

## **Qualitative bereavement research: incongruity between the perspectives of participants and research ethics boards**

Jennifer L. Buckle<sup>a\*</sup>, Sonya Corbin Dwyer<sup>a</sup> and Marlene Jackson<sup>b</sup>

<sup>a</sup>*Sir Wilfred Grenfell College, Memorial University of Newfoundland, Corner Brook, NL, Canada A2H 6P9;* <sup>b</sup>*Regina Qu'Appelle Health Region, Regina, SK, Canada*

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A central feature of the majority of qualitative research is the interactive nature of data collection which generally involves direct and meaningful communication between the individuals conducting the research and the individuals participating in the research. This core aspect of data collection, however, is frequently flagged as the most concerning or potentially harmful aspect of qualitative bereavement research by research ethics boards. Further, there has been a tendency to conceptualize the bereaved as vulnerable and in need of protection in the research process. Instead of thinking that a research interview which explores the complex, personal issues of grief would potentially harm participants, it may be seen as potentially beneficial to participants when the therapeutic aspects of the interview are considered. Participants' responses to the interview process in two bereavement studies are offered as illustrations to complement the literature on the potential for the researcher-participant relationship and the research interview to be perceived as beneficial by bereavement research participants.

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Over the past two decades qualitative research has been gaining momentum and acceptance in a variety of disciplines, including psychology (Rennie, 1996; Rennie, Watson, & Monteiro, 2002). Qualitative methods provide access to areas of study that are complex and generally impervious to quantitative research methods. A central feature of the majority of qualitative research is the detailed, interactive nature of data collection, which generally involves direct and meaningful communication between the individuals conducting the research and the individuals participating in the research. With its focus on the achievement of understanding, the recognition of collaboration with participants, and the emphasis on holism, qualitative methodology has much to offer the researcher interested in the vast complexity of human experience (Rennie, 1994, 1995a, 1995b).

Researchers studying bereavement have also embraced the qualitative approach, stating that it may more appropriately and adequately represent the experiences of the bereaved than quantitative, positivistic methods (Fleming & Robinson, 2001; Riches & Dawson, 1996; Silverman & Klass, 1996). A qualitative approach to bereavement research makes possible the exploration of questions regarding meaning, experience and understanding after the death of a loved one, the results of which contribute to an

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\*Corresponding author. Email: [jlbuckle@swgc.mun.ca](mailto:jlbuckle@swgc.mun.ca)

ever-developing model of grief that focuses on the complexity of human relationships and the connectedness of individuals to those living and to those who have died (Neimeyer & Hogan, 2001; Silverman & Klass, 1996).

Despite the growing acceptance of qualitative research, members of research ethics boards (REBs) frequently flag the method of data collection (generally consisting of in-depth, open-ended, one-to-one interviewing) as the most concerning or potentially harmful aspect of the research process for potential participants (Hadjistavropoulos & Smythe, 2001). Coupled with this is the reality that research proposals in the area of grief, death and trauma are more likely to be rejected by REBs than proposals to research other dimensions of human experience (Ceci, Peters, & Plotkin, 1985; Cook, 1995; Dyregrov, 2004). Given the proliferation of qualitative methods in the study of bereavement, one can begin to appreciate the two-pronged resistance frequently encountered by qualitative researchers in this area when submitting proposals to REBs. The concern of REBs appears to run counter to the experience of bereaved research participants, who frequently comment on the personal benefits they derived from the process of sharing their perspective in a detailed manner with an interested and engaged researcher. The apparent gap between the experience of participants in qualitative research on bereavement and the concerns of REBs is important to explore as the decision of the latter has the potential to influence the experience of the former.

### **Ethical concerns about qualitative bereavement research**

REB members are often concerned about the impact of the core method used in qualitative research – the detailed, interactive, generally discovery-oriented interview (Hadjistavropoulos & Smythe, 2001). This method of data collection is the foundation essential to the construction of the understanding of the phenomenon that will follow. The first of these concerns about the interview involves informed consent.

Hadjistavropoulos and Smythe (2001) state that the main ethical concern with the discovery-oriented interview method, the hallmark of qualitative research, is that it complicates the informed consent process. They argue that participants cannot provide true informed consent because they are not informed of how the interview will unfold. They state that due to the typically open-ended nature of the qualitative interview, neither the interviewer nor the interviewee knows exactly what will transpire in the session, thereby complicating informed consent.

An extension of REBs' concern regarding informed consent arises when bereaved individuals are conceptualized as vulnerable and in need of protection. The question then becomes, are the bereft in a position to give informed consent? The term 'vulnerable' is sometimes used to describe populations considered to be above minimum risk if they participate in research. According to the Guiding Ethical Principles of the Canadian Institutes of Health Research (CIHR), the Natural Sciences and Engineering Research Council of Canada (NSERC) and the Social Sciences and Humanities Research Council of Canada (SSHRC), vulnerable persons are defined as 'those whose diminished competence and/or decision-making capacity make them vulnerable' (MRC, NSERC, & SSHRC, 2003, p. i.5).

Another risk raised by REBs regarding qualitative research, especially on sensitive topics like bereavement, is the potential for the research interview to induce a negative mood state or cause emotional pain (Hadjistavropoulos & Smythe, 2001; Rosenblatt, 1995). Beck (2006), in an innovative study of ethical issues in bereavement research, quantified the experience of bereaved individuals and the perceptions of REBs. Beck

compared the perspectives of bereaved individuals who had not previously participated in a bereavement study with those of REB members. An important finding of this study was that participating REB members tended to overestimate the importance of risks to bereaved individuals as a result of participating in research when compared to the perceptions of bereaved participants, such as the experience being stressful, having difficulty providing informed consent, regretting participation, feeling exploited and offended. This overestimation of risk, however, needs to be interpreted within the context of the role of REB members. As Dixon-Woods, Angell, Ashcroft, and Bryman (2007) correctly note, should a problem arise with a research project, the REB who approved the project 'can come under intense scrutiny' including a 'judicial review by the courts of the reasonableness of their decisions' (p. 800). This level of responsibility can shift the focus more on potential risks than potential benefits. Even in this role, an approach that assesses the full range of participants' experiences must be considered.

### **The voices of participants**

Despite the concerns of REB members regarding qualitative bereavement research, we have received positive feedback from participants about their involvement in our research and the impact it had on them. Through the results of two bereavement studies, we will describe our participants' reactions to illustrate some of the incongruities between the perspectives of participants and REBs. The first study explored the experience of parenting surviving children after the death of a child. The second study asked about ongoing connections with deceased family members.

#### ***Most bereaved parents enjoy talking about their children***

In this study, the grounded theory method was used to explore the experience and process of parenting surviving children after the death of a child (Buckle, 2003). Five bereaved mothers and five bereaved fathers, ranging in age from 40 to 51, were interviewed individually (six were unrelated, two mothers and two fathers were married). All had surviving children present before and after the death. The time since the death ranged from three to eight years. The age of the deceased children ranged from 2 to 20 years. Systematic feedback about the experience of participating in the research was received from all parents. Spontaneous comments made during the interview itself and requested feedback received in a follow-up telephone call to every parent within 48 hours after the interview demonstrated that all of the participants had positive comments about the process of being interviewed and the research topic itself. One of the mothers reported feeling tired after the interview but felt that she was on 'some-what of a high' because she was talking about her deceased child. Another mother explained that she felt fine afterward, but was surprised at how tearful she was in the interview. Despite this, or maybe because of it, she stated that she felt very positive about the research and would not have changed anything about it. In commenting on the uniqueness of the interview situation she said, 'You don't sit and talk about a lot of the things that we've talked about tonight'.

Another mother commented that she was exhausted after the interview, explaining that her eyes were probably tired from crying. She stated that she enjoyed the process and the opportunity to talk. She felt that the interview was very 'well done' and would not have changed anything. During the interview she spontaneously stated:

I think you find that most bereaved parents enjoy talking about their children...I don't know whether other people get upset or not, I knew that would happen with me. It's just talking about a situation that is a very painful thing. I'm still fine. I can joke and talk. I'm happy to talk about it...Thank you for choosing [me]. I enjoyed doing it.

Fathers also had positive feedback about participating in the study. They offered comments that the interview was conducted 'quite professionally', they were at ease throughout, 'very comfortable' and that the format and process were 'terrific' and 'quite interesting', adding that 'the questions really made you think' and 'it was a pleasure'. Many noted that they were looking forward to the results.

One of the fathers commented that the interview covered a broad range of issues – 'it covered everything'. He also shared that it 'opened my eyes to look into certain areas, I got a lot from it'. He ended the phone call thanking the researcher for the opportunity to participate. Another father shared that he experienced the interview as therapeutic, 'I mean, like what we're talking about today. This is probably a bit of therapy for me too'.

The final father interviewed in the study also expressed his positive feedback on the interview. He explained that it 'provided an opportunity to explore' in a focussed and private manner. He said that this exploration was important to him and that 'focusing on the experience in an in-depth manner was wonderful but it felt a little self-indulgent. I hope you got what you needed'. He was assured that the interview was mutually beneficial. He added that it was very 'meaningful' and that 'life doesn't really allow for these types of in-depth, focussed interactions' stating that it was 'good to get in touch with that again'. He closed the telephone conversation expressing his appreciation for the opportunity to talk.

As is obvious from the feedback of every parent who participated, the qualitative interview can be a powerful research tool, allowing entry into previously untouchable, complex, human experiences and a rewarding experience for the participant. The parents who participated in this research all appeared to personally gain from the experience. Although tears came for some during these interviews, this was not seen as a negative consequence or 'risk' by the participant or the researcher. Indeed, it is clear that these parents felt grateful to have the opportunity to engage with an interested other who was willing to sit with them in their pain. This is their daily lived experience, so, clearly their pain would be evident in the interview as well. Based on the feedback of the participants, the interview did not cause pain, it allowed for its expression. In interpreting this feedback, one must consider the potential that participants felt pressured to report the positive aspects of the experience when asked about it by the researcher. The concern, however, is somewhat allayed by the numerous spontaneous comments offered by participants during the course of the interview and afterward that correspond with the requested feedback.

### *It's helped me to be able to say some of this stuff*

Using a phenomenological approach, four people were interviewed about their sense of an ongoing connection with deceased family members (Jackson, 2003). One of the first questions explored in the second interview was how it was for them to read through the transcript of their first interview. Georgie (all names are pseudonyms) responded by saying:

...it really helped me to talk it over with you though. And I know I blathered on quite a bit and went sort of off the beaten trail, but I felt it really helped me to talk it over with you though...and I realize that wasn't the purpose of your [research] to do some counselling, but I felt almost that's what I got. Just the fact of being able to talk about it. That's really helped me to be able to say some of this stuff that I would have kept to myself. I just felt like someone kind of understood what I was talking about. You've had other experiences and have talked to a lot of other people, because lots of times I felt like maybe am I the only one that this has happened to or feels this way, so it really helped me in that way and I really appreciate all that you've done for me.

Jack shared, 'I've relived things because of it, but I don't think that's done any harm....I think probably it was somewhat helpful because it sort of regenerates what we've gone through with the bereavement seminars'. He later added:

It's kind of like reliving it again, mind you, it's the story that I've been telling over and over and over, right? Only to close friends, you don't spell a lot of it out, so no, I don't think it hurt any to do it again. Oh, it brings back memories, but they're not all bad memories either.

Lynn said at the end of the first interview:

You've probably helped me, too, because you're a stranger to me, so you can be more objective, whereas people are sometimes too emotionally involved, relatives or whatever. It gives me an opportunity to get it off my chest to someone that is neutral, which is healing for me too.

When asked what it was like for her to read through the transcript of her first interview, she commented:

I surprised myself as to how much there was there, the volume, and even how it came out. I think I surprised myself...It was like I was reading a story and sometimes I have to stop and think, 'is this me? Is this my story?'

Toward the end of the second interview she revealed:

I'd read it sometimes before I went to sleep at night in bed and tears would come to my eyes. I've lived it, but it was almost like reading another story. I knew it was my story, and yet I had to see it from a reader's point of view.

Edna reported that she had difficulty reading through the transcript of the first interview. In the second interview she shared, 'I read parts of it, but it bothered me'. When asked if it stirred things up for her she replied:

Yeah, that's what it did. I don't know if, I just thought 'What am I reading this over for?' And, that was about the main idea. I thought 'Boy, oh, boy, I sure went back and went into a lot of detail'.

Edna further commented:

I think if I had of thought of it as being my story, it would be a good way to read it over. Well, at the time it did me good to talk about it. And then again, when I was reading it, maybe it wasn't the right day to be reading it. I know that can happen.

She explained, 'There's going to come a day when I can read it and not get too upset about it. But, no, it's been an experience, a learning experience in more ways than one'.

These comments indicate that taking part in this research was generally beneficial for the participants. Even though this was not the primary purpose of the discussions, they appreciated being able to talk about their bereavement experience and to share their story with someone else. While participants' reactions to seeing their stories re-narrated was not a specific focus in either of our two bereavement studies, Josselson (1996) notes that it is possible for participants to feel a range of reactions upon seeing their stories in print, re-told by the researcher. These reactions can include a sense of betrayal and a feeling of loss of ownership.

Consistent with previously published research, these two studies further illustrate the gap between the perspectives of REBs and the experience of bereaved individuals who participate in qualitative research. Participants appear to be benefiting from the approach, while REBs are not aware of or are minimizing this potential. What is it about the qualitative approach to bereavement research that proves beneficial to participants? We posit that the source of the positive impact can be found in the core components of the qualitative method: the interview and the relationship with the researcher. The qualitative approach emphasizes the relationship between the researcher and the participant, actualized in the interview method of data collection; the very component that raises the most concern for REBs.

## **Revisiting ethical concerns**

### ***The interview***

As previously stated, Hadjistavropoulos and Smythe (2001) argue that participants in qualitative research cannot give true informed consent because they do not know how the interview will unfold. It is true that a qualitative interviewer employing the discovery-oriented approach cannot predict, with 100% certainty, how the interview will unfold. When research participants are regarded as experts of their experience, the researcher assumes the role of learner and therefore does not presume to know, *a priori*, what is essential to the individuals' experience, laid out in the form of a series of structured questions. In our experience as qualitative researchers, we advocate addressing this issue by thoroughly communicating to participants that their involvement in the research is completely voluntary and they can withdraw at any time, removing any data they have contributed. Furthermore, it is important that the interview process be described in detail so participants have a sense of what to expect. To achieve this, it should be explained to participants that, as researchers, we cannot completely predict the course of the interview but we can provide a guideline of the types of questions that may be asked and the assurance that our utmost concern lies with the welfare of the participant, not the welfare of the research. This concern applies before, during and after the interview. This point is further communicated by the characteristics of the interview itself, in that the qualitative approach allows the participant to shape the focus and rate of the interview, discussing what they feel is most relevant at a level at which they are most comfortable (Hynson, Aroni, Bauld, & Sawyer, 2006). As Smythe and Murray (2000) point out, it is important to inform participants of the aspects of the study that would affect their decision to participate. While not all negative outcomes can be anticipated, most potential participants in qualitative research have a sense of

how talking about a particular topic will impact them and they still consent to participate.

Further to the issue of informed consent, Rosenblatt stated:

researchers carrying out intensive qualitative interviews are in a better position than people carrying out other kinds of research to recognize ethical issues, to acquire information that could help in ethical decisions, and to engage in a genuine give-and-take about ethical issues with people being studied. (1995, p. 140)

The qualitative researcher is not a distant, observing other. Instead, she or he is in a personal interaction with the participant, witnessing the impact of the interview process and able to address concerns that arise (Grafanaki, 1996). It would be incorrect to assume that a questionnaire requesting the assignment of numbers to represent experience sent to a bereaved participant presents far less risk than the interview procedure. In fact, it could be argued that the procedure of mailing questionnaires to bereaved participants leaves the researcher less able to observe and address the impact of data collection. The qualitative interview, therefore, may be more effective at assessing ongoing informed consent than other research methods deemed less problematic by REBs. The typical way of securing informed consent in research, the one time signing of a consent form, is insufficient for qualitative research. The recommended approach, process consent, is a mutually negotiated, ongoing process (Smythe & Murray, 2000) integrated into the ongoing relationship between the researcher and participant (Burgess, 2007) while opening up opportunities to erase the differential power relationships between REBs, researchers and participants (Halse & Honey, 2005).

Further to the issue of informed consent, should bereaved individuals be considered vulnerable with diminished competence or decision-making abilities? Cook (1995) calls for perspective on this issue. When REBs begin to conceptualize bereaved individuals as vulnerable, it is important to consider the societal perspective on this issue. Society expects bereaved individuals to return to their roles and responsibilities within days or weeks after the death of a loved one, including to their place of work (Cook, 1995). Bereavement leave in many employment settings allows for two to three days of paid leave. This policy sends the message that after a very short period of time, bereaved workers are competent to resume their employment duties. Furthermore, bereaved individuals are considered competent to make significant financial decisions, in the form of funeral arrangements, often immediately after learning of the death of a loved one. When considering this issue of competency, it is also important to be aware of the heterogeneity among bereaved individuals, even when they have experienced the same type of loss (i.e., spousal bereavement). Evolving theories of grief are consistently moving toward recognizing the individuality inherent in the experience, instead of outlining universal themes or pre-determined stages (Neimeyer, 2001). In considering the issue of informed consent, it is important neither to assume homogeneity among potential participants (Cook, 1995) nor diminished decision-making capacity.

The potential for the research interview to induce a negative mood state or cause emotional pain has been another concern for REBs (Hadjistavropoulos & Smythe, 2001; Rosenblatt, 1995). As qualitative researchers, we think it is important to be clear in the definition of this concern. Are we *causing* or *inducing* pain when we ask research participants about their experience of the death of their loved one or are we bearing witness to the pain that is already there? We would argue the latter. As members of North American society, many of us carry a level of discomfort with

witnessing intense emotion, especially when it is considered 'negative' emotion (i.e., sadness), which can lead to a position that it is best not to ask about topics that could elicit an emotional response. It is this cultural norm that often leaves bereaved individuals feeling isolated in their experience as a result of no one talking about their deceased loved one, appearing to have forgotten him or her. Qualitative bereavement researchers do not set up experimental situations or use deceptive means to induce pain in individuals. Rather, we ask about experiences that are often shrouded in sadness and we empathetically listen to the person, even if the message is accompanied by tears. Bereaved participants almost always expect the discussion of their losses to be painful, but are not deterred by this awareness. In fact, the majority welcomes the opportunity to express their grief and may take exception to the researcher attempting to circumvent their pain (Parkes, 1995).

Part of the overall research design in many qualitative projects is to provide a context for the interview through a briefing before and after (Kvale, 1996), which include processes to deal with the possibility of the emergence of disclosure reactions. Debriefing sessions can allow participants to bring closure to the process and to be provided with a list of available support services, should they need it. The process can also include terminating any interview that becomes too stressful for the participant. This termination is often a judgement call for the researcher to make, in communication with the participant, because what is too stressful for one individual might not be too stressful for another. How much stress is reasonable, and when does an interview stop being an interview and turn into a counselling session? How should researchers deal with participants' requests for advice? How can researchers deal with stories they hear from participants about pain and suffering they have experienced? Madak and MacDonald (2000) state, 'it is difficult to predict what will happen in an interview situation, and, therefore, the researcher must always be prepared to handle the unexpected' (p. 227). In his discussion of ethical issues, Kvale (1996) suggests that 'the potential closeness of the research interview to the therapeutic interview should be considered' (p. 111) and one 'must avoid allowing the interview to turn into a therapeutic situation' (p. 125), although specific guidelines are not offered. It is the responsibility of each researcher to ensure participants are not harmed, either purposefully or accidentally. Researchers should seek the advice of colleagues and ethics committees to reflect on the research process and be clear about the research purpose of the interaction.

The idea of similarities between the research interview and the counselling interview is not new (Birch & Miller, 2000; Bochner, 2001; Coy, 2006; Hart & Crawford-Wright, 1999; Rennie, 1994). In fact, Gale's (1992) study of couples' meaningful moments in therapy found that the research interviews themselves were reported to be more therapeutic than the actual therapy that was being investigated. Bereavement literature indicates that the bereaved often find the research interview to be therapeutic and meaningful (Jordan, 2000; Parkes, 1995); they consistently rate the experience of being a research participant as positive, despite frequently experiencing strong emotional reactions in the interview (i.e., crying) (Cook & Bosley, 1995; Dyregrov, 2004; Hynson et al., 2006; Riches & Dawson, 1996; Rosenblatt, 1995; Steeves, Kahn, Ropka, & Wise, 2001). Rosenblatt (1995) claims that the emotional release, integration, naming and story-telling often exhibited by participants in a bereavement interview can be part of the overall healing process. Reconstructing their narrative, with an interested other listening and witnessing, may be one of the most beneficial aspects of the qualitative interview for bereaved participants (Riches & Dawson, 1996; Steeves

et al., 2001), as this 'disclosure' creates the potential for participants to develop a new understanding of past events (Birch & Miller, 2000). Birch and Miller (2000) assert that it is the process of transforming narratives which creates the parallels between the role of the researcher and the role of therapist. As an extension of this point, Rennie (1994) reports that research participants generally find the interview to be 'a creative, enlightening experience...It becomes a therapeutic intervention, whether it was intended that way or not' (p. 241). Bereaved participants also noted altruistic benefits inherent in the research process. They spoke of sharing their experience to help others (Cook & Bosley, 1995; Dyregrov, 2004; Hynson et al., 2006), giving hope to others who are bereaved (Cook & Bosley, 1995), contributing to a better understanding of grief issues and promoting a more open discussion about death and grief (Cook & Bosley, 1995) and reducing their isolation as a result of their experience being overlooked by society at large (Riches & Dawson, 1996). In Beck's (2006) study of REB members and bereaved individuals' perspectives on bereavement research, REB members consistently downplayed potential benefits as opposed to bereaved individuals who appeared to value the benefits of participating in research such as sharing their feelings, educating others, gaining personal insight and providing hope to others. Based on these results, Beck (2006) concluded that REB members may not be very accurate in estimating the benefits and risks of research with bereaved participants. Qualitative research participants appear to frequently encounter the potential beneficial and therapeutic (side)effects of the research interview.

Hart and Crawford-Wright (1999) explain that '[t]he difference between a research interview and a therapy session [is that] in the former the participant is helping the researcher, whereas in the latter the therapist is helping the client' (p. 206). Consequently, they state, 'it is not possible for one to become the other without the motivations of the players changing dramatically' (Hart & Crawford-Wright, 1999, p. 206). Kvale (1996) noted a similar distinction highlighting 'the emphasis on personal change in a therapeutic interview and on intellectual understanding in a research interview' (p. 26). While we do not dispute that the participants are helping the researcher, we suggest that this view of qualitative research is incomplete. Results from our own research illustrate that participants often feel helped by the research interview and can benefit directly from the experience. Therefore, it is not only the researcher and the consumers of the research who benefit, but also the participant in a direct and tangible way.

### ***The relationship***

The interpersonal relationship between researcher and participant is fundamental in qualitative research. The 'rapport and trust that develop allow for interactions that deepen our understanding of the phenomena we study' (Cartwright & Limandri, 1997, p. 224). Rennie (1994) states that qualitative research is emotionally involving in ways seldom experienced in quantitative research. Perhaps for this reason, the qualitative interview is structurally very similar to the counselling interview because, like the counselling interview, the research interview is a 'co-constructed endeavour', in which 'participants can be engaged at every step of the study' (Rennie, 1994, pp. 240–241). Qualitative researchers are empathic listeners with an emphasis on partnership between the researcher and participant (Schulz, 2000). There is a purposeful effort made to move away from defining the researcher as the expert knower and the participant as the object of study and move toward a relationship with an emphasis on equality

(Kvale, 1996; Schulz, 2000). Although not always the case, the qualities of the relationship, specifically empathy, collaboration and empowerment, has the potential to be therapeutic for the participant. In particular, bereaved participants have indicated that the interviewer's empathetic approach, compassion, authentic interest, warmth, kindness, nonjudgmental stance, attentive listening and ability to contend with their powerful emotions were considered to be most beneficial (Cook & Bosley, 1995; Hynson et al., 2006). 'As researchers we encourage a therapeutic setting especially if we are trying to construct a social relationship of reciprocity, friendship and shared understandings with the aim to uncover what is being felt at a deeper level' (Birch & Miller, 2000, p. 199). It is clear that the core skills that make a good therapist are very similar to the core skills that make a good qualitative researcher.

While it is beyond the scope of this paper to fully explore the feminist debate, it is important to note that this emphasis on collaboration and empowerment is also evident in the feminist perspective on research, which highlights that engaging in research does not mean intentionally drawing boundaries between those doing the research and those being researched, although each person has a different relationship to the work being done (Lloyd, Ennis, & Alkinson, 1994). This can be especially seen in feminist participatory action research (Coy, 2006). Kirby and McKenna (1989) asserted that research methodology should empower participants by enabling 'people to create knowledge that will describe, explain, and help change the world in which they live' (p. 17). By participating in the process of producing knowledge, participants may come to a deeper understanding of their own lived experience, thus maximizing the benefit to research participants on an individual level.

It is important to acknowledge the longstanding feminist critique of qualitative research as well. Based on her experience as an ethnographer, Stacey (1988) developed a concern about the exploitation of participants. Stacey states that participants are at a 'grave risk of manipulation and betrayal by the ethnographer' because of the engagement and attachment involved in the ethnographic process (1988, p. 23). She also points out the dissonance between collaborative fieldwork and the research product which is ultimately that of the researcher. Since ethnography involves intensive participant-observation, the same risk may not be as high for other approaches to qualitative research. In addition, some researchers work closely with participants to create their final product, including member-checking.

There is a second relationship that is important to consider when exploring the beneficial aspects of qualitative research for the participant. This second relationship is the one the researcher has with her/himself. In many respects, this relationship is fundamental to the overall qualitative process. This relationship is based on being as honest, clear and self-reflective as possible about what the researcher brings to the process. It is based on the concept of 'self-as-instrument' and implies personal control, personal responsibility and personal creativity (Ely, Anzul, Friedman, Garner, & Steinmetz, 1991).

There is no neutrality in any research endeavour, there is only variation in the extent to which researchers recognize and document their subjectivity and bias. To effectively conduct qualitative research, beginning with the interview, the researcher must cultivate and fine tune personal awareness and a reflective relationship with the self. Ray (1990) stated, '[O]ne must know and understand the self first before entering into the lifeworld of another' (p. 175).

Elliott, Fischer, and Rennie (1999) refer to the importance of 'owning one's perspective' (p. 221). Qualitative researchers should identify their theoretical orientation,

expectations, assumptions, values, previous relevant experience and any other aspect of their world view that may play a role in the execution of the research interview and in the analysis of data. This self-awareness may neither come immediately nor easily. Although some influences are obvious, it takes practiced self-reflection to identify others that contribute to the researcher's subjectivity. Identifying the presence of these factors does not negate their influence; however, it does heighten personal awareness for the researcher and allows the participant and the consumers of the research to be aware of the identified subjectivity of the researcher. Qualitative researchers must learn these skills of self-reflection as part of their education and application of qualitative methodology.

The researcher's relationship with her or himself has the potential to enhance the beneficial aspects of the research experience for the participant in two main ways. First, the qualitative researcher is not in pursuit of objective truth, but rather acknowledges and values subjectivity, both in the researcher and the participant (Rennie, 1994, 1995c). This perspective sends a clear message to the participant that the researcher places high value on personal experience, so much so, the researcher is willing to spend a significant amount of time with a participant in an attempt to understand the participant's experience. Through the in-depth interview, researchers communicate to participants that their personal, subjective perspective is valuable and important. The participants are viewed as experts on their own experience and the researcher is attempting to learn from them. This is not unlike the therapy context. It is not surprising, therefore, that many participants find this interaction validating and therapeutic.

The second way in which the researcher's relationship with her or himself has the potential to enhance the therapeutic aspects of the research interview is by using the awareness of subjectivity to facilitate the goal of understanding the phenomenon of interest within the participant. This may take the form of sharing subjective experience with the participant or clarifying a point of confusion or misunderstanding. Alternatively, it may also take the form of identifying personal reactions as such and attempting to put these aside in an effort to maintain focus solely on the participant's perspective. Again, parallels to therapy are clear. The qualitative researcher, like the therapist, attempts to remain open, empathetic and focussed on the person being interviewed, using the self as a tool to enhance the interaction instead of a distraction or a competition of interests. Acknowledging and understanding the impact of one's own subjectivity can enhance the research interview, just as it can enhance the therapeutic process. Subjectivity that goes unrecognized and misunderstood has the potential to negatively affect the interview, likewise the therapy process.

### **Bereavement research from a participant-centred perspective**

The Canadian *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (MRC, NSERC, & SSHRC, 2003) recognizes that research participants contribute enormously to the progress and promise of research in advancing the human condition. Likewise, in many areas of research, participants are involved in the development of a research project and collaboration between them and the researcher is imperative to the study. Such collaboration requires direct and active involvement by research participants. This approach assures that participants' interests are central to the research and that they will not be treated simply as objects to be studied. In their discussion of interactive methodology, Stanley and Wise (1993) state, 'This research insists that the primary recipients and users...should be the people who are its *subjects*

rather than the researchers' (p. 33). Further, in a participant-centred perspective, one research role is the researcher as learner (Glesne, 1999) as we learn from and with our participants.

In the Canadian *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*, MRC et al. (2003) also acknowledge that in certain areas of the humanities and social sciences, this collaborative approach is essential and the research could not be meaningfully conducted in any other way. This participant-centred approach also recognizes that the harms and benefits of a research project may not always be seen in the same way by REBs, researchers and participants. Further, even within the same study, individual participants may have a different understanding of the information provided in the informed consent process. The extra demands this places on the researcher for accuracy, candour and sensitivity in informing potential participants about proposed research helps to build a trusting relationship between researcher and participant. The topic of bereavement typically falls under the 'sensitive issues' category for most REBs due to its emotional nature, so bereavement studies in particular provide relevant illustrations of the personal benefits participants derive from the process of sharing their experiences in a detailed manner with an interested and engaged researcher.

There is mounting evidence to support the assertion that participants in qualitative bereavement research frequently realize benefits as a result of their participation. Just as REBs and researchers must take these findings into consideration when deliberating the risks and benefits associated with participation, they must also consider the recommendations about this type of research provided by bereaved participants. These recommendations primarily address the recruitment process and the interview.

Firstly, bereaved participants have offered ways of minimizing the potential for harm in the recruitment process. They generally recommend indirect recruitment (e.g., letters of invitation distributed by third parties not involved in the research, advertisements). There does not appear to be a clear consensus on the most appropriate time to initiate recruitment, but an indirect process with sensitivity to avoiding special dates (such as major holidays and anniversaries) is clearly recommended and allows people to decide for themselves if they feel ready to participate in research (Beck, 2006; Dyregrov, 2004; Hynson et al., 2006; Parkes, 1995). Secondly, although researchers are not acting as therapists in the qualitative interview, it is important to be cognizant of the often painful issues associated with grief and loss and the skills required to appropriately interview individuals about this topic (Cook, 1995; Parkes, 1995). It is recommended that researchers receive sufficient training to conduct the interview in a professional and supportive manner, with knowledge of the process and expression of grief (Dyregrov, 2004; Hynson et al., 2006; Parkes, 1995). The training and preparation of interviewers is an essential component of ethical research in this area (Gottlieb & Lasser, 2001; Hynson et al., 2006; Smythe & Murray, 2001).

In reconceptualizing the ethical principles of informed consent and minimizing harm, the very aspect of qualitative research which is considered potentially harmful – talking to participants about sensitive and emotional topics – may be seen as potentially beneficial. Ethical decision-making and informed consent must consider the risks *and* the benefits to participants. It appears that it is not that qualitative research is inherently problematic but, rather, standard research ethics protocols are inadequate for such research (Halse & Honey, 2005; Smythe & Murray, 2000). While this shift in emphasis may appear evident to researchers who conduct bereavement research from a qualitative perspective, it may be less apparent to those working

within quantitative or positivistic paradigms still prominent in many fields, including psychology. In honouring bereaved participants' contributions to research, it is necessary to honour their experiences of the qualitative research process. The participants themselves provide the bridge to negotiate the gap between the interpretations of the research process by REBs and by researchers. As qualitative researchers, we have to follow our participants' lead.

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### **Notes on contributors**

Jennifer L. Buckle is an Assistant Professor in the Department of Psychology at Sir Wilfred Grenfell College, Memorial University of Newfoundland, Canada.

Sonya Corbin Dwyer is an Associate Professor in the Department of Psychology at Sir Wilfred Grenfell College, Memorial University of Newfoundland, Canada.

Marlene Jackson is the Bereavement Coordinator with Palliative Care Services, Regina Qu'Appelle Health Region, Canada.

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