, their interviewers always did their best to ensure that respondents were "feeling comfortable and at ease." They sat in "close proximity" to the participants, shook their hands, explained things, and

offered things like a seat, water, and coffee. The interviewers' concern for the participants was evident in their promises to "let [the participants] know where [we] can reach for any kind of help"; their integrity was evidenced by their follow-through. One interviewer, who engaged with a participant in an ongoing study, started bringing a chocolate bar for him once she realized he "had a thing for chocolate."

Professional

Respondents regarded the interviewer who had interviewed them as a professional. They noted interviewers' credentials as scholars or health professionals. One participant noted that the person who interviewed her "was well informed"; she conveyed "she knew what she was talking about" and had the ability to connect participants with resources, even expedite their provision. Participants believed that the interviewer's professional expertise derived from her education as well as the knowledge she obtained from conducting other interviews, which ensured her capacity to understand their experience. The interviewer's competence was noted—"She was probably briefed or trained to deal with this sort of thing"—meaning her hearing about difficult circumstances and the emotional voices with which participants shared them and responding to them.

Skilled Interviewer

All participants described their interviewers as "a person to whom you want to say things," who created "a comfort zone" such that "it didn't feel like it was a 60 minute interview." Participants recognized that to conduct an interview "requires a lot of skill." The questions—their content, phrasing, and vocalization—were identified as a critical component to the interview. Participants remarked that interviewers "asked the right questions," both "the questions she asked first and then the ones while I was talking." Questions were sensitively phrased and clearly communicated: she had a "pleasant voice," was "very, very soft spoken," and "I could understand her very easily." Of particular significance was that "she would leave you the time to think" about things; she was not watching the clock.

Compassionate Listeners

The participants reported that interviewers were good listeners: "like a good friend who didn't say much." Because participants did most of the talking, the interviewers' nonverbal behaviour conveyed their support and understanding; for example, "constant eye contact" and gestures such as "nodding." One participant, however, stated that this support and understanding could be conveyed over the telephone as well despite the absence of visual cues.

Participants reported that interviewers responded to participants' sharing of experiences with understanding and compassion. Participants were certain that the interviewer understood their situation: "Absolutely, I know that [she] knew that going through a situation like that is not easy. And I'm sure [she] could understand"; "she didn't seem shocked." Participants found that interviewers responded to their emotional distress, and if they cried, the interviewer did not stop them but provided comfort and offered to pause the interview.

According to one participant, "If the interviewer can make the person feel okay about himself then the interview will go okay." Accordingly, participants perceived the interviewer to be someone who "really made me feel at home . . . she said she has all the time in the earth for me . . . I just felt that there is somebody listening to me."

Relationship With Researcher: Reciprocity and Rapport

Participants felt that they had good rapport with the interviewer: "I could relate to her." They stated feeling "on the same page" as the person who interviewed them, having "some common experience" with her and emphasizing that she was "not clinical or officious." According to one respondent, this rapport was "all about power": The participants had "control over the discourse." "In addition, the participants believed their relationship with the interviewer to be reciprocal: "I mean she's doing research that's going to help her and that is going to help me." Indeed, some (male) participants, particularly those with whom the research relationship had extended over time, evidenced the exchange of personal information: They knew her marital status and whether she had children. They stated that they now considered her a "friend." Such

participants recommend that the same interviewer be used for multiple interviews so that the participant can "look forward to connecting again in the future." The female participant whose interview was conducted over the telephone stated "But I think that possibly when I emailed her back to thank her for doing the research [it] was 'cause I think I was still trying to make a connection with the person that reached out and cared." This suggests perhaps that for some participants connection is easier to establish face-to-face.

Perceived Benefits

Participants described the following benefits derived from their participation in unstructured qualitative interviews.

Insights/revelations. It was the epistemological/ontological dimensions of the interview experience that was the most compelling, according to participants. It was remarkable to participants how the interview had evoked such deep thoughts and discovery of meaning: "I never thought that I could cry" and "I do have a heart of my own and that came out in the interview."

Transformation of self. Participants reported being changed by the interview experience: "I'm thinking about myself now"; "I remember feeling completely different that I have ever felt."

An opportunity to tell their whole story. Participants were grateful for the opportunity to share their experience, often for the first time and for the first time in its entirety. The interview was like a sanctuary for the sharing of secrets: "I think it's an opportunity to say what you feel, what you think" to someone who is "bound by confidentiality"; "By verbalizing the whole story, you are laying the whole thing out that you have never been able to do before."

Emotional release/catharsis. Among the "gamut of emotions" experienced during the interview, the feeling of relief and the replacement of worry by serenity was common: "I just felt that some of the burden from my chest is gone . . . I felt very relieved after the interview" and "It is an "unburdening to be able to tell your whole story."

Fostering connection. For participants, sharing their secrets was relational: "There's something in just saying it out loud and knowing that somebody's hearing you-you're not

standing by yourself"'; "It was comforting to know that I wasn't the only person that went through this kind of thing, I'm not by myself in this."

Coming out from hiding. Many participants bore burdens of worry, shame, and guilt in isolation. The interview was a conduit for them to come out: "I hid my sexuality"; "I used to hide a lot of things from people . . . [the interview taught me] how to be open with people and especially in friendship"; I had my own pain that I was hiding from my children or something . . . [in the interview] I could talk about it freely."

Receive care. "I just felt that there is someone listening to me."

Compensation. Although most participants said that receiving material compensation such as money was not the primary incentive for their participation, they did mention money as a fringe benefit and also specifically cited the provision of resources and, in particular, that these were expedited by their interview participation, "like a push to the front of the line," as beneficial.

Altruism. Participants participated in interviews that were personally meaningful to them. Part of this meaning was translated into helping others as they were helped or contributing to something (like research) that they felt was important—"I felt I was doing a good deed"; "some benefit can be derived for the greater whole."

Social action. Some participants felt that by participating in the interview, they had done their part to effect change. There was hope that research outcomes would effect change: "help people realize that there are problems and that problems should be addressed"; "there is always the benefit of making change."

Pleasure. Pleasure was within the gamut of emotions that participants experienced during their interview: having fun, receiving chocolate bars or coffee, something to "break up my day."

Perceived Harms/Disadvantages

None of the participants interviewed in this study believed they had been disadvantaged or harmed by their participation in unstructured qualitative interviews: "Can't think of any"; "Can't see any"; "No." When conjecturing about disadvantages or risks in a hypothetical way

they mentioned breaches of confidentiality, time and emotional commitment. They opined that some people may have trouble dealing with the impact of looking at their experience and cited persons they knew who had refused to participate in studies. In one participant's view, these people hadn't yet resolved their experience or risked being re-traumatized by re-telling an event. This may suggest that people at real risk in interview research opt not to participate in them.

Responses to Statement: "Interviews Are Risky"

Several participants responded to the statement "Interviews are risky" by asserting that they were not risky. Others asserted that risk in interview research was not objective, absolute, or measurable, i.e., not absolutely devoid of risk, but that risk was emergent, subjective, relative and interpretive:

I suppose there's the potential for them to be, but it's not like a flat out rule. It depends how they're worded and at what stage or what's going on for the person at the time of the interview—that would certainly have more of an influence than the questions themselves.

Participants proffered that the ethical conduct of research was key to ameliorating risk. One male participant implied that the lack of informed consent would constitute risk, "if you don't know beforehand, the parameters" of the interview. Referring to his own interview experience he stated,

You know, I didn't feel they were withholding information or anything. You know, and also, they talked about confidentiality. And they also talked about ethics.

Similarly, another participant referred to the ethical conduct of the interviewer in respecting his boundaries as an important factor in ameliorating risk. He stated, " I think it depends on who the interviewer is and what the subject is…I suppose if an interviewer wanted to get really personal, I might get defensive or something."

Participants re-iterated that their control over the telling of their experience was a powerful factor in protecting them from harm:

Yes, they assured me that I was going to be retelling the story. And, they said I could disclose what I wanted and withhold and, you know, they didn't say I had to include everything I t wasn't the whole truth and nothing but the truth sort of thing. It was my recounting of it.

Participants did refer to the significance of emotional distress and insight as both potential risk factors as well as benefits:

Experiencing a situation is like a real slap in the face. But also, talking about it could be like a slap in the face, as well, you know an awakening or a realization. So, it could go both ways. It could be really powerful, talking about it, or possibly not. It can go any way.

Another participant also spoke of risk, "So, I mean that is where the risk is: it is two things: Is the interviewer compassionate enough? And do you have the emotional strength to face your whole experience?" When this respondent was probed, 'If interviews are risky, how do interviewers protect participants?' she said,

You make sure that there is time, that there is enough time to let the woman tell her story. See, I think as you are telling your story it is like circling the drain, right? You start off circling the drain. Then, you go down the drain into the depths of what happened. And you need the time to pull yourself back out again on the other side.

Discussion

Disjuncture refers to the seismic lines of fault between textual representations of a particular experience and people's experiential knowing. In the following section I identify and

discuss six disjunctures that I have found through this study between dominant discursive conceptualizations of risk to participants inherent in unstructured interview research and participants' actual experiences of benefit and harm resulting from their participation.

Disjuncture Between Researchers' Conceptualization of Risk and Participants' Experience of Harm

Telling secrets can be beneficial. Researchers believe that sensitive research poses risk to participants because of its intrapsychic cost and foreboding implications and consequences. Participants agreed that "the emotional costs of participating must be acknowledged." Indeed, many participants felt uneasy talking about their experiences, many for the first time. Indeed, what researchers regard as sensitive "topics" are experienced by participants as "secrets," and the data from this study suggest that people suffer shame, stigma, fear, and guilt regardless of whether they disclose them. The difference between telling and not telling is that keeping secrets meant suffering alone in silence, what one participant referred to as "crumbling on the inside." Telling secrets in relational contexts morally "bound by confidentiality" alleviated this suffering. Implications and consequences of participating in sensitive research were beneficial. The participants in this study reported several benefits from disclosing these secrets, including relief from alienation through the fostering of connection, coming out from hiding, healing, catharsis, and enhanced self-esteem. Predictions of risk to participants by talking about sensitive and personal health-related topics were not verified in this study.

Vulnerable participants are competent. Research ethics boards conceptualize participants as vulnerable others; some ethicists believe that participants do not know enough to protect themselves. Thus, risk assessment is an epistemological claim that REBs believe they are uniquely qualified to make. In authorizing themselves to make these surrogate decisions, they claim that positivist epistemology is superior to subjective epistemology. Indeed, the quintessential scientist within the positivist tradition was imbued with the unique capability of

133

abjuring subjectivity to prevent it from biasing his objective reason. Similarly, most countries that have research ethics guidelines embrace an absolutist rather than a relativist definition of minimal risk. They endorse a more objective, universalistic approach, some (those that consider risk in a routine medical or psychological exam rather than risk in terms of everyday life) even attempt to move as close as possible to scientific laboratory conditions in their risk assessment. Only Canada subscribes to a relativist definition of minimal risk wherein the participants' own assessment of risk in comparison to their own everyday life, counts.

The data from this study, however, demonstrate that participants are knowers capable of deciding whether to consent to participate in research and who are able to mitigate their own risk during unstructured interviews. The knowledge they draw from, however, is subjective, emotional, relational, contextual, and interpretive. One participant indicated that he would not participate in research the topic of which might provoke "nightmares"; another did volunteer to participate after evaluating that he or she was now in a place where he or she could talk about the trauma. Who better than the participants to answer the question one respondent posed as the critical one in deciding whether to participate: "Do I have the emotional strength to face my circumstances?"

Participants also evidenced their agency in mitigating risk to themselves. Participants drew on reason as well as intuition and embodiment to employ strategies to protect themselves. One person described vetting prospective interviewers over the telephone. From another study, a small girl who was asked about her experience of participation in research regarding her history of sexual abuse stated that she knew not to answer any question that made her feel faint (Heltne, 2007). Emotional distress during interviews is often associated with insight; that is, heightened information with which to act, not a reduction in competency. Furthermore, the literature provides examples of the fallacious thinking that positivist epistemology is superior in this regard; indeed, surrogate decision-making is itself subjective, representing REB membership (Palmer, 2003). Decisions made on behalf of participants have not represented their perspectives and have had the

134

potential to harm them by excluding them from opportunities to participate. One such example is the study conducted by Terry, Olson, Ravenscroft, Wilss, and Boulton-Lewis (2006), who investigated hospice patients' views on research in palliative care. They found that "patients did not share the concerns of ethicists about the difficulties and hazards of research with the terminally ill. These patients' views are not reflected in the professional consensus" (p. 406). Ethicists felt that dying persons should be protected from research participation; patients themselves stated that to be denied the opportunity to decide for themselves meant that they were being treated as if they were already dead.

Researchers are moral agents. Participants had extremely positive regard for their interviewers. Participants felt cared about as people, not exploited or betrayed. Their accounts of researchers' attributes and comportment attest to the moral commitment researchers have to protect the dignity of the participants.

Emergent design is protective. Participants reported that the unstructured interview provided a unique opportunity for them to share their life stories. They emphasized the freedom and control they were granted as important to the safety and security they felt in the sharing of their stories. Contrary to posing risk, therefore, the emergent design of the unstructured interview was protective. Furthermore, participants attributed their interview experience to the emergent design of the interview that enabled them to talk, acknowledge, feel, think, reframe, and transform. Indeed, participants experienced these interviews as "upheavals of thought" evoking deep thinking and deep feeling, leading to insight, revelation, and even transformation.

Emotional distress is paradoxical. Metaphors such as a good cry or weeping with joy illustrate what is meant here. Participants experience "a whole gamut of emotions," and they are mixed: Crying is despair and joy and hope. Contemporarily, emotion is culturally defined in terms of valence and polarity such as negative versus positive or love as the opposite of hate. This simplistic definition of emotion has obfuscated the understanding of the paradox of participants' emotional distress: How can they report emotional distress as well as benefit? Emotional distress

135

is a complex concept that participants in this study evidenced as subjective, interpretive, contextual, and critical to communicating authentic stories. Emotional distress is not an absolute, negative valence emotion that is the opposite of pleasure or benefit. Emotional distress is not absolute harm. Thus, the conceptualization that participants are psychologically harmed by recounting personal or sensitive, even traumatic, circumstances is not empirically supported by the literature (Dyregrov, Dyregrov, & Raundalen, 2000).

Interviews do not cause emotional distress. Participants in this study clearly attributed their emotional distress to the stories they were telling, not to the interview. The literature evidences that the distress evoked from recalling a traumatic event must be distinguished from the intense fear, helplessness, or horror that comes from direct experience, implying that although trauma research may be distressing, it is not traumatic per se (Newman, Kaloupe, Keane, & Folstein, 1997; Straus, 1981).

Implications

As a result of this study, the following implications have been identified.

1. Sensitive research might be beneficial to participants as well as to society. The implications to this are twofold: First, research ethics governance must take these possible benefits to participation into consideration. To deny participants the opportunity to participate or to refuse approval of unstructured interview research on the exclusive concern for risks that may not bear out or are grossly overestimated is to cause harm to participants and to society. Second, researchers, as listeners, are morally charged with great responsibility. "The encounter between listener and speaker can be extraordinarily helpful, at times illuminating; but it must be conducted with the utmost respect for human dignity." (Bok, 1983, p. 84).

2. Risk assessments are knowledge claims that should be informed by subjective epistemology. "Subjects' are people and citizens with the same rights as anyone else, including the right to be at risk and the right to put themselves in positions that others

might define on their behalf as putting them at risk" (Holland, 2007, p. 909).

Furthermore, there are no absolutely vulnerable people, no universal criteria for surrogate decision makers to use as a sieve to permit or exclude people from participation. Especially in contexts where the nature of risk is personal and sensitive, subjective epistemology should be valued and influential. With respect to research ethics governance, the subjective relativist definition of minimal risk should prevail. Canada, the only country currently to incorporate such a definition in its ethics guidelines, ought to preserve and protect this as the research ethics governance enterprise is globalized.

3. All eventualities in research cannot be known a priori. Unstructured interview research projects are moral unfoldings more properly guided by an ethics-in-process approach.

4. Research governance must take emotion into account in moral reasoning. Current ethical theories and principles such as utilitarianism force the reduction of emotion to single valences that can be plotted on a harm-versus-benefit scale, or are too acontextual, rational, and absolute to consider emotion at all.

5. Research ethics governance should ensure the protection of participants and the unstructured research interview method from harm; for example, subversion of this method secondary to imaginary or overestimations of risk.

Limitations

I experienced difficulties recruiting participants for this study. This limited the adequacy of the data I collected. Adequacy refers to informational adequacy and refers to the sufficiency and quality of the data obtained (Morse, 1991). In order "to ensure adequacy, one assesses the relevance, completeness, and amount of information obtained" (Morse, p. 135). Although the data collected is relevant with each participant yielding rich information the data is not yet sufficient. "Thin" areas include the ways in which participants decide whether or not to participate in interviews and the strategies they employ to mediate risk during interviews. In order to assert a theory regarding participants' perspectives regarding risk inherent in unstructured

qualitative interviews I first need to saturate such thin areas. Although this study concludes my

doctoral research I intend to continue to recruit until theoretical saturation has been achieved. The

findings of this study, therefore, are preliminary.

Conclusion

Despite predictions of risk to participants inherent in their participation in unstructured

interviews, no participant reported harm despite experiencing emotional distress. Participants

regarded their interview experiences as a unique opportunity to tell their stories, a profound

experience that provoked deep thinking and deep feeling leading to insight, revelation, and even

transformation. These preliminary findings contribute a virtuous feedback loop to researchers and

REBs who are mandated to conduct interviews with the utmost moral commitment to human

dignity and oversight that protects participants' right to participate and sensitive research to be

produced.

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INTEGRATING CONCLUDING CHAPTER:

DISCUSSION AND CONCLUSION

The current crisis in research ethics oversight constitutes the background for this dissertation research. As previously stated, the need to ascertain participants' perspectives of risk inherent in unstructured qualitative interviews is urgently needed for its own merits as well as for the elucidation it might confer on the appropriateness of the current normative context of research ethics oversight for qualitative inquiry. Indeed, people's experiences of harm (or experiences of no-harm) are critical to inform the conceptualization of research risk to participants: its definition of minimal risk and the practice of proportionate review. This dissertation research, therefore, contributes evidence that is currently lacking. Indeed, it responds to the urgent call for this evidence from an interdisciplinary perspective.

The strength of this dissertation research lies in its exclusive focus on participants' perspectives of harm inherent in unstructured qualitative interviews and not other types of interviews or focus groups. Its findings are particularly relevant to elucidation of risk as this type of method is considered to pose the highest risk to participants. Furthermore, unlike most other emergent studies regarding participants' perspectives, the participants I recruited were not my previous interviewees but participants who had been previously interviewed by various other researchers regarding various sensitive topics.

Current Crisis in Research Ethics Oversight Characterized by Disjuncture

The current crisis in research ethics oversight was precipitated by the norming of research ethics governance. Prompted by the imposition of normative guidelines regarded as biomedically hegemonic, a subset of social science and humanities researchers resisted its governance of their work. Their resistance was underpinned by their conviction that the risk posed to their participants was qualitatively different from that to which participants in clinical trials are exposed. Thus, research ethics oversight and social science and humanities research were

constructed as two solitudes. The problematic of this dissertation research is situated within this crisis: What are participants' perspectives of risk inherent in unstructured qualitative interviews, and how is this risk conceptualized within the current context of oversight?

The term *disjuncture* (Smith, 1990) is a metaphorical seismic fault line between the conceptualization of an experience and the experience itself. Disjuncture frequently exists between institutional governance of a phenomenon and people's experience of it. Certainly, research ethics boards (REBs) are among those institutions that govern knowledge production, and their proportionate review of risk is their primary ideological practice. Governance in contemporary societies is accomplished in part through concepts such as risk. Disjuncture figures prominently in the background of this research, and therefore it needed to be featured in its methodological approach.

Institutional Review Boards and the Ethics of Emotion

In the first paper, I contextualize this issue by taking up the problematic of emotional distress as risk to participants in interview research. This conceptual analysis of emotional distress both lays the foundation for the study itself and informs the findings (which corroborate the conceptualization of emotional distress) and implications. (See Figure 4.0) First, I begin by discussing the implications of selecting the semistructured interview as the method for this study, after which I will discuss the findings and implications of the study.

Paper 1: REBs and the Ethics of Emotion

- Emotion is the essence of qualitative inquiry.
- Emotional distress is conceptualized as paradoxical, contextual, interpretive, and subjective.
- Emotional distress is not absolute harm.
- Interviews are moral unfoldings.
- Emotion informs the moral conduct of interviews.

Paper 2: The Diversification, Utilization, and Construction of the Semi-Structured Interview

- The proliferation of the semi-structured interview was evidenced.
- A heuristic typology of semi-structured interviews was identified.
- Participants' actual experiences of risk were ascertained.
- Participants' actual experiences of risk were compared to dominant conceptualizations of risk.

Paper 3: Participants' Perspectives of Risk Inherent in Unstructured Qualitative Interviews.

Disjunctures between dominant conceptualization of risk and participants' actual experiences:

Categories	Conceptualization	Actual Experience
harm	prediction of high risk	no actual experience of harm
emergent design	lack of control risky	participant control is protective
participants	vulnerable	competent; self-mediation of risk
emotional distress	harm	paradoxical, contextual, interpretive, subjective
sensitive topic	prohibitive intrapsychic cost	telling secrets in confidence may confer benefit
benefit	outweighed by risk	participants report multiple benefits

Tentative Implications of Findings to Research Ethics Governance

Subjective epistemology must be valued and should influence ethics oversight.
Ethics of emotion must augment existing ethical perspectives.
Interviews are unfoldings most congruent with ethics-in-process.
Subjective relativist definition of minimal risk is best for interview research.

Figure 4.0 Overview of Preliminary Research Findings

The Proliferation, Diversification and Construction of the Semi-structured Interview

The second paper in this dissertation introduced a typology of semistructured interviews, including the discovery/corrective type used for this study. Researchers who investigate social activist organizations recognize the value of the semistructured interview to critical research (Blee & Taylor, 2002). The particular utility of semistructured interviews to critical research generally, similarly, benefited the purpose of this study. First, the semistructured interview enabled access to the motives and perspectives of those whose views are underrepresented—in this study, research participants—compared to those whose conceptualization of participants' risk are discursively predominant, those of some researchers and REBs. Second, this method enabled the comparison of these perspectives. I constructed the interview schedule from the identification of the dimensions or categories of the domain of risk. Question stems and scheduled probes were wrought from these categories and informed by the literature that underpinned them. The semistructured interview facilitates the ascertainment of participants' perspectives in a controlled way, such that they must respond to the dominant conceptualization category by category. In this way the disjunctures between these perspectives became critically visible. Furthermore, this approach enabled the participants to elaborate, refute, or confirm this conceptualization, thereby offering a unique opportunity for their voices to be heard. Third, as this method ascertained the perspectives of people, it emphasized the human agency of research participants, easily lost within the abstraction of conceptualization, and also distinguished them as people, not simply generic "participants." Finally, the open-ended nature of semistructured interviews allowed the participants to convey their meaning of participation. Nonparticipants can theorize about such issues as emotional distress ad infinitum, but only the person experiencing it can tell you what it meant to him/her.

I also selected the semi-structured interview method for this study because of its status as a mixed method. My original intention was to recruit a large enough sample to be able to apply nonparametric statistical analysis to the qualitative data. I hoped that the patterns identified via

content analysis could be confirmed, or new patterns identified, through this statistical analysis. The recruitment problems I experienced undermined the timely recruitment of the required sample size for this purpose; however, I have committed to continuing my recruitment and delaying the publication of my results until I have achieved a sample size of 60 participants.

The small sample notwithstanding, the findings do demonstrate several disjunctures. Of course, these findings might be confirmed or undermined with the achievement of a larger sample. At present, however, there are strong corroborations with other such literature currently emerging. I present this literature in the following section.

Participants' Perspectives and Experiences of Risk in Unstructured Interviews

Despite the presumption that unstructured interviews pose high risk to participants, no participant reported experiencing harm as a result of participation. This finding is congruent with the literature emerging from similar qualitative inquiries that indicate that harm to participants is significantly overestimated or rampantly imagined (Haggerty, 2004). Participants neither reported harm resulting from their interview participation nor regretted their participation (Carter, Jordens, McGrath, & Little, 2008; Dyregrov, 2004; Dyregrov, Dyregrov, & Raundalan, 2000; Morecroft, Cantrill, & Tully, 2004; Scott, Valery, Boyle, & Bain, 2002). Indeed, these findings are so consistent that social science researchers suggest that ethics review of their proposals cite the identifiable harms presumed to exist in their studies as a way of countering this overestimation of risk.

Positivist Presumptions of Risk are Incommensurate with Risk in Qualitative Inquiry

The reason these presumptions were not verified is that the conceptualization of risk that is inherent in the presumption is incommensurate with the nature of risk in qualitative inquiry. Indeed, the very notion that risk is itself predictable is an example of this problematic conceptualization of risk that is confounded by the absence of actual harm. My results elucidate participants' experience of risk inherent in their participation in unstructured interviews. Their experience of risk does not conform to non-participants' conceptualization of risk. The findings

148

of this study contribute to the resolution of the debate whether risk is methodologically specific by providing empirical evidence of the different nature of risk that is experienced in interview research. Qualitative researchers since Cassell (1980) have been asserting the different nature of risk that exists in qualitative research compared with risk posed to subjects in clinical trials. The findings of my study affirm this stance.

The basis of the incommensurability between predictions of risk and actual harm is epistemological. Predictions of risk are themselves a kind of knowledge claim wrought out of the positivist epistemology that underpins research-ethics guidelines. Qualitative research, however, is underpinned by subjective epistemology. Positivist conceptualizations of risk (appropriate to biomedical research) regard risk as predictable, statistically calculable, objective, absolute and generalizable. Risk in qualitative inquiry, however, is subjective and objective, contextual, interpretive, relational, embodied and emergent. It is no wonder that emotional distress, the epitome of subjectivity, confounds ethics review.

Simple statements of risks and benefits are insufficient to capture the complexity of participants' actual responses to research participation. Braunack-Mayer (2002) expressed this well: "Ethics committees may be able to separate out the risks and benefits conceptually, but in people's experience of taking part in research, as in other areas of our lives, things are seldom so tidy" (p. 177).

Conceptualizations of risk to participants inherent in unstructured interview as constituted by participant vulnerability, emergent research design, and talking about sensitive issues were not verified because they were conceptualized in positivist terms. Between the a priori assumption of risk and the outcome that refutes it, is the unstructured interview itself. My findings suggest that the unstructured interview is a dynamic, complex moral unfolding constructed by competent participants (including the researcher) and mediated by emotional disclosure of sensitive stories difficult to tell but beneficial in their telling.

Participants' Perspectives and Experiences of Interviews

Participants are Competent and Resilient

The participants in my study demonstrated a capacity for deciding whether to participate in research based on a consideration of the impact it would have on them or others as well as the capacity to mediate risk to themselves during the interview itself. This finding was corroborated by the findings of other researchers. Several researchers indicated that a significant percentage of prospective participants decline to participate in their studies, suggesting that people who might be at risk of harm elect not to participate. Like one of the participants in my study, who stated she mediates risk by refusing to reflect deeply, participants in other studies use similar strategies. Cook and Bosley (1995) reported one participant's statement, " I did not know if I would answer fully, but I believe I did"; this might suggest he was prepared to not engage fully in the interview. Other researchers reported participants who stipulated from the outset that they were not prepared to answer emotionally sensitive questions (Corbin & Morse, 2003). According to Carter et al., (2008), participants

> were not passive subjects but active and critical co-creators of knowledge. They turned the tables, invited critique of their own performances, commented on the limitations of the knowledge that was being created, and talked their participation as changing their selves and their knowledge about their experience. (p. 1273)

Dyregrov et al., (2000) remarked on the "surprisingly frank and confident way" their participants told their stories, "although [becoming] emotionally involved from time to time" (p. 419). Antithetical to the conceptualization of the experience of research participation as dominating and oppressing, some findings suggest that participants become less vulnerable and more empowered as a result of their participation. In addition, participants in my study indicated that they were less vulnerable as a result of their interview participation. Indeed, as I discuss in my results, they were transformed by it. Similarly, Brannen (1993) indicated that her participants

(mothers returning to work after maternity leave) become empowered and politicized via their participation.

Conversely, surrogate decision-making, (i.e., REBs deciding on a participants' behalf how much risk is appropriate for them to be exposed to, rather than the participant deciding this for himself), might be harmful. One of my participants said that the decision to participate or not is predicated by the question, "Am I emotionally strong enough to face my circumstances?" Who else but the person can answer this? Erroneous assumptions regarding risk to "vulnerable" others results in gatekeeping that might themselves be harmful. Certainly, research findings suggest that decisions made on behalf of others are not commensurate with the decisions people would themselves have made (Terry, Olson, Ravenscroft, Wilss, & Boulton-Lewis, 2006). In particular others over-estimate the risk. Terry et al.'s study of hospice patients' views on research in palliative care exemplifies this disjuncture, quoting ethicist George Annas (2006) as saying, "Terminally ill subjects with fewer than 6 months to live should be disqualified from human subjects research. Desperate, and, therefore, too vulnerable, they are unable to distinguish research from treatment" (p. 406). The patients, however, refuted this idea, stating that there was a freedom in being close to death to be precise about their wishes and that they had nothing at all to lose by voicing their own opinion: "I wouldn't feel obliged [to participate]. If they could talk to you they wouldn't be worried that you couldn't say no" (p. 411). Furthermore, from their own proportionate review, the prolongation of life was regarded as an adverse event rather than as a benefit" (p. 412). Palmer (2003) described how risk assessments are made differentially according to whom the people are who are making them. Research-ethics boards are comprised of members who bring their subjectivity to their reviews of risk. Certainly, participants' views should trump those of other subjectivities when the decision is so personal in nature.

Participants Embrace the Opportunity to Tell Their Stories

Participants in my study regarded the interview as a unique opportunity to tell their stories, often for the first time. Similarly, deMarrais and Tisdale (2002) reported that participants felt comfortable in telling personal and intimate experiences that they had not previously shared with others. Participants in Dyregrov et al.'s (2000) study believed it was helpful to be given the opportunity to talk about their experiences to someone interested in what they had to say and appreciated being able to talk about "the worst things, the war and everything" (p. 420). Scott et al., (20002) reported that half of their participants regarded the interview as an opportunity to discuss their child's illness. One participant in Lowes and Gill's (2006) study stated that the interview gave her permission to talk; others appreciated the opportunity to dedicate time to talking about their experiences, which they had not found time to do in the normal course of their lives. Dyregrov's (2004) participants emphasized the importance of having the opportunity to talk about their loss. Being allowed to express the pain, confusing thoughts, and anger to an understanding person from the outside was an opportunity seldom offered by friends and family, who believe that there is a danger in re-experiencing the pain. Participants report that their social network could not tolerate to listen to accounts of what happened for as long as they would prefer.

Unstructured Interview Viewed Positively

Participants in my study appreciated the freedom and control afforded them by the emergent design of the unstructured interview. Other participants reported their positive evaluation of this research method. Their reports are synthesized by the researchers who stated: "Two thirds of the adults emphasized the positive effect of the open, unstructured interview, which gave them the opportunity to associate and go beyond a strictly defined topic of interest" (Dyregrov et al., 2000, p. 422). Similarly, participants appreciated the "empathic, open-ended style . . . including the researcher's ability to following feelings and ideas which emerged throughout the interview process" (Cook & Bosley, 1995, p. 418). Participants emphasized being

able to tell their stories from beginning to end. Dyregrov (2004) reported that the grieving parents in her study appreciated the conversational format of the interviews and reflected on how it contributed to their positive experience. They specifically referred to the give and take dynamic of it. Scott et al. (2002) reported their participants (grieving parents) stating, "We particularly liked the interview, for the chance to sit and talk face to face with a wonderful lady who was professional, compassionate, understanding and answered all our questions honestly" (p. 508). In a third study participants made it clear that they much preferred the interview to questionnaires with their limited range of forced choice responses (Brannen, 1993).

Concomitantly, the unstructured interview did cultivate an emotional space in which difficult experiences and emotions are relived (deMarrais & Tisdale, 2002; Lowes & Gill, 2006). Indeed it was quite common for participants to relive many of the emotions that were present during the initial incident they were describing. Participants found it difficult to discuss emotive issues but found it helpful to talk about their experiences (Lowes & Gill, 2006). Dyregrov et al., (2000) reported that the overall perspective of their participants were captured in the statement given by one participant who said, "It hurts to talk, but it also feels good and we need to talk" (p. 415).

Insight, Reframing, Revelation, Transformation

Carter et al., (2008) pointed out that interviews do not simply retell but reconstruct experience. The insights experienced by my study participants corroborate this. Furthermore, Carter et al., suggested that the epistemological and ontological implications of research participation to participants were the most significant to them; that is, had more impact than emotional distress. Dyregrov et al., (2000) indicated that their participants intentionally agreed to participate because "of the possibility that the interview could help them to rethink and analyze their situation" (p. 418). This turned out to be one of the most positive aspects of being interviewed for the whole group (Dyregrov et al. 2000). Other participants confirmed the views in my study that telling their stories forces you to acknowledge your circumstances. Participants

referred to the opportunity the interview provided for them to reorganize their story into a coherent one and gave meaning to their experiences. Beck (2005) reported that her participants emphasized the usefulness of the interview in making sense of it all.

Emotional Distress

In the following section I demonstrate how aptly the conceptual analysis of emotion in the first paper of this dissertation captured participants' experiences and perspectives of emotional distress in my study as well as the literature generally.

Emotional distress is paradoxical. Participants who discuss sensitive topics in unstructured interviews become emotionally distressed. Participants report that it is painful to talk, that it was hard to talk about their situation and memories for such a long period of time. It grieved them to remember. They felt "depressed, sad, angry, nervous and upset" (Dyregrov et al., 2000, p. 420). Yet, when asked what they wanted to talk more about, they said "the worst things, the war and everything" (p. 420). Emotional distress was manifested by wiping away tears and openly crying. Scott et al. (2002) indicated that the benefits gained came despite the pain of talking about distressing events (Braunack-Mayer, 2002). Emotional distress is paradoxical; pleasure is also present: "It's good to get it out" (deMarrais & Tisdale, 2002, p. 121).

Emotional distress was a surprise. Participants in other studies, similarly, felt surprised by the depth of emotion evoked during the interview (Cook & Bosley, 1995; Scott et al., 2002). Lowes and Gill (2006) reported their participants were "unprepared for the intensity of their emotions" (p. 592).

Literature supports the statements made by my participants that their emotional distress was a function not of their interview participation but of their situation (Balk, 1983).

Emotional distress is complex. Participants in my study referred to feeling a "gamut of emotions" and described their crying as despair, joy, and hope. In de Marrais and Tisdale's (2002) study their participants' experience of anger "clustered with guilt, sadness, rage,

frustration, and disappointment" (p. 116), prompting them to regard anger as a difficult rather than a negative emotion because they see cultural interpretations of emotion as simplistic.

Emotional distress is interpretive. An emotion, for example anger, is not a single valence (negative) or polar opposite (to empathy) phenomenon; furthermore, it is itself different depending upon the context in which it arises and how the person interprets it. De Marrais and Tisdale (2002) reported asking a participant (teacher), "And do you feel like the anger was different, too, because of the different incidents?" The participant responded,

> Good question let me think . . . I feel they [several incidents of anger in a classroom setting] were close to the same but the root cause was slightly different. Pride was still in evidence but in the latter cases there was provocation . . . in the first case there was no provocation, there was no reason, that anger stemmed solely from me and not from . . . [crying, catching breath] goodness gracious, I need to stop. (p. 115)

Emotional distress may manifest itself similarly, in this case, she recollected experiencing anger, but the context and interpretation were different. Similarly, when Dyregrov et al., (2000) asked participants if the questions posed were too personal or too importunate, "the adults laughingly reassured that where they came from everybody could ask everyone very personal questions without offense" (p. 420).

Benefits

Emotional distress is concomitant with participants' reports of deriving benefit from their participation. Participants assert the therapeutic value of their interview participation (deMarrais & Tisdale, 2002; Lowes & Gill, 2006). Beyond psychological benefit, there is evidence that participants derive physiological benefits as well. Morecroft et al., (2004) reported that participation in in-depth research interviews regarding hypertension and its management facilitated a more meaningful appreciation and understanding of their participants' condition (p. 247). Brannen (1993) reported that her participants experienced enhanced political awareness as a

benefit they derived from their interviews. For some participants the interview was a catalyst for family members to dare to start talking about the suicide and begin mourning (Runeson, 1993). Like some of my participants, who felt alienated and underrepresented in social discourse, one of Beck's (2005) participants said, "Thank you from the bottom of my heart for giving us a voice" (p. 420)

Attributes of the Researcher

Like the participants in my study, other participants valued similar attributes of the interviewers: they consistently cited the researchers' compassion, respect, professionalism, and skill. In their own words, participants referred to interviewers who "clearly understood our situation," "posed the right questions," "listened empathically and respectfully," "gave room for our sadness and crying," "did not withdraw from our pain," "was very professional, confident and engaged," "let me express my feelings," and was "not embarrassed by emotion" (Cook & Bosley, 1995; Dyregrov, 2004; Dyregrov et al., 2000; Lowes & Gill, 2006; Scott et al., 2002).

Rapport With the Researcher

Participants indicated a positive rapport with the interviewer. Two respondents in Cook and Bosley's (1995) study found it helpful that the researcher shared that she, too, had experienced the death of a loved one. Participants in other studies indicated their preference to be interviewed by the same person when multiple interviews are planned and where possible (Brannen, 1993; Terry et al., 2006).

Dominant conceptualizations of risk that presume high risk to participants in unstructured interviews are not borne out by actual experiences of harm because the presumptions within their conceptualization are not absolutely true. What, then, are the implications of this feedback loop, and how might it be virtuous?

<div align="center">Implications</div>

The mandate of research-ethics governance is to protect participants as well as the production of knowledge. From the outset of this dissertation, participants' perspectives were

ascertained in hopes of informing research ethics: the ethical conduct of interviews and the normative context of oversight of interview research.

Participant Protection

The tentative and preliminary findings of this dissertation research that participants do not experience harm as a result of their participation in unstructured interview research does not imply that participants ought not to be protected. What is apparent is that participant protection is not conferred by the a priori proportionate review of risk but the moral conduct of the interview itself. Unstructured interviews are moral unfoldings; risk is emergent during such interviews and is responded to by the interviewer. Researchers and participants are competent knowers whose reason is informed by emotion. Like emotional distress itself, risk in qualitative inquiry is subjective, interpretive, contextual, complex, and paradoxical. Hence, ethics-in-process approaches are most congruent with the nature of this risk. In addition, ethics oversight of interview research needs to recognize the inadequacy of a-contextual, objective, rational ethical theories and principles with which to inform the ethical issues inherent in research methodologies underpinned by subjective epistemology such as interviews. Emerging ethical perspectives such as relational ethics, feminist ethics, nursing ethics that account for subjectivity, context, relationship and emotion are better suited to guide the moral conduct of interview research and its ethics-review.

Protection of Sensitive Research

The literature substantiates that qualitative research, sensitive research in particular, is at risk of subjugation (Church, Shopes & Blanchard, 2002; Haggerty, 2004; Lincoln & Cannella, 2004; Shea, 2000; van den Hoonaard, 2001, 2002; Gunsalus, 2004; Gunsalus, Bruner, Burbules et al., 2007; St. Pierre, 2004). In 1985 Ceci, Peters and Plotlin found that sensitive topic research was twice as likely to be rejected by REBs on the basis of sociopolitical consequences. In 2003, at the annual meeting of the American Educational Research Association, Grover J. Whitehurst, Director of the U.S. Department of Education to oversee educational research addressed the

audience of researchers. According to St. Pierre, "He ridiculed session titles in the conference program that he surmised did not conform to his agenda of 'what works.' Not surprisingly, these sessions were grounded in the epistemologies and methodologies of race theories, queer theories, postcolonial theories, feminist theories, postmodern theories, and so forth…The gist of his talk was that research that does not mobilize randomized experimental trials will be highly suspect and unlikely to be funded" (2004, p. 132). One wonders what are the sociopolitical costs to the subversion of sensitive research. In her book *Ecological Thinking*, Lorraine Code (2006) has developed her theme of epistemic responsibility, that knowledge and morality are conjoined such that good knowledge is both sound and moral. Epistemic responsibility means that social governance ought to be informed by sound knowledge i.e., produced from a variety of methodologies and encompassing various perspectives. Code privileges the testimonial as a critical source of knowledge and challenges its lowly place within the hierarchy of knowledge. If participants' perspectives constitute a virtuous feedback loop to ensure ethical research, then sensitive research constitutes a virtuous feedback loop to ensure a just society.

Conclusion

A just and sustainable society requires the knowledge of particular circumstances of suffering in order to alleviate it. Code (2006) has argued that good moral decisions depend in large part on the quality of the imaginings that shape and inform them. Stories such as those told in unstructured interviews cultivate our collective moral imagination such that we "understand ourselves well enough to talk good sense in ethics" (Nussbaum, 2001, p. 2). The real harm inherent in sensitive research is the failure to protect it. Human dignity is preserved, protected, and celebrated by these stories of suffering.

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HAVE YOU PARTICIPATED IN AN INTERVIEW ABOUT A PERSONAL TOPIC OR ISSUE?

Your interview was:
◦ **Face-to-face with an interviewer**
◦ **The interviewer asked one main question and then listened to your story**

I am a researcher interested in understanding what it is like for people to participate in this type of interview. Interviews provide important knowledge that can benefit others and society–but what was it like for you? Did you experience benefit, risk or harm as a result of being interviewed? I hope my research will help to ensure the best possible interview experience for those who participate in them. I need your help. Will you share with me your thoughts and experiences of being interviewed?

Please contact me so we can arrange to speak over the telephone or in person. Thank you, Michele McIntosh

Email: mjm19@ualberta.ca
Tel: (416) 736-2100 Ext. 21017
Collect Calls: (416) 467-8181

TITLE OF PROJECT: Participants' Perspectives on Risks Inherent in Unstructured Qualitative Interviews
DOCTORAL STUDENT RESEARCHER: Michele McIntosh

CO-SUPERVISORS: Dr. Katherine N. Moore & Dr. Janice Morse

Faculty of Nursing.
University of Alberta, Edmonton, Alberta, Canada.

This study has been approved by the University of Alberta's Health Research Ethics Board (Panel B), For complaints or concerns about this research, please contact: Charmaine Kabatoff, Administrative Coordinator to the Board (780) 492-0302.

UNIVERSITY OF ALBERTA

TITLE OF PROJECT: **Participants' Perspectives on Risks Inherent in Unstructured Qualitative Interviews**

DOCTORAL STUDENT RESEARCHER: **Michele McIntosh**
EMAIL: mjm19@ualberta.ca   PHONE: 416.736.2100 ext. 21017 or Collect Call 416.467.8181

CO-SUPERVISORS: **Dr. Katherine N. Moore & Dr. Janice Morse**

To Former Interview Participants

Dear Former Interview Participant:

As a person who has taken part in an interview, you are invited to talk with me about your thoughts and feelings regarding your interview experience.

I am a graduate student in Nursing at the University of Alberta who is studying what it is like to be interviewed. Doing this study is a requirement of my doctoral degree.

BACKGROUND INFORMATION AND PURPOSE OF THIS STUDY

Interviews in health research are a very important way of understanding the meaning of many human experiences that affect health. What does it mean to have a baby? What is it like to be told you have cancer? How do people manage with mental illness? Much of what we know about these experiences was learned from people like you who volunteered to be interviewed–but what was the interview like for you? Will you talk to me about your interview experience? My hope is that this study will contribute to better interviews and better research.

YOUR PARTICIPATION IS IMPORTANT

Participation in this interview is voluntary and may be of no direct personal benefit to you. However, your co-operation and information about your experience in participating in an interview is very important for this study.

DISCOMFORT OR RISKS

While there are no foreseen risks to your participation, you can refuse to answer any questions and you may stop the interview at any time. If you feel upset as a result of your interview I will, if you wish, provide you with a counselor to talk with.

WHO SHOULD VOLUNTEER TO BE INTERVIEWED?

Please volunteer if you:

- are over 18 years of age, speak English and live in Canada or the United States
- your interview was face to face, you were asked one question and then you talked about your experience
- you were interviewed about a personal or sensitive topic
- You have access to a telephone and agree to a one hour telephone interview (personal interviews may be conducted where possible, if requested)

IF I VOLUNTEER TO BE INTERVIEWED, WHAT IS INVOLVED?

Step 1

If you volunteer to participate, please contact:

Michele McIntosh
19 MacPhail Avenue
Toronto, Ontario
Canada M4K 4A1

Email: mjm19@ualberta.ca
Phone: 416.736.2100 ext.21017
              Collect call: 416.467.8181

Step 2

Upon contact I will arrange a date and time for your telephone (or, in person) interview.

Step 3

If you would like a copy of the results of this study, please e-mail Michele McIntosh at: mjm19@ualberta.ca
requesting results from the Participants' Intview and giving your email or mailing address.

STATEMENT OF CONFIDENTIALITY

Please be advised that the information you share with me is confidential except when the law or codes of ethics require reporting. The researcher who originally interviewed you will not know that you volunteered to participate. No personal identifiers will be linked to the responses you give in your interview. Your personal information (email address, telephone number), will only be known by myself. This information will be securely stored by Dr. Katherine N. Moore in the Faculty of Nursing at the University of Alberta for 7 years.

FREEDOM TO WITHDRAW

If at any time, you would like to withdraw from this study, you are free to do so. At any time you may refuse or cease to respond to any questions.

CONTACT INFORMATION

If you have any questions regarding this study please contact the persons named at the top of this page.

TIMELINE

Please contact me immediately.

Many thanks for your help,
Michele McIntosh

Appendix B: Letter to Researchers

Michele McIntosh RN BA MScN PhD(c)

19 MacPhail Avenue
Toronto, Ontario
Canada M4K 4A1

Tel: 416.736.2100 ext. 21017
Email: mjm19@ualberta.ca

UNIVERSITY OF
ALBERTA

January 15, 2009

Dear Researcher:

We request your assistance in helping us recruit participants for our study entitled *Participants' Perspectives of Risk Inherent in Unstructured Qualitative Interviews.*

Background

What are participants' perspectives regarding their participation in unstructured interactive and/or other qualitative interviews? Unstructured interactive and/or narrative interviews are used in all of the major qualitative methods (such as ethnography, phenomenology, grounded theory and narrative inquiry) and are an important strategy for eliciting meaning and developing an understanding of health issues from the perpectives of those who experience them. Yet little is known about what it is like to be interviewed–in particular, any inherent risk, harm or benefit–and few attempts have been made to solicit this information from research participants themselves.

Purpose

This study aims to ascertain participants' perspectives and experiences of risk, harm and benefit resulting from their participation in unstructured interviews. This information will contribute to the identification of risks, harms and benefits in interview research, their prevalence, the timing of their occurrence, the temporality of these and the level (compared to everyday life) of these risks, harms and benefits (if any).

We request your assistance in helping us to recruit participants for this study. Participants for this phase must be English-speaking persons over 18 years of age who participated in an unstructured qualitative interview within the past 3 years (2006/2007/2008) in North America. We request that you forward the enclosed materials (cover letter and brochure) to any of your current or former interviewees who meet these criteria. Snowball recruiting helps to ensure that those interested in participating in our study truly participated in an unstructured interview.

Harms and Benefits

Of course, your assistance in helping us recruit these participants is voluntary and may be of no direct personal benefit to you. Similarly, the participation of your former interviewees is voluntary and may be of no direct personal benefit to them. Please read the accompanying materials intended for potential recruits for assurance that ethics guidelines are being met. Please note that we give our assurance that privacy and confidentiality will be strictly maintained and any data collected that could connect the researchers-interviewees will be anonymized.

Please read the enclosed participant recruitment brochure. We will be conducting semi-structured interviews by telephone or in person based on feasibility and participant preference. Participants may withdraw their participation at any time. Discomforts or risks associated with participating in our interviews are anticipated to be minimal. If participants experience distress as result of the interview, a counselor will be made available to them for post-interview de-briefing if they wish.

Confidentiality

We re-iterate our assurance that privacy and confidentiality will be strictly maintained such that researcher and participant identities are protected. Transcripts will be immediately anonymized and any identifying information within the data collected will be anonymized or deleted. Data will be securily stored at the Faculty of Nursing, University of Alberta, for seven years.

Procedures

We invite you to forward the attached Invitation to Participant Materials to any former participants who meet the prerequisites below:

- Former interviewees participated in an unstructured interview
- The topic of the unstructured interview was sensitive or personal
- Former interviewees' participation was in 2006/2007/2008
- The research project had received ethics approval
- They have access to a telephone
- They can communicate in English
- We are hoping to get 4 recruits from each researcher

If you are willing to recruit participants for our study, kindly forward the enclosed cover letter and brochure to them. No other action is required on your part.

If you would like a copy of the results of this study, please e-mail Michele McIntosh at mjm19@ualberta.ca requesting results from the Participants' Interview Survey and give your e-mail or mailing address.

If you have any questions regarding this study, please contact any of the following persons identified at the bottom of this letter.

Many thanks for your help,

Michele McIntosh

Title of project: Participants' Perspectives of Risk Inherent in Unstructured Interviews

Doctoral student researcher: Michele McIntosh Email: mjm19@ualberta.ca
Tel: (416) 736-2100 ext. 21017

Co-supervisors: Dr. Katherine N. Moore & Dr. Janice Morse

Associate Dean Research, Nursing: Dr. Christine Newburn-Cook Tel: (780) 492-6764

This study has been approved by the University of Alberta's Health Research Ethics Board (Panel B). For complaints or concerns about this research, please contact: Charmaine Kabatoff, Coordinator (780) 492-0302

Appendix C: Letter From Researchers to Their Former Participants

January 7, 2009

Dear _____

You are receiving this letter because you have had experience being interviewed.
Michele McIntosh, a graduate student in Nursing at the University of Alberta, is
studying what it is like for people to participate in research interviews. Her project
is separate from the study you participated in with me, but your experience of
our interview will be helpful to her study. She would like to talk to you over the
phone, or, in person if you prefer, about what being interviewed was like for you.

If you would like to participate in the University of Alberta project, please read
the attached invitation and contact Michele McIntosh by email or telephone if
you are willing to participate:

Michele McIntosh
Email: mjm19@ualberta.ca
Tel: (416) 736-2100 ext 21017

UNIVERSITY OF
ALBERTA

I will not know what you say about the interview you had with me. This study is
separate from the one you are currently or have participated in.

Thank you for your assistance.

_____
PI/Researcher

Hi:

I am a doctoral student in Nursing at the University of Alberta who is conducting an REB approved qualitative research study to explore the experiences of participants who have participated in unstructured interviews regarding a sensitive, health-related topic. I would value your assistance in finding participants for my dissertation study. I hope my study will contribute to the ethics governance of interview research.

If you have conducted a study that used such unstructured interviews recently, would you be willing to invite your participants to be in my study?

The attached letter to researchers explains the study in more detail. Then, if you are willing, please forward the attached recruitment letter and brochure on to your former participants so they may contact me, should they be willing to be in my study.

Thank you.

Michele McIntosh, Doctoral Candidate (mjm19@ualberta.ca)
Supervisors: Dr. Katherine Moore and Dr. Janice Morse
University of Alberta

Appendix E: *NOW* Magazine Advertisement

Appendix F: NCEHR Conference Poster (February, 2009).

Appendix G: Interview Guide

Participant Responses to Interviews: Questionnaire

When the time comes for an interview I will initiate the telephone call and speak with the participant. I will say:

Hello, this is Michele McIntosh calling from the University of Alberta. I am calling about the interview we arranged, to talk about the interview you did for the other person's study. In this interview I am going to ask you about how you felt being interviewed in that other study. I need to remind you of a few things before we get started. Our conversation will be tape-recorded. The other researcher will not know that you participated in this study or know what you say. I need to remind you that you can take a break during this interview at any time, refuse to answer any questions and even stop the interview if you wish. Now I need to check with you: 'Do you agree to participate in this interview?' Are you comfortable where you are? Are you alone? Is there anything you need to do to ensure that we are not interrupted for the next half hour or so? Do you have any questions for me before we get started? First I want to ask you a few formal questions regarding you . . .

1. Gender (self-evident).

2. What country do you live in?

3. What is your occupation?

4. May I ask your age?

Thank you. Now I will proceed with the interview.

1. Do you remember the topic of the research you were previously interviewed about?

2. How did you come to participate in that study? *Prompt: How did you decide?*

3. Tell me about the interview. *Prompt: Tell me what happened that day? How long did the interview last?*

4. Where was the interview held? *Prompt: Was this significant to you in any way?*

5. Who was present at the interview?

6. Did the interviewer tell you what would happen to your interview results ? *Prompt: Have you seen the transcript? Did you make any changes?*

7. Did you understand that you could stop the interview at any time? Withdraw from the study?

8. What was it like for you to tell your experience?

9. Did you really feel you had the opportunity to say all that you wanted to say? *Prompt: What made that possible? Or, What would have needed to be different?*

10. Were there things that you chose not to say? *Prompt: Why? How?*

11. Did you say anything at the interview you later regretted? *Prompt: Was there anything you didn't tell but wish you had?*

12. Tell me about your feelings during the interview? *Prompt: Did you cry? Get upset? Laugh?*

13. What was that like for you? *Prompt: Were you uncomfortable in that situation?*

14. What did the interviewer do? *Prompt: Did you feel free to take any offers made to you? If not, why not?*

15. Tell me about the interviewer. *Prompt: What did you make of him/her?*

16. What was it like to talk to him/her? *Prompt: How did you get along with him/her?*

17. Do you think he/she understood your experience?

18. How did you feel after the interview?

19. Do you ever think about that interview now? *Prompt: How? Why? What?*

20. Was the interview what you expected? *Prompt: Would you do it again?*

21. Did you ever feel uneasy at any time during the interview?

22. If there were benefits to being interviewed, what would those be? *Prompt: Were you paid?*

23. If there were disadvantages to being interviewed, what would those be?

24. How do you respond to the statement: Interviews are risky.

The interview is now over. Thank you very much. Would you like me to send you a copy of the results of this study? Good-bye."

Appendix H

Informed Consent Checklist for Taped Telephone Interviews

UNIVERSITY OF ALBERTA

TITLE OF PROJECT: Participants' Perspectives on Risks Inherent in
Unstructured Qualitative Interviews
DOCTORALSTUDENT RESEARCHER: Michele McIntosh
EMAIL: mjm19@ualberta.ca
PRINCIPAL INVESTIGATOR: Dr. Katherine Moore and Dr. Janice Morse
EMAIL: katherine.moore@ualberta.ca

The following questions will be asked of participants at the beginning of their taped interview to
ensure informed consent:

	YES	NO
Do you understand that you have been asked to be in a research study?	☐	☐
Have you read and received a copy of the Information Sheet?	☐	☐
Do you understand the benefits and risks involved in taking part in this research study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand that you are free to withdraw from the study at any time, without having to give a reason?	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Do you understand who will have access to the tape of this interview and how this tape will be stored?	☐	☐

Who explained the study to you? _____

	YES	NO
I agree to take part in this study:	☐	☐

Name of Research Participant: _____

Name of Investigator: _____

Date:_____