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Article

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Abstract

Qualitative researchers are compelled to use their personal judgements before, during and after interviews, particularly when their interview subjects are drawn from vulnerable groups. This paper discusses the dilemmas qualitative researchers encounter when collecting data that is ethically 'sensitive'; and situates the discussion in the realm of the Australian Occupational Health & Safety (OH&S) legislative requirement of 'duty of care' using the Rapidly Degenerative Neurological Diseases Pilot Program in Western Australia as the case example. The paper is focussed upon the practicalities and ethical concerns of the researchers conducting qualitative data collections. The discussion seeks to provide practical reflections on lessons learned and suggestions for self-care practice for researchers in the field and calls for policies that instruct and protect them.

Keywords

duty of care, ethical dilemmas, qualitative data collection, sensitive data

Introduction

What do we mean by sensitive data? Cowles (1998) describes sensitive data as 'intensely personal experience(s)' whereas Lee (1993: 4) defines sensitive research as that 'which potentially poses a substantial threat to those who are or have been involved in it'. This notion of 'threat' can be interchanged with the concept of 'risk'. There is risk to the participants involved in sensitive data collection in that they rely on adequate ethical procedures from the researcher (Mertens and Ginsberg, 2008). Conversely there is risk to the

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researcher in that they can be emotionally challenged and in some cases may be collecting data in the participant's homes; a situation that has the potential to impact on their personal safety. In 2003, Johnson and Macleod Clarke (2003: 423) stated that there was a 'lack of any systematic inquiry into the experiences of field workers while collecting sensitive data'. However, a recent report and subsequent article by Bloor et al. (2007, 2010) details a commissioned inquiry into risk and the well-being of researchers in the UK. Whilst Australia is one of the world leaders in occupational health and safety practice, it appears that limited inquiry may have led to a lack of focus on duty of care for researchers.

Lee and Renzetti (1990) write that probing into participants' personal experiences has a higher probability of causing distress to the interviewee, and numerous authors have published research on the issues of collecting sensitive data as a researcher, including psychological harm and emotional distress (Booth and Booth, 1994; Corbin and Morse, 2003), and desensitising of emotional feelings (Dickson-Swift et al., 2007; Johnson and Macleod Clarke, 2003). What appears to be missing from the literature is the impact on the researcher as the guardian of ethical practice during such story telling.

There appears to be some discussion regarding personal safety (Bloor et al., 2007, 2010; Howell, 1990; Lee, 1995); however many of the scenarios presented in this research illustrate the risks of contacting physical illnesses such as hepatitis and malaria (Lee, 1995; Peterson, 2000) or the dangers of collecting data in risky environments such as working with drug dealers (Lee, 1995; Sampson and Thomas, 2003). This paper acknowledges that collecting data in these situations is indeed risky and steps should be taken to protect the field researcher, and because of the obvious safety risk universities have adequate processes in place to provide protection. However, we argue that latent risk lies within all data collections that occur in people's homes and that this risk is often overlooked. This paper presents the aforementioned issues with supporting verbatim quotations gathered from the field researchers involved in the evaluation of the Rapidly Degenerating Neurological Diseases Pilot Program in Western Australia (WA). As part of this study, researchers gathered the stories of vulnerable participants who were either in rapid decline, caring for a loved one who was dying, or had been caring for a loved one who had recently passed away, as well as the debriefing stories of the field researchers. Although the paper does not report the results of the program evaluation it presents issues raised for the researcher including physical safety and emotional stress in the light of 'duty of care'. The Australian OH&S legislation is presented and the data collection process is discussed from a risk perspective. The paper acknowledges that universities are addressing risk management responsibilities within the ethics clearance process. However, as Bloor et al. (2010) note, although formal risk assessments are becoming more common in social research projects, they are not a universal occurrence, nor are they developed to a global standard. In cases where risk assessments are required, universities rely on heads of departments, researchers and PhD supervisors to make correct judgements in relation to the level of risk they place themselves, their student or their field researcher in while collecting data. This is problematic as determining levels of risk is subjective and relies on personal judgements or previous experience when assigning appropriate safeguards. The paper discusses the problems associated with field work data collections in relation to risk and presents examples of dilemmas field researchers encounter. It concludes with recommendations that may go some way to alleviate the risk for field researchers.

Background

OH&S legislation

Current Australian Occupational Health & Safety (OH&S) legislation requires employers to provide a 'safe system of work' for their employees with considerable penalties being attached for failure to comply. Under the law employers are required to:

- provide and maintain a safe working environment and safe systems of work; and
- provide information to employees in relation to health, safety and welfare in the workplace.

Employees also have a duty of care. They are to follow and adhere to the safe systems of work put in place by their employers and to look out for their own safety as well as the safety of their workmates. Within the Australian OH&S Act (Government of Western Australia, 1984) the 'duty of care' legislative requirements are described in the guidance notes that accompany the Act as:

> 'General duty of care' and 'general duties' are terms used to refer to the duties that the Act places upon people to ensure their own safety at work and that of others who are at the workplace or who might be injured by the work. These general duties are aimed at preventing anyone being killed, injured or contracting an illness because of work or activities at a workplace, including using plant or equipment (Commission for Occupational Safety and Health, 2010).

The provisions within the guidance note of preventing anyone from 'contracting an illness' extends to emotional stress. While this can be applied to vulnerable participants this paper contributes to qualitative research methodological scholarship by focusing on the impact on the field researchers collecting sensitive data, the difficulties in recognising risk and strategies to increase the personal safety of field researchers.

What the literature says

Mertens and Ginsberg (2008) highlight the complex ethical dilemmas that qualitative researchers encounter when collecting data from vulnerable people that is sensitive in nature. In order to delve into the participant's intimate worlds to collect data, researchers need to establish trust and rapport with participants as well as empathy and understanding. This is particularly important when collecting sensitive data as it delves into the participant's personal issues such as life threatening disease, physical abuse, or disability and comes with potential issues for even the most experienced interviewer. Lee and Renzetti (1990) suggest that topics of research including those that probed into participant's personal lives or experiences had a higher probability of causing distress to the interviewee. Liamputtong (2007) notes that vulnerable people who lack the ability to withdraw from the interview if they become uncomfortable, or raise the issue if they experience harm, are at risk. She goes further to question whether collecting data from vulnerable people can ever be ethical and concluded that to not allow their voices to be heard disempowered them even further than their suffering had already done. She insists though that researchers must pay careful attention to ethical considerations throughout the life of the research project.

Dickson-Swift et al. (2007), Johnson and Macleod Clarke (2003), and Durham (2002) raise the issue of increasing participant vulnerability while they tell their stories in that they 'relive' traumatic experiences. Additionally, Shaw (2003) notes that when participants retell their story the researcher invariably becomes an actor in the tale and is at risk of emotional distress. However, although some interview participants over a number of international studies reported emotional distress after participating in interviews most enjoyed the chance to tell their stories (Brzuzy et al., 1997; Frank, 2000; Kavanaugh and Ayres, 1998; Turnball et al., 1998; Wong, 1998).

Bastida et al. (2010) stress the importance of respecting participants involved in sensitive data collection. Due to the health of the participants in this project, field researchers had to use self reflective practices (Shaw, 2003) in order to make judgements on whether to conduct the interview on that day, or re-schedule; or to use the information collected. While all researchers had experience in qualitative interviewing, it should be noted that none had current qualifications that would make them reliable sources to make decisions based on the health and/or well-being of participants, thus providing further potential emotional distress for the field researchers. Johnson and Macleod Clarke (2003) and Campbell (2002) conducted in-depth interviews with small numbers of researchers collecting data for sensitive health research projects. They found that researchers developed friendships with participants, were challenged emotionally with the data they collected, encountered conflict over roles and considered their physical safety.

Booth and Booth (1994) stress the need for researchers to care for themselves as well as their participants as they reported feeling tired and exhausted due to the emotional strain of interviewing vulnerable participants. Coulter (2005) reported distress while researching female circumcision rites in Sierra Leone, and Moran-Ellis (1997), whilst interviewing support workers involved in child protection. Dickson-Swift et al. (2007) found that researchers become desensitised when talking about their own experiences conducting sensitive research because they had heard so many difficult stories. We found that field researchers conducting social research may also become 'desensitised' to the possible risk to their personal safety as they are regularly in the participants' homes when collecting sensitive data.

To address these issues Corbin and Morse (2003) noted in their paper discussing the risks involved in conducting interactive interviews that some review boards of institutions: that is, those panels that review qualitative research proposals are so concerned about the risks of psychological harm and emotional distress that they require researchers to develop strategies to deal with these issues prior to commencement of the data collection. Bloor et al. (2007) noted that universities provide risk guidelines in their ethics applications to support the development of these strategies. However, in order to develop strategies to protect the field researcher, the grant holder must first acknowledge that the risk exists. This is where the slippery subjective slide begins. What one researcher perceives as low risk another may view as much higher. An example of this can be found when asked to 'risk rank' a task. Differences between rankings can vary considerably from one person to another and may be the result of previous past experience or 'close calls'. Lee (1995) described risk for field researchers as 'ambient' or 'situational'. Ambient danger is risk that is situated in the environmental setting where the data is collected, for example, the risk of exposure to tropical diseases and parachute jumps. Situational danger is described as risk that occurs while collecting data in a particular setting, for example, threats of violence towards researchers while collecting data from drug dealers or prostitutes. Based on Lees (1995) work we maintain that any field work in people's homes is situational risk, however, this risk becomes amplified in that it may not be recognised by the grant holder, PhD supervisor or field researcher as a threat to their personal safety. When collecting data from sick, dying, or disabled participants in their homes, there are often other individuals working and providing services within the home at the same time. Although the participant may not pose a physical threat to the field researcher, this cannot be guaranteed from the other individuals. It is the unknown that poses the greatest risk and it is the unknown that diligent risk management demands be foreseen and addressed.

Research method

An interpretative phenomenological analysis (IPA) (Eatough and Smith, 2008; Smith, 1996) was adopted in this study to analyse the data collected. This methodology acknowledges that the relationship between what people say and what they think and feel is complex. Accordingly, IPA adopts an interpretative approach to analysis which accepts that the research process is a dynamic one. The depiction of participants' personal worlds involves two stages of interpretation: participants attempt to make sense of their experiences, and the researchers attempt to make sense of, and interpret, the participants making sense of their experiences. As a methodology, IPA itself raises many opportunities for the potential for researchers to make decisions on data collection which may impact on their own psychological or emotional well-being.

While acknowledging that one cannot obtain direct access to the participants' worlds, the role of the researcher is to engage with participants' accounts in such a way that an 'insider perspective' (Eatough and Smith, 2008; Smith, 1996) is obtained. However, in doing so, it is recognised that a researcher's interpretation is influenced by that researcher's own thinking and understanding. Rather than being viewed as biasing, these factors are necessary in order to be able to interpret and make sense of someone else's experiences. For example, with the participant's thoughts and feelings, the IPA researcher's role is to interpret their mental and emotional states from what they do and say. Such inferences are made with recognition of the participant's contextual and cultural background. This paper draws on the personal reflections of the field researchers after the initial data collection for this study.

Sample

The research design for this evaluation included a number of clients with a range of rapidly degenerating neurological diseases. The purposively selected sample included six service providers, ten clients and ten carers in both city and rural areas. Data was collected over two years in two collection rounds.

Data collection and analysis

Data was collected through recorded semi-structured face-to-face interviews, and telephone interviews by experienced qualitative researchers. Semi-structured face-to-face interviews were conducted in most cases, and occurred in the participant's family home. However, where this was not possible due to distance, availability of participants and stated participant preference, telephone interviews were substituted. In three instances, because of the failing health of the clients, the carer and the client were interviewed together. In order to ensure accuracy, the field researchers transcribed the interviews.

Discussion

The following discussion presents areas of concern for qualitative researchers conducting 'sensitive' data collections. This is achieved by examining the processes undertaken, in order to highlight the areas of potential emotional stress and the risk to personal safety within the role of the field researcher. Verbatim quotes were collected from the field researchers involved in the data collection for the evaluation. The discussion includes the challenges field researchers may face when required to collect data in participant's homes including: their personal safety may be 'at risk'; 'sensitive' data can be emotionally draining or difficult, and processes to debrief are recommended; they may find it difficult not to take a counselling or advisory role when interviewing vulnerable participants; judgements need to be made on the fly whether to conduct a scheduled interview or not; there are issues around treating vulnerable people with dignity when collecting data; and researchers and colleagues should recognise the importance of 'self care'.

Importance of protecting yourself – collecting data in 'risky' environments

Researchers may place themselves at risk when collecting data. For example, qualitative data collection with vulnerable people will often require researchers to work within participants' homes. The risk that can arise from these situations includes one of personal safety. The researcher is entering a stranger's home and does not know the stability of the interviewee or indeed who else may be in the house. Further, field researchers may not have a full understanding of any potential physical dangers.

Stevens et al. (2009) focussed on the duty of care of vulnerable participants in their study of families caring for children with life-limiting conditions. However, they did not take into account the responsibilities of the researcher except to provide debriefing. Experienced field researchers may become blasé to the possible dangers. What is the duty of care to oneself, and if sending in a field researcher to collect data for the project, what is the duty of care for that person? How do we guard against instances of abuse, physical violence, and sexual harassment? Furthermore, how do we support junior researchers in their apprenticeship or more experienced ones with their perceived insensitivity and their lack of acknowledgement of the risks to their personal safety?

Review boards of institutions such as universities are concerned about the risks of psychological harm and emotional distress, and require researchers to develop strategies to deal with these issues prior to commencement of the data collection Corbin and Morse (2003). However, there appears to be limited policy and procedural requirements in place to protect the field researcher in the case of their personal safety when collecting data in participants' homes. In reality, institutions are failing in their duty of care because limited provision has been made to provide a safe system of work for employees (field researchers) in this situation, even though it is a requirement of the Australian OH&S legislation. Where they fail most is that they rely on heads of schools, PhD supervisors and grant holders to make subjective decisions as to the level of risk and the strategies they put in place to protect field researchers. Furthermore, when strategies are developed, such as field researchers working in pairs or using a call-back system at the beginning and end of an interview, research budgets are often too tight to afford to put them in place (Bloor et al., 2010). Bloor et al. (2010) argue that using limited funds as an excuse not to implement such safe procedures is simply poor planning by grant holders, but in our experience there are no in-built safety measures or a culture of research focussed OH&S training except for a requirement to provide a risk rating prior to the data collection. Bloor et al. (2010) maintain that this is not a structural support issue but rather one of institutional culture. We agree and while it could be argued that it is not practicable for institutions to do a full OH&S review for settings where field researchers may be undertaking their work, or indeed that researchers would support an increase in ethics paperwork, our research indicates that safety for field researchers barely appears on the radar and that the institutional culture begs for change. As Bloor et al. (2010: 51) state, 'the inadequate management of researcher risk by universities should not be seen as simply symptomatic of wider corporate failure'.

Physical safety for researchers

Once field researchers enter a participant's property, it becomes their workplace. Unless participants are known to be physically violent, or known to be living in dangerous surroundings, a field researcher is unlikely to have considered issues of their physical safety. There are further considerations when entering the homes of participants, in that field researchers are unlikely to know or have control over other occupants (Bloor et al., 2010). Universities are relying on field researchers to have had enough experience or knowledge to instinctively know how to take care of themselves in this working environment (Bloor et al., 2010).

> *Somehow I just knew to draw on a previous close call. I parked my car on the street and not in the driveway – and had it pointing towards the entrance of the cul-de-sac, ready for a quick getaway if needed. I'd been caught in my car in the drive with an unsavoury family member in the past and there was no way I would put myself in that situation again. No one taught me this trick though. I learned it the hard way, the frightening way.*

In this particular research project, field researchers often entered homes which had adjustments made to them for the medical and physical care of the dying participants. Small family homes packed with large hoists and electrical equipment with cables running across floors would not be considered a 'safe working environment' under Australian OH&S regulations. However, this is the unfamiliar environment field researchers can find themselves in.

> *First I nearly tripped on the home made chipboard ramp at the front door on the way in – and then I was greeted by the family pet – gnashing his teeth at me. I was more worried about quickly establishing a relationship trust with the family for the interview than my own safety. Of course I wouldn't say anything about the safety issues. Looking back I certainly chose not to say anything about cables across the lounge room floor or the ventilator cable passing over the kitchen sink either. You might call it my 'workplace' but what I saw was their 'home' being turned into a proxy hospital. Not my place to say anything even if it was potentially dangerous for me.*

Importance of debriefing for researchers – supporting each other

In designing a methodology for research involving work with vulnerable people there is much emphasis on ensuring an ethical stance and an almost protective approach to the people who are to be interviewed. However, while the support of field researchers (be it qualitative or quantitative) is considered, it is often no more than a 'throw away' line in an ethics committee application saying that 'ongoing support and, if needed, counselling will be available', without any instructions on how, where and when to access this. Sometimes, such support for research staff is not so explicitly considered but just known to be part of the support services staff can draw from.

> *I knew we had something set up for the participants. But suddenly I wondered if we had it set up for research assistants. If I carried this story home in my head for a couple of days, what might be the impact on a more junior team member? I must make a point of meeting up with < > for a chat. It will be useful for me too. Self awareness can be such a draining thing, ha ha!*

In research projects where there are no critical incidents, it is rare that researchers turn to formal debriefing. However, in research which is personal in nature, and interviews in particular, researchers will often share their experiences with other researchers as a form of debriefing (Johnson and Macleod Clarke, 2003) – something that is often invisible in methodology sections of research reports. Where informal debriefing does take place, however, it might also provide a space for field researchers to develop their future interview skills and sometimes they may also gain from informal brainstorming sessions that might arise.

> *Poor < > just popped in [to my office] about something totally different and we got on to the topic of the interviews. I don't think I took a breath for a few minutes telling her about some of the wonderful people I had met.*

There is a need to ensure that in the management of researching sensitive topics, and in particular when briefing researchers about to spend time with vulnerable people, there is an explicit conversation about the supports available to them. It is important to emphasise that it is as important as the support for participants; whether this is done formally or informally.

> *As an experienced researcher and still having current links to the field, I really didn't give debriefing a second thought. I did one interview. Ok. I started the second – in fact I just walked in through the front door and met his wife, and I knew I had to set up something for myself. You wouldn't be human if you did an interview with someone going through these life changes and thought you could keep it all to yourself. There is so much privilege in our part to just listen to their stories ... and while recording them for the research is all fine and good, they stay in your head. Until you share.*

Visible and peer support for researchers investigating sensitive subjects may act as a valuable debrief. It seems, in our experience, that many qualitative researchers absorb often traumatic data and internalise the suffering of those they interview and relive these experiences when transcribing recorded data (Opie et al., 1992). The importance of discussing this data with peers cannot be overemphasised.

> *It's nice to know I'm working with good people. Not just for my own processes like an informal debrief and chat about the project, but I feel better knowing that these really good people are the ones doing the other interviews too. That alone indicates to me that I have some attachment to participants, despite my longest face-to-face time being under four hours.*

> *What do you do with all this stuff in your head? There is the stuff that is used for the research, and then the stuff that ends up on the cutting room floor (and swims in your head in your quiet moments). No matter how experienced you are, it has to go somewhere or I think I would carry these people around with me for a long time.*

> *I found myself checking the death notices in the paper, a habit long given up when I left clinical practice years ago. It was a way of finding out 'how the story ends' when I was nursing – and here I was doing it again; a form of personal debriefing really.*

In order to facilitate a cultural shift in institutions, the importance of debriefing needs to be recognised by research team members, even the highly experienced researchers. A mechanism to encourage the importance of informal and formal debriefing is to schedule it into research budgets and time lines. Additionally, there is room for explicit policy support from research institutions in this area.

Advising during interviews – objectivity

The notion of objectivity has a different tone to its meaning when interviewing vulnerable people on sensitive topics. For example, one member of the research team said that for her, objectivity was more about making sure the participant's story got told with reverence and respect (Bastida et al., 2010), and minus her own voice, saying that to be objective at all was unrealistic on a project such as ours.

> *I still feel pangs of 'Oh dear'. Despite being skilled in qualitative research methods I still feel the tug of the old 'objective researcher' from my early research student days. I dare anyone to interview a man facing his own death head on, a man who is literally a shadow of his former physical and psychological self, and remain objective. In fact if I ever found one I wouldn't have them on my team!*

According to Nagel (1961: 473), objectivity in research is 'value-free' and 'unbiased'. This resonates soundly with the more recent studies of Johnson and Macleod Clarke (2003) and Campbell (2002) regarding blurred boundary relationships between interviewers and interviewees. Researchers face the dilemma of their objectivity in collecting data at each encounter in qualitative research. This is often an unavoidable consequence, particularly for the experienced researcher.

> *It was mid interview when it hit me that my past profession in the field was influencing how I acted and reacted during the interviews ... and yet I couldn't really use any of that knowledge I had and still be an 'objective' researcher. Still, I couldn't help myself. When < > said one of her issues was finding appropriate clothing now she was wheelchair dependant, of course I gave her the information I had at hand. To NOT give it to her, when the woman is rapidly degenerating towards her own death, would be a waste of time and my knowledge. It would have been unethical NOT to be involved where I could assist. Oh dear; so much for objectivity.*

Participants and researchers enter the interview with their own set of past experiences. The degree to which these experiences determine the discussion is mediated by the role the interviewer takes. The interviewer can choose to have either a more participatory or more observatory role within the interview. The difficulty when interviewing participants about sensitive issues such as dying is that the researcher unconsciously takes on the participatory role. Methodological literature appears to say little about the impact of this tension on the researcher.

Judgements made whether to interview or not

Where the interviewee has a rapidly degenerating condition, despite all care being taken, by the time a researcher visits the participant, significant changes may have occurred. In some cases the researcher telephoned in the morning to confirm the interview for the afternoon and when she arrived, needed to make a decision on whether to continue. Some of the field researchers working on this project came from clinical backgrounds;

however, none were current practitioners. While the choice to conduct the interview is made by the participant and their carer (and spouse), there is a degree to which the researcher must also be happy that they are not causing harm by continuing with people who might be feeling that they can't retract their consent to interview (Liamputtong, 2007). These judgements can weigh heavily on a researcher, especially if they lack clinical skills to make an assessment.

> *I was no longer qualified to say whether he was ok to go on with the interview. All I could do was ensure they both understood that they could pull out and that that was fine by everyone.*

During interviews with participants – particularly face-to-face interviews in their own homes where the researcher also has the advantage of observation of a sample of their home environment and relationships – another type of assessment happens 'on the run'. While in this project it was intended to interview pairs of participants and carers (interviewing them separately) there were times when an interview with a participant either brought forth new knowledge that would indicate that it was inappropriate to separately interview one or other of the parties. In this case, the interview with the carer was cancelled. Although the field researcher made this decision, was that really her decision to make? Did she have 'capacity' to make that decision for herself? Was it a 'protective power' of the researcher and was that appropriate? If a researcher witnessed what might potentially be seen as abuse of a participant, was it their duty to report? All these add to the emotional pressure on field researchers.

> *She appeared to be at the end of her tether, I doubted that she was coping at any level – more just going from moment to moment and dealing with what was most urgent in that minute she faced. Then when she was distracted by visitors, < > lent forward as far as he could and whispered to me: 'She is cracking up. Sometimes I am scared to ask for anything 'coz she just slams it down at me. We've got her seeing somebody next week'.*

In other cases, despite being given a list of people who had agreed to be interviewed, it was noted by behaviour on the telephone during the arrangement of interviews that it was not appropriate to conduct the interview. Once again, it should be noted that this type of decision-making leads to tension for the field researcher between expected research outputs and ethical standards. For example:

> *I just took it on myself to say 'How about we remove you from the list?' I wasn't going to ring back a third time, after being told 'Look, I know Mum said yes to this but Dad is so drugged on morphine right now I'm not sure when he will be with it'. I refused to interview a man on his death bed and use up his precious energy and compos time when that belonged to his wife and two sons I had been talking to over the past week.*

A further example was when the carer used the interview as a form of respite for the field researcher to 'look after' the patient and conduct the interview, while the carer ran an errand. Each judgement comes with internal tension for the researcher.

> *I was a little shocked when he asked if it was ok for him to pop up to the shops as I was there with his wife. But I felt comfortable with that and said yes (goodness knows if I was covered by our insurance if anything had gone wrong – but I was relying on my past work experience almost intuitively at the time).*

Judgements made whether to use the information collected or not

There are times when the researcher is faced with the dilemma of using or discarding the information they have obtained in the interview. When there are obvious signs that one or more of the participants are not coping emotionally, is the data a true reflection of their situation? Or has the interview merely taken advantage of people in a moment of vulnerability Liamputtong, 2007).

> *She grabbed me as I walked to my car; we stood there probably nearly as long as the interview. She had so much to say about her fears about estate planning and getting ready for the practicalities around his impending funeral. So open; so scared. Of course my tape was off. I did ask her if I could include some of her ideas and issues in the research report – she said yes. I drove around the corner and once out of sight I pulled over and wrote copious notes from my memory of what she had said. Now I have to decide whether to use it or not … I think I will send it in to the senior researchers to decide what to do with it – it's just that her idea to suggest some support for estate planning is such a great one for future program development that I would hate for it to be missed.*

In our experience this dilemma is difficult to make a judgement on. In some cases, as in the quote above, information and new ideas were obtained 'off the record' that was not revealed in the formal interview setting. Once again personal judgements had to be made in this situation. Additionally, the time between undertaking an interview and having debriefing available might be problematic, leading to ineffective debriefing or decisions made 'not to bother'.

Vulnerability of participants

For this research study the requirement was to gather the perceptions of vulnerable participants who were either in rapid decline or caring for a loved one who was dying or had recently passed away. This placed the researchers under enormous pressure to ensure the participants were treated respectfully (Bastida et al., 2010).

> *You're recording the thoughts of dying people for goodness sakes. The pressure to represent them right is enormous. They might be vulnerable, but I was feeling a real pressure to perform at times.*

In some cases, participants were uncomfortable with their new communication styles, brought on by their debilitating conditions. Examples include: speech becoming unclear and laboured with their breathing, or using a new communication tool such as text-to-speech equipment.

> *I had to work a little harder to get < > comfortable. I knew that he would easily allow his wife to speak for him, and I thought that the best I could do is to co-interview (which might save this couple some time too), but also make sure they could both have different opinions. So first I spent some time talking with < > about his new technology, it helped that I knew about it (and other models) so we could have a good chat, and he did relax. I already had relative trust of his wife, having helped her out with a hint about the hoist, so I developed a repartee with < > by using humour. Then when the time came to check if they both had the same opinion I could make it easier for them both to have a voice by making a joke about relationships and having a different opinion. Not only did < > tell me quite clearly when he disagreed [which meant slowing down considerably as he was very slow at his typing] but he started joking back with me, even teasing me with either hand signals or on his text. It was a fun atmosphere between the intense bits.*

In these instances interviews that should have been completed in thirty minutes extended well beyond the allotted time. This placed the researcher in a further dilemma in that they may have overstayed their welcome, and/or now be under time pressures for planned appointments.

> *Because it took longer, I felt quite awful that I had stayed longer than I had predicted to them, I felt guilty when she thanked me and said I had made their day by visiting. What do you say to that?*

Feelings of guilt and personal responsibility for the plight of the interviewees arose with the researcher a few days after the interview.

> *While I was working on something totally different Mr and Mrs < > kept popping into my head. I felt like visiting them, you know, just to pop in for a cuppa and* do *something; something that would make things better for them.*

It seems, in our experience, that interviews with vulnerable participants have the possibility of emotional distress for both the participants and the interviewer.

Sensitivity required of researchers when asking questions

When interviewing people with significant physical issues due to their rapidly degenerating condition or their very busy carers (often a spouse), there are a few things which need to be noted prior to arriving at their home.

> *As I did a quick scan of their home environment I actually thought to myself thank goodness I have a background in this field. All this equipment, their openness to talk about catheters, bowel movements and peg feed issues, and obviously physical degeneration could be overwhelming for someone never exposed to it before.*

People who are in rapid decline require the interviewer to assess their physical state ‘on the run’. We found that although some interviews began well, the participant’s energy drained quickly. The interviewer needed to be skilled at obtaining the information quickly before participants and their carers became too tired to continue.

> *Although < > was obviously enjoying her chat, I could see her getting tired and more laboured in her breathing. I cut the interview short as soon as her husband returned. They both looked so tired, emotionally and physically.*

The researcher needs to have an ability to work with participants to intuitively sense whether to finish the interview, take a break or come back at another time.

> *They had just finished telling me how isolated they were feeling from friends. Near the end of the interview thank goodness, some visitors arrive. When faced with a dying man and his tired and lonely wife, as researcher, I chose to quickly finish the interview so that they could have their time together. I felt this was a much more important way to spend his time when he won't be around in a few months. I had useful information for the project that he had shared. I called it quits for the day and thanked them, most sincerely, for their precious time.*

Carers' social isolation can mean that the researcher is placed in the position of being a friendly ear about things that are not part of the research. This dilemma was discussed by Bogolub (2010: 10) who maintains that 'social work research is guided by the ethical principle of beneficence, and social work researchers are also obligated to bring about good'. Researchers are faced with making decisions about providing the carer with a sympathetic ear or sticking strictly to the research topics.

> *I found I went right back into 'nurse mode'. I could see how important it was to quickly establish both trust and rapport. I was pleased that I felt very centred and authentic about the privilege of doing these interviews; almost to the point of being quite protective of the participants.*

This research highlighted the many points for possible emotional or psychological stress from quick decision making, in order to provide a safe environment for all concerned. However, there is tension in balancing this with research outputs. This project is a reminder that there are many shades of grey in qualitative research. Interviewers are human, and come to the interview with their past history and their own belief about capacity and ethics that have an impact on the research process. It raises questions around effective preparation for field researchers, and the provision of effective policies to ensure that psychological and emotional duty of care is provided for; along with an extension of physical safety when entering the homes of research participants.

Support strategies for field researchers collecting sensitive data

Following is a checklist that we suggest could be used to support field researchers collecting sensitive data. Universities could adopt such a checklist for qualitative research projects to assist researchers in identifying risk and applying support strategies.

1. Has a cell phone call-in been established?
2. Has the field researcher had experience in working with these types of participants?
3. Can the field researchers work in pairs?
4. Can the field researchers be issued with a personal duress alarm?
5. If the data is to be collected in the participant's home are other colleagues aware of their whereabouts and has an exit strategy been planned (parking in the street for an easy get away)?
6. Is counselling or debriefing support available?
7. What types of safety training should be provided?

Conclusion and recommendations

Both experienced and inexperienced researchers will be quick to share 'war stories' of close calls and experiences they have had in the field. This does not, however, necessarily expand to professional reflection prior to or during research processes. This may initially appear as simple as 'listening to the life story of an individual in their home'. We posit here that Australian research institutions need to take more responsibility to ensure that policies and processes for field researchers explicitly consider some the issues raised in this paper, particularly when researching with participants in vulnerable populations. Emotional stress and distress, levels of decision making required by qualitative researchers in particular, and physical safety when entering the homes of others where there are numerous unknown elements to consider are as important as research outcomes. It is unlikely any cultural change will occur without the support of administrative processes that explicitly highlight potential issues and potential strategies, in the same way that participant safety is protected through institutional ethics application processes.

This proactive approach can be further developed by providing safety training for field researchers on the topics raised. Working through possible scenarios, opportunities to discuss possible proactive strategies with mentors, and formal training could be components of such safety training. We recommend that the inclusion of debriefing and safer data collection practices be included in research project timelines and budgets and that policy be developed to support the adherence to duty of care requirements.

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