

Ethical dilemmas encountered in researching sensitive issues

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ABSTRACT

Data gathering through repeated in depth interviews on sensitive issues such as HIV/AIDS, grief and child abuse, poses ethical dilemmas for the social researcher. These arise from the interaction of: the self as the chief instrument; the interpersonal context of the interview; and the sensitive nature of the topic. Recent qualitative research on loss and grief in school communities will be used to exemplify the dilemmas encountered. These included: the ontological beliefs favouring a collaborative approach to research, brought to the research by the researcher; the spontaneous intimate self disclosure of participants; the acknowledgement of interviews as a form a intervention in people's lives; the dilemma of maintaining distance in interviews, but also developing rapport; the clash of the various "I's" the researcher brought to the research process; and the impact of the emotionality inherent in the research topic. Mechanisms for coping with these dilemmas will be presented including the use of a research journal as a form of debriefing and the development of trust in the research process by the return of interview transcripts.

This paper examines ethical dilemmas involved in researching sensitive issues. It is based on the beliefs that, firstly, it is the elements that make an issue sensitive that are the source of the ethical dilemmas that are likely to be encountered and that secondly, the nature of these dilemmas has the potential to create harm for both the researcher and the participants. Awareness of this potential means that provision needs to be made for it, before research on sensitive issues begins.

Firstly this paper briefly describes the elements that make an issue sensitive, then recounts some dilemmas encountered in researching loss and grief in school communities and concludes with recommending some strategies for managing the dilemmas encountered in researching sensitive issues.

What makes an issue sensitive?

There is no clear delineation in the research literature about what makes an issue sensitive. A central factor is the involvement of the individual, that is, their inner thoughts, emotional reactions, beliefs

and behaviours (Rowling, 1991). For the purposes of this paper those individuals involved would be both research participants and researchers. Sensitive issues have the capacity to arouse intense and deeply felt personal reactions. These emotional reactions are a result of the interaction of the issue, a person's beliefs and experiences, the context and the meaning of the issues to the individual.

ELEMENTS IN SENSITIVE ISSUES

Factors, beliefs, Individuals
experiences

politicalparents
religiousemotionalityteachers
cultural-----students
personal meaning school administrators
gendercommunity members

Context(Rowling 1991)

Figure I

That is, sensitive issues can be defined by the emotionality and personal meaning of the issues to the individual; and the individual's beliefs, thoughts, feelings and behaviour. Whilst the key element is the individual, the meanings are made more sensitive by the social context (Rowling, 1991).

The study

The research process reported here involved a case study design using qualitative methods of in-depth repeated interviewing, participant observation and document analysis over two years of fieldwork. School sites for the case studies were chosen that optimised the potential for explicating the substantive topic of concern - loss and grief in school communities (Ely, 1991, Stake, 1994). One of the schools, Kair High School is a large multicultural comprehensive high school in the Sydney metropolitan area of New South Wales. There are approximately 120 teaching staff and about 1350 students, 75% of whom come from Non English Speaking backgrounds. The other school, Midway High School is a semi-rural school about 300 kilometres from Sydney. There are about 90 staff and approximately 700 students attending the school, drawn from the town and from the surrounding countryside. The results reported here relate to experiences of teachers, parents and students, information that was gained principally by unstructured

repeated interview with interview transcripts being returned to participants as the basis for a subsequent interview. Oakley (1981) highlights the gaps in the reporting of interviews in research. She maintains that the conventions relate to such things as number, length and format, and ignore issues such as social/personal characteristics of those doing the interviewing and the interview relationship itself.

The nature of repeated interviewing is such that the research process is 'interactive'. In this study importance was placed on anonymity and confidentiality. Principles and Procedures under which the research was to be conducted were negotiated with participants and these formed the basis for the conduct of the study, as well as the use of pseudonyms for people and places in feedback throughout the study and subsequent public domain reporting.

I as the interviewer was the chief instrument. Therefore another source of data was my research journal. Nothing that I read in planning this study, prepared me for the emotionality of the research process. I read recommendations about how I should address confidentiality, harm, deception and privacy, but there was not much written on such things as the impact on the researcher of listening to people talk about their grief, their fears and anxieties, sometimes being expressed for the first time and in times of crisis. Kelleher (1989) refers to this as the "trauma" in the research context. There was no detailed discussion in the existing literature of the ramifications of getting participants to pursue thoughts that they might have otherwise left hidden, or how you decide if any information is too personally sensitive to record

(Cowles, 1988), or when to probe more deeply in interviews and when to leave well alone.

Participants told me of events in their lives that had great emotional impact on them: at the time they occurred, and in their retelling. These accounts often impacted on me as I heard them.

Subjectivity then, rather than being a hindrance, was vitally important to begin to develop an understanding of grief experiences in the context of school communities. Because of the nature of sensitive issues, subjectivity is important in researching them. Not only the subjective experiences of the participants, but also the researcher's subjectivity. In my case my knowledge of the field of loss and grief and experience as a teacher, counsellor, academic and researcher.

In other words, the knowledge I wanted to construct was from particular experiences and expressions of human beings in a particular context. I as the researcher was one of those human beings. This orientation to research has been emphasised by many feminist researchers (Oakley, 1981, Stanley & Wise, 1991). It is a key element in researching sensitive issues: "personal involvement is more than dangerous bias -

it the condition under which people come to know each other and to admit others into their lives" (Oakley, 1981, p. 58). Researching sensitive issues needs this personal involvement because of the intimate nature of the research topics and consequent subjective nature of the research process.

In this paper, verbatim quotes of the participants will be used to exemplify particular issues. They were obtained from the transcribed tape recordings of interviews. Excerpts from my research journal kept throughout the field work will be used to exemplify my role as the chief instrument.

The origin of the dilemmas

The specific areas that framed the dilemmas encountered involved:

- *using myself as the chief instrument;
- *the interpersonal context involved in the interviews; and
- *the sensitive nature of the research topic - loss and grief.

Relating these areas back to the framework of sensitive issues means that the dilemmas were encountered because of my beliefs, experiences and my gender; similarly, the dilemmas were encountered because of participants' beliefs, experiences and gender; the dilemmas were also a result of my collaborative non-exploitive intent in carrying out the research; and finally they were a result of the emotionality and private nature of the research topic.

The dilemmas will be described within the two areas of self as chief instrument and the interpersonal context. The third area, the emotionality of the topic is interwoven through the other two.

Self as instrument

As already indicated a number of dilemmas were encountered by me as the researcher in this study. The documentation of the role of 'self' and my reflexivity in this study, was necessary for two reasons. Firstly, because I was the chief instrument in the research and secondly, the personal nature of the topic. The principal way the documentation of self was achieved was through the use of a research journal (Holly, 1989). I kept field notes on each school, but I chose to separate my

field notes from my personal dialogue, principally because the former I knew would become bulky and with the latter I wanted it to be small enough to be easily carried, so that as thoughts came they could be committed to paper. The research journal documented my conversation with myself about problems I encountered, my emotional reactions to interviews, aspects of the research that concerned me and my dialogue with the research literature. The process of the research was not

helped by the emotionality of the research topic and the consequent at times, unpredictability of the process.

The 'trusting the process' (Ely, 1993) was supported by the keeping of the research journal. I needed a monitoring system that would guard me against becoming so involved, that I was unable to stand back and articulate the principles underlying the developing ideas. I re-read work on loss and grief as the study progressed. In this way the journal not only recorded my experience of the research, my 'being in the research' but how the emerging issues and ideas, did or did not match current knowledge. The dilemmas encountered and were explored through my research journal were:

1. The need I felt to maintain distance between myself and the interviewee but also develop rapport.
2. The clash between the various 'I's' (Peshkin, 1988) brought to the research process.
3. The effect of the emotionality inherent in the research topic on the researcher.

Maintaining distance yet developing rapport

The intent to establish a collaborative non-exploitive approach in a constructivist paradigm (Punch, 1994) to the study of this particular research topic, created a major dilemma for me. The interpersonal nature of this research meant that I could not leave my humanity out, but I also felt I could not be a full participant. I believed I had to maintain some distance.

This not only clashed with my desire for collaboration, but also with the social relationships that were involved in a study about such a personal issue. Textbooks (e.g. Bailey, 1987) warn about maintaining interviewer/interviewee distance. I needed to be human but also detached enough to look at the bigger picture so that I did not become submerged in the minutia of day to day survival and politics of the schools and the teachers' and students' lives.

The concern of maintaining distance also involved me in the practical dilemma of how to build rapport and trust without the normal reciprocity in social relationships being a 'normal human being'. My research journal recorded my feelings about this about 12 months into the fieldwork:

The problem is, I have developed trust with these people, who are sharing personal concerns and experiences of loss. Now they treat me as a friend, a confidante. Natural social reciprocity in social relations would have me talking about everyday things about myself. But I dare not do this.
(R/J, 12/92)

I eventually accepted the dilemma of 'distance' as a part of the

researcher's role in this type of study with grief as the topic. Whilst maintaining a researcher role had been of great concern to me in terms of social reciprocity, it was not experienced as dissonant for at least one of the participants, as Harry explains in our final interview:

Harry: I must admit I hadn't thought about your role

in the research. It is an interesting point, because it would be difficult to step out of what you are doing. I guess in a sense I have seen what your role has been as very comfortable, it seems pretty natural, as well as being able to achieve your professional goal. We've talked about a lot of things of a fairly personal nature, in one sense, certainly from what I have talked to you about... You have been able to keep that at a professional level. Yet I think that for what I have been talking about there must have been some personal connection with your own experiences. You haven't shared any of that except when you said you had to come to terms with your mother's death. I thought you were human then!

Louise: When you say 'You thought I was human, had you had a concept that there was distance there?

Harry: A little, yeah. But I thought you are here to find out about us, we are not here to find out about you. I didn't find that offensive at all. I didn't think it was a requirement of what you were doing that you had to tell me every detail about your life... In a social setting if you and I were meeting, I would probably be as nosey as hell! (Harry, 11 years experience)

The parts of myself I presented in the interview were perceived by Harry as my professional role, with a touch of 'being human'.

In hindsight I might have been too restrictive in maintaining 'distance' but the fact that this research was for a dissertation and the paradigm I was working in was a new one for me, prompted me to err on the side of caution. This stance is one that researchers need to work out for themselves, but male participants reported that my gender lessened the "distance". This is an issue that space does not permit elaboration on in this paper. But feminist researchers (Oakley, 1981, Stanley & Wise, 1991) would support the influence of gender of the researcher in research. The position I adopted was influenced by the 'politics' of writing a dissertation.

Clash between the 'researcher I' and the 'counsellor I'

Another dilemma faced in this research related to a past career as a counsellor and my current role as a researcher. As a counsellor what kept running through my mind was the thought 'at least do no harm'. In the beginning, the research process had been slow. This was probably a reflection of my concerns at that time, trying to get a feel for the schools - an attempt to develop ideas. I failed to probe too deeply

early in the research about loss and grief firstly, because the precise role I should adopt was not clear in my mind, 'How much distance should I maintain from my participants to keep my research role?'; and secondly, 'How could I care for my respondents?' This I now understand to be a clash between what Peshkin (1988) refers to as the various "I's" we bring to the research process. In this case it was a clash between my 'Research I' and my 'Counsellor I'. In my research journal after I had interviewed a teacher about his experience telling a class about the death of the parent of one of their class mates was recorded:

The territory I was charting hit me... a teacher revealed the impact of recent personal loss experiences on his role as a teacher. This was the heart of what my research was about, but I had been unprepared for it. I came away from that interview feeling disturbed and uneasy. I had let someone down - that "I" as a researcher had opened up some issues - but the "Counsellor I" had, mindful of my research role, not reached out to help. The bell had rung, we had not made a contract that if what we talked about raised difficult issues, that I would provide a safety net. The realisation of the dilemma between the two roles haunted me

for days. It resulted in the resolution, to preface future interviews where I was specifically going to focus on loss and grief, with the proviso/contract that if anything did arise that they felt they needed to talk more about, that I could supply them with names of people who could help. I also resolved to tell them that they could stop the interview at any stage and to ask them at the end, if they were okay to return to class (R/J, 9/92).

Two days later the dilemma was still being explored:

If I cause problems in people's lives, that is, disturb their equanimity by my questions - does the responsibility as a human being [to me that meant 'do no harm'] override that of a researcher or can I be a human being and still be a researcher by saying something to them at the beginning of the interview? (R/J, 9/92).

Interestingly whilst this was an extremely difficult interview for me, the teacher in the following interview, reported finding it valuable. Once this dilemma was identified it was subsequently decided to maintain my research 'I', but allow for the counsellor 'I' by checking with participants at the end of the interview about whether they felt alright.

The nature of the topic, grief, meant that I could have very easily slipped into a 'counsellor role', particularly as these were not one-off interviews, but on-going dialogues. The 'staying out' was a way of protecting myself from becoming too involved in their lives.

But I did 'step out' of this role on a number of occasions. This

`entering' or `situational ethics' (Punch, 1994) was prompted by my perception of vulnerability in students, where I had information that might help them. The entering occurred:

- * during interviews with vulnerable adolescents either individually or in groups;
- * when I had acquired information about a grieving adolescent and a planned school intervention would be harmful to the adolescent;
- * when staff asked my advice on how to support grieving adolescents.

In all these instances the motivation was a desire to see the young people treated fairly, but in doing so maintain their confidentiality.

The emotionality of the research topic - loss and grief

Grief is a highly emotive topic to research. Some of the stories retold were of great sadness and pain. I was aware that doing research using qualitative methods, using myself as the main instrument would involve emotional experiences. Not only was the topic itself highly emotional but the spontaneous sharing by participants of their life experiences, sometimes caught me unaware and left me feeling humbled and with a deep respect for the resilience of the human spirit. It also meant that there were times when the events and reactions that were being described resonated with my own life experiences.

This always presented a dilemma for me, do I say `I too have experienced that' in an attempt to normalise and connect with them, knowing I ran the risk of the interview being diverted to me, yet revealing my humanity? Or do I maintain my research distance and document my response in my research journal? It was the latter response that I chose most times, for in the back of my mind was the message from grief counselling, that peoples' experiences are unique and that likening their experience to yours is not helpful.

As the researcher I continually experienced emotional reactions to interviews. I was unprepared for the intimacy and spontaneity of revelations and the prolonged impact of two years of fieldwork on this topic. Interviews were affected by feelings of anxiety "heightened by the anticipation of interacting with vulnerable subjects involved in sensitive situations" (Cowles, 1988, p. 173). I experienced anxiety in making contact with people, who because of their traumatic experience, became the focus of my interest. I experienced anxiety when I knew I was going into an interview where I would be probing someone to tell me about their feelings about current events - their own impending death, the death of a spouse or the death of a parent. Thoughts that ran through my head included, `What will this parent who has cancer look like?' `Do I have a right to question someone about a recent deeply personal loss?' `How can I provide some sort of protection for them

after I leave?' I had to console myself with the fact that it was voluntary, they could tell me as much or as little as they wanted.

Sometimes situations caught me by surprise. In the last few months of the study, I was interviewing Warwick, a new member of staff at one of the schools. I had given him a copy of a paper I had written as he expressed an interest in my findings so far. My research journal records my surprise at his revelations:

Warwick had highlighted sections of the paper, but as he began to comment on one section he deviated into telling me his own personal story about his father's suicide and his mother having Alzheimer's Disease. He talked about his feelings and his preoccupation with his father's death because of the suicide... He had not told anyone at this new school about his father's death [the death had happened about two years ago]... This is only the second interview with this person, yet he is telling me about feelings that maybe only his wife knows. Why is that? Maybe he needs to tell his story. Maybe he feels he can trust me. (R/J, 9/93)

I realised that I had not been prepared for these revelations, when I transcribed the interview. I noticed in the transcript that, as a researcher I had missed many opportunities to probe the meaning of this event in his role as a teacher. Fortunately, I was able to do that in a subsequent interview. Whilst I was not tempted here to be a counsellor, I was stunned as a human being, and thrown off track as a researcher.

The journal keeping provided me with a form of `debriefing' - the writing process had a cathartic effect after emotionally charged interviews. On another occasion I had interviewed a parent who had cancer. After the interview I recorded in my research journal:

As I drove away from my two hour interview with Mrs. Papadopoulos I felt humbled by her honesty in sharing with me the experiences of the last two years, by her determination to survive for the sake of her children and by her commitment to the need for families and schools to be open about these experiences. The words that stayed with me were "The doctor says 'I'm a walking time bomb', `All we've ever handled is just leukaemia and cancer!'"
(Mrs Papadopoulos, Interview 1)

`Debriefing' with a group of colleagues was utilised by Cowles (1988) in her research on the experiences of the adult survivors of murder victims. But she worried about confidentiality issues in using this strategy. I chose the journal for debriefing, firstly because of confidentiality concerns and secondly, I was reluctant to ask busy

colleagues to be available during two years of fieldwork.

There were things in interviews that I could not control, for example my gut reaction when people recounted experiences similar to my own. What in most instances, I chose to control was my outward reaction. The inner reaction was recorded in my research journal. In hindsight I might have been too restrictive on my use of self disclosure. Just as teachers found it valuable when used judiciously, perhaps I too could have used it more as a researcher.

The interpersonal context of the research

Whilst feminist researchers have identified intersubjectivity as creating dilemmas because of the co-researcher role of participants (Olesen, 1994) the dilemmas encountered here were different. The interpersonal context prompted spontaneous self disclosure from participants and resulted in the interviews being experienced as interventions in the lives of the participants.

Self disclosure

The spontaneous self disclosure by participants presents problems. It was the experience of teachers in the interview situation that encouraged this self disclosure. Grant's description of interviews indicates how the rapport that developed influenced him:

On the surface it is just you asking me questions and me talking to you. Beyond the surface and because of my involvement in teaching [about loss and grief] we have had other conversations. I have seen it more as 'our time together'. I am not going to call it 'interview time'. It has become more like a discussion of different things. I think that is the way you have done your research. You haven't necessarily asked me to write things, you haven't asked me to record things or interview people or do questionnaires, you have just wanted to talk to me. I think that is why I have felt so at ease, and felt comfortable in being open... You have asked my permission to use my life experiences in reports and in the workshop, the anonymity, the reporting back. It has been non threatening. You have made me feel comfortable to be open and frank with you. (Grant, 14 years experience)

The intimate details of participants lives that were disclosed presented me with an ethical dilemma of when to include this information in reports. The decision made was based on the importance of the disclosure in the illumination of the substantive research topic. Sometimes I would indicate to participants the information I wanted to use and ask their permission to use their comments (anonymously) in reports. The voluntary nature of the interviews meant that people could tell me as much or as little as they wanted. I accepted that self disclosure was their choice.

Researchers need to be aware of the possibility of intimate self disclosure as a result of the ongoing interaction and consequent trust that develops in repeated in-depth interviewing. This necessitates that a researcher act responsibly and with integrity in relation to the information gained from participants.

Interviews as interventions

The impact of the research on a personal level for some participants was profound. Alan Kelleher (1989) in his study of dying people,

referred to this impact as 'interfering with people' (p.62). One participant was working through a bereavement. She reported the therapeutic effect of the interview.

I have found it very good [being involved in the research]. I found it like a counselling session for two years. I found it helped motivate me to do things around the school. It has helped me to put things in perspective. I have enjoyed being a participant. I find myself extremely emotionally drained after some sessions we have had. That is why I said you have really been like a counsellor to me... After the interviews I used to think 'My God! I really needed that! I didn't realise how much I had bottled it up and to be able to talk to what is really a stranger, even though I don't feel you are a stranger, you still portray yourself as such in an interview situation. (Gail, 15 years experience)

An important point made in this statement is that the perception of me as a stranger facilitated the research process. One of the things that encouraged these participants to be open was that it was 'research'. The intent of discovery of the issues on my part and for teachers, students, parents and other school community members, the possibility of others benefiting from their involvement in the research, motivated their participation. This desire to tell their story has been found by other researchers (Kelleher, 1989). It is possible that the participation in research facilitates disclosure. Despite it being an emotional experience, people did not refuse being repeatedly interviewed. The return of their interview transcript facilitated their reflection and helped develop rapport. It appears that someone 'doing research' gives permission for people to talk about what for many is still a taboo topic.

I became aware of the support the interviews were providing for some staff when I was asked directly for advice by a teacher. He had been supporting a student whose parent was dying. Whilst the teacher's own parents had died six or seven years ago and he had learnt a great deal about grief from those experiences, the teacher had never actually worked with a student who was experiencing their parent's terminal

illness. I was aware that the teacher needed support and tried to encourage him to seek out another member of staff to provide that support. At one point I was asked by Harry if I thought he should give the student his home telephone number. Harry had not been able to establish any real support in the school for the role he was performing. I felt he was taking on more than he should, given his lack of support and I could not take any responsibility given my role and geographic distance from the research site. I advised him against giving out his telephone number. In my research journal I recorded my reasons:

Why did I give the advice? 1. Having agreed that Harry should support John [the student] I now can't ignore his request for advice. 2. I think Harry is at risk of not protecting himself. 3. I cannot be at the school frequently enough to give Harry support. (R/J, 9/93)

This was what Ely (1991) calls 'judicious entering' and whilst I did intervene in this way, I did it sparingly.

In summary, researching sensitive issues through interviews has the potential to create problems for the researcher and the participants. Cowles (1988) has identified timing, flexibility, trust and objectivity as issues of concern. This research adds to that list. For the participants the researcher needs to recognise that the interviews

themselves are interventions in people's lives. The research process may prompt intimate self disclosure. Measures need to be adopted to manage these situations. It is important for researchers to be aware of the impact of the research process on participants, in maintaining their anonymity, treating them with respect and accepting the power of the interview as a form of intervention in people's lives.

Conclusion

Researchers need to anticipate ethical dilemmas by examining the framework presented that delineates sensitive issues for potential sources of those dilemmas. This then allows for the protection of participants, before the research begins.

For the researcher the keeping of a research journal is recommended. It proved to be an extremely useful tool for facilitating my reflexivity about my research role and the knowledge and values I brought to the research. It was of vital importance for my own emotional debriefing. Through the process of keeping a journal and reflecting upon the experiences recorded there I also learnt more about myself, my role and the dilemmas facing a researcher using qualitative methods to explore sensitive issues. Through a re-examination of emotional responses written in the journal dilemmas have been identified and areas of risk

for researchers. As an educator about loss and grief I had frequently experienced people coming up to me after educational sessions and divulging personal experiences. I knew that this would happen in this research, but the suddenness of the disclosures and the intimacy of them was emotionally draining. What I had overlooked was the potential degree of harm of these emotional experiences, to me as a researcher and therefore the influence on the research process. This potential needs to be acknowledged by all people involved in research on sensitive issues. Existing ethical guidelines may be insufficient to accommodate all these issues (Kelleher, 1989).

But there was a positive impact. Doka (1989) believes that people who work in the area of loss and grief are 'aged' in terms of their spirituality and existential beliefs. My research experience would add another group, not just those who work in the area, but researchers in the area of loss and grief and on other sensitive issues, as well. The research process was personally draining, but the honesty and openness of worthwhile.

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