



Sensitive interviewing in qualitative research

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Introduction

Much of nursing and health research focuses on aspects of living that may be considered sensitive (Enosh & Buchbinder, 2005). While all research topics have the potential to be sensitive (Corbin & Morse, 2003), some studies elicit more distress than others, often causing the risk of harm to participants and evoking emotional responses such as sadness, anger, anxiety and fear (Elmir, Schmied, Jackson, & Wilkes, 2011). Furthermore, when sensitive research is being undertaken, reasonable and appropriate safety measures must be taken to reduce the risk associated with breaches of confidentiality and invasion of privacy (Mealer & Jones, 2014).

For sensitive topics, many researchers choose a qualitative design using in-depth interviews (Liamputtong, 2007). Face-to-face interviews are an ideal method of data collection when exploring sensitive topics (Elmir et al., 2011; Taylor et al., 2011). Interviewing requires the skill of conducting an incisive interview that yields rich and meaningful data, while at the same time allowing participants to feel safe and at ease discussing difficult or sensitive experiences with a stranger (Knox & Burkard, 2009).

In this paper we describe the experience of gaining access to and conducting interviews with family carers who provided end-of-life care for individuals with end-stage dementia. Using examples from field notes, reflections and extracts from interview transcripts, we detail some of the challenges encountered when interviewing family carers and how these influenced the recruitment process and quality of our data. We provide some suggestions for improving access to participants and conducting sensitive interviews with this vulnerable population through the use of a framework (Table 1) developed to guide and assist novice researchers.

Study Context

Our study was designed to increase understanding of family carers' experiences of providing end-of-life care for those dying with dementia at home. While qualitative studies have been conducted on the experiences of family carers of a person with dementia, they have mostly been conducted in nursing homes or long-term care settings. Less is known about family carers' experiences of providing end-of-life care to persons with dementia at home or the impact of

providing end-of-life care to a family member with dementia (Dempsey et al, 2015; Hennings, Froggatt & Keady, 2010).

The research was guided by interpretative phenomenological analysis (IPA). This research design was selected over alternative qualitative approaches as the most appropriate methodology to address the research question. Methodologically, IPA concerns itself with examining the lived experience and how individuals make sense of their experience (Smith, Flowers & Larkin, 2009).

Purposive sampling was used to select participants who provided care for a family member with end-stage dementia at home. Participants were selected for homogeneity and diversity, including men and women who lived in urban and rural locations. Participants were primary caregivers to persons with end stage dementia or who had been carers for persons with dementia who died at home in the previous 12 months. Participants included 15 current carers and five past carers for a family member with dementia. The first author conducted semi-structured interviews in participants' homes.

A Sensitive Topic and a Vulnerable Population

Sensitive research is difficult to define but has been associated with taboo topics or those “laden with emotion or which inspire feelings of awe or dread” (Lee, 1993; p. 6). Renzetti and Lee (1993) defined sensitive research topics as those which intimidate, discredit, or incriminate the participant. Health researchers conduct research on a wide variety of topics that could fall into these categories, such as research focused on rape, post-traumatic stress disorder, drug use, death, grief, or birth (Lowe, Chan & Rhodes, 2011; Mealer & Jones, 2014; Taylor et al., 2011). Dickson-Swift, James, Kippen, and Liamputtong (2008, p. 2) favored the definition, “research which potentially poses a substantial threat to those who are or have been involved in it,” acknowledging that all who participate may be affected. The topic itself may be perceived as sensitive, or the research may evoke emotions from those participating in it. Researchers also may be affected and should prepare to disengage both physically and psychologically on completion of the research. Studies of this nature require careful planning and consideration on the selection of an appropriate research design and data collection method (Dickson-Swift et al., 2008; Ashton, 2014).

Although sensitive topics do pose an element of risk to participants, avoiding this research may be seen as evasion of responsibility and disempowering to the individuals involved (Dickson-Swift et al., 2008; Sammut Scerri, Abela & Vetere, 2012). Often,

researchers cannot predict how participants may be affected because some issues are not always apparent at the outset (Corbin & Morse, 2003). Dickson-Swift et al. contended that the experience of participating in such research may bring about a change in participants, which may be positive or negative.

The benefits of undertaking sensitive research must outweigh the risks. Ethical guidelines provide useful advice when planning research on sensitive topics (Ashton, 2014). Corbin and Morse (2003) recommended following a code of ethics to guide the research process, from framing the research question, to selecting participants, through to writing up and disseminating findings. The moral complexities of the research relationship need to be addressed and sensitivity shown for participants' needs throughout the research process (Hewitt, 2007).

The term "vulnerable" when referring to target populations for research is often used interchangeably with other terms, such as hard-to-reach, sensitive, or hidden populations (Liamputtong, 2007). Vulnerable groups may hold a social status that diminishes their autonomy and marginalizes their lives. Participants in the dementia carers study were vulnerable as members of a population known to experience mental and physical illness, social isolation, financial difficulties, stress, and difficulty coping (Flynn & Mulcahy, 2013; Jones, Tudoe Edwards & Hounsome, 2014). The population also is emotionally vulnerable due to their involvement in end-of-life care.

A Framework for Sensitive Interviews with Vulnerable Groups

Qualitative researchers must attend to special considerations when planning and conducting interviews on sensitive topics to ensure a good outcome for both the interviewer and interviewee. The framework described here (Table 1) was developed by the first author after revisiting reflective field notes on the challenges presented when conducting such interviews. The framework encourages researchers to plan for a variety of considerations before embarking on data collection, to improve the effectiveness of sensitive interviewing with vulnerable groups and to avoid omission of critical information.

Access to vulnerable groups and participant satisfaction may be enhanced with a standardized framework for sensitive interviewing. In addition, strengthened interpersonal relationships between the researcher and gatekeepers may result from an approach that places the participants' needs at the forefront. In this framework, we offer points for consideration

prior to starting the research, in hopes of guiding interviewers through the swampy lowlands of data collection and avoiding common pitfalls along the way.

Table 1. Essential Elements in Qualitative Interviewing Framework

| Elements | Considerations | Action |
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| Preparation, Planning & Implementing an Interview Schedule | Preparation is vital. Select the correct research methodology and data collection tool/s to acquire data from participants. Develop an interview schedule and have a thorough knowledge of this interview schedule. Use the interview schedule flexibly as a guide to facilitate meaningful discussion between the researcher and participant. | Liaise with research supervisor or research team to decide which research methodology best addresses the study's research question, aims and objectives. Develop an interview schedule with predetermined questions focusing on the study's research question and aims. Conduct pilot interviews to troubleshoot issues with interview schedule questions. Pilot interviews will aid skilful and effective questioning. |
| Accessing Vulnerable Groups | Consider issues with accessing gatekeepers of vulnerable groups and negotiating access to participants. Participants require sufficient information to make an informed decision to participate. Consider how participants may contact researchers to self-select to participate in a research study (text message, telephone call, or return postal consent form). | Meet gatekeepers in person to facilitate relationship building, develop trust, allow questions to be asked and clarification to be sought. Explain to gatekeepers the perceived benefits of taking part in research. Provide detailed study information to potential participants and contact names and numbers if they wish to partake in the research. Consider utilizing social media to recruit participants. |
| Time & Location of Interviews | Flexibility on the part of the researcher. | Conduct interviews at a time and location which is suitable for the participant. |
| Rapport & Relationship Building | Consider how to deal with distress and emotions. Care is required for the participant and researcher. Interviews may be therapeutic for participants. Relationship development which is mutually trusting and positive facilitates discussing sensitive topics. | Effective listening is required. Support structures may be required to deal with distress. Rapport development and a trusting relationship are key to facilitating discussion of sensitive topics. |
| Therapeutic Interviewing | Know your interview questions so that your schedule is a guide, allowing free flow of conversation. Develop skills in empathic listening and being comfortable with interview silences. Consider how you will deal with distressed participants. Location of the interview is key to allow for free flowing discussion. Consider the need for refreshments and tissues during interviews. | Thorough knowledge of interview questions is required for free flowing conversation between researcher and participant. Avail of qualitative interviewing training. Develop a distress protocol. Source a quiet, private interview location free from interruptions. Provide water and tissues to participants to promote comfort. |
| Concluding Interviews | Closing of relationship after data has been collected. Ensure positive closures for the participant and the researcher. Reflexivity is required to consider values, beliefs, perceptions which may influence the research process. | Debriefing with participant after interview has ended. Provide contact numbers of support services as required. Meet with supervisor or research team to discuss the interview process. |

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| | | Bracket interviews: meet with a critical friend/supervisor/research team to challenge self-deceptions, keep a reflective diary. |
| Ethical Considerations | Trust. Informed Consent. Anonymity and Confidentiality. | Devise a risk assessment and distress protocol. Adhere to ethical research principles. |

Preparation, Planning and Implementing an Interview Schedule

Qualitative researchers aim to understand people’s lives as they are lived generating deeply contextual accounts of participants’ experiences and their interpretation of them (Schultze & Avital, 2011). The participant has experiential expertise and should be the sole focus of the researcher’s attention (Smith et al., 2009). By listening intently to the participant’s story, the researcher conveys interest in what the participant is saying and facilitates the conversation to flow freely.

Semi-structured interviews are the most common type of interviews used in qualitative research (Holloway & Wheeler, 2016). In-depth interviews can be conducted on a one-off basis, however many authors suggest that researchers should develop a relationship and rapport prior to conducting sensitive interviews (Murray, 2003; Liamputtong & Ezzy, 2005; Liamputtong, 2007).

Development of an interview schedule is advised, especially for novice researchers, but it should be used in a flexible manner as a guide, incorporating ideas of how best to phrase questions and how to move from broader issues (emic) to more specific and sensitive (etic) topics (Doody & Noonan, 2013). In the dementia carers study, after four pilot interviews, it was found that having a predetermined schedule of questions in front of the researcher was off-putting to participants and made the interview more formal and less conducive to open and free flowing discussion. Therefore, we recommend having an interview schedule as a guide but remembering that the researcher’s role is that of active listener and in the case of vulnerable participants, it is often preferable to set aside the structure to fully concentrate on the participants’ needs instead (Smith et al., 2009). The onus is on the researcher to be sufficiently familiar with the interview questions in advance so as not to rely on the schedule during the interview.

Naturally, an interview does not have to follow the sequence of the schedule. The participant may move completely away from the schedule and follow an alternative course. Probes are valuable to find out more on interesting topics (Doody & Noonan, 2013). This

requires intent listening on the part of the researcher to be ready to ask relevant follow-up questions (Smith et al., 2009). Knowing when to probe and how to choose the correct probe requires skill and an understanding of the purpose of each question (Polit & Beck, 2012). Nondirective probes refocus the discussion in a natural way, eliciting more detailed information from the participant.

In this study, it was the first author's intention to make participants feel at ease in the familiar surroundings of their own homes and facilitate a conversation between two people, as opposed to a question and answers type session between strangers. Therefore having a thorough knowledge of the interview questions and topics prior to data collection was crucial.

The researcher asked participants at the start of each interview to *"describe your experience of providing care for your family member who has dementia."* This broad question allowed scope and flexibility for each participant to tell his or her personal story. When participants discussed topics which were of particular interest to the research, the researcher probed further by asking, *"Can you tell me a little more about that?"* or *"You mentioned how difficult this has been for you, can you explain what these difficulties are?"*

Accessing Vulnerable Groups

Accessing participants for research purposes is often problematic if the sample is seen as vulnerable or the research topic under investigation is sensitive in nature. Gatekeeping is the process by which researchers are permitted access to a research setting under investigation and/or to the participants in that setting (Kawulich, 2011). Obtaining the support of gatekeepers when conducting research with minority groups or vulnerable groups is vital (Berg, 1999). Gatekeeping means more than meeting the right people to open doors; involving gatekeepers can have great benefits in that they may have local influence and power to add credibility and validity to research by their acceptance of it (Seidman, 2013). However, gatekeepers can also block research and prevent access to participants (Sixsmith, Boneham & Goldring, 2003).

Two problems have been identified in relation to gatekeepers and the consent of study participants. The first concerns the over-protectiveness of gatekeepers, which may result in people being denied the opportunity to participate in research (Heath, Charles, Crow & Wiles, 2007). The second concerns a failure of gatekeepers to provide opportunities for potential participants to exercise choice in participating in research (Miller & Bell, 2002), which may occur in schools or institutional settings. Seidman (2013) classified gatekeepers into two groups: absolutely legitimate (to be respected) and self-declared (to be avoided), cautioning

that self-declared gatekeepers may be working to their own agenda, attempting to influence the research process by selecting participants approved of by themselves.

While gatekeepers correctly serve to protect individuals in their care, Alderson (2004) highlighted that this may also exclude and silence potential participants without consulting with them in person and may result in a biased sample. Access to participants may be denied by gatekeepers due to pressures of time and inconvenience, reluctance to expose organizations or institutions to public scrutiny, or inappropriateness of the research topic and/or its methods (Heath et al., 2005). The latter reason must be respected, as it is acknowledged that the role of gatekeeper is to prevent harm and protect those in their care. Researchers have little choice but to respect gatekeepers' judgments but may on occasion seek to contest them (Heath et al., 2005).

The first strategy is to secure access to the organization from which participants will be recruited. Researchers often must negotiate access to a research site with influential gatekeepers at multiple points or with multiple gatekeepers in different sites. When the researcher or others from the researcher's organization have conducted research in the institution, positive relationships may have been formed before recruitment begins, but novice researchers should consider strategies to gain access to organizations and participants in advance of data collection.

Negotiating access is based on building relationships with gatekeepers, which is an "ill-defined, unpredictable and an uncontrollable process" (Wanat, 2008, p.192). Having knowledge of the organization and the appropriate gatekeeper to contact will assist in negotiation, keeping in mind that lower-level gatekeepers may not appreciate feeling ordered to co-operate by their superiors. LeCompte and Preissle (1993) advised meeting gatekeepers in person, which is integral to acquiring cultural or organizational knowledge. Developing a rapport is vital to fostering research relationships that are honest and respectful to both parties (Kawulich, 2011). In a face-to-face meeting, information about the research can be shared in an open and transparent way. Any questions pertaining to the research can be answered and clarification provided. This meeting allows the gatekeeper to evaluate the researcher's professional suitability and allows the researcher to emphasize the value of his or her personal contributions (Shenton & Hayter, 2004).

Researchers should detail the level of involvement required of gatekeepers. Gatekeepers may decline to be involved in research if it will add burden to their workload. Co-

operation is often influenced by what gatekeepers perceive as a benefit or a threat to participation (Kawulich, 2011). If gatekeepers recognize the benefit of the research to themselves or participants, they may be more likely to co-operate. However they may be less likely to take part if they feel a threat to themselves personally or to their role. Furthermore, gatekeepers can avoid cooperation, shift responsibility to other organizations, control communication, request additional information, or forget to follow through on promises of assistance.

Shenton and Hayter (2004) posited that entry is best ensured if the researcher is in a position to offer something back to the organization and participants. This reciprocity may take the form of incentives to gatekeepers or participants or sharing study findings with the collaborating organizations. In the dementia carers study, the researcher endeavored to provide a sense of reciprocity by offering gatekeepers copies of published papers from the research data and bringing a cake and flowers to each participant's home. Giving back to the participants who share their experiences is customary because without their stories, the research would not exist (Kawulich, 2011). Each research setting is unique, and it is noteworthy that gaining permission from an authority does not mean that entry has been achieved (Kawulich). However, these strategies may result in greater cooperation (Wanat, 2008).

The recruitment process for the present study relied on gatekeepers who selected individuals deemed suitable. Initial contact by telephone was made with gatekeepers (managers of carer support groups, home help services, or nurse managers working with people with dementia) to describe the study in detail and its potential benefits to participants. Without doubt, speaking to gatekeepers and allowing an opportunity for them to ask questions and seek clarification on aspects of the study facilitated access. Once the gatekeepers understood what was involved and had information about the first author's background and experience in this area, they were extremely encouraging of the research and willing to provide access to suitable participants. Gatekeepers then distributed research information letters to potential participants, which allowed them to self-select to take part in the research by contacting a named researcher.

One gatekeeper denied access to potential participants, deeming those who satisfied the entry criteria to be "too vulnerable." While this was frustrating and disappointing, the gatekeeper had a good knowledge of the individuals and of their situations, and the decision was respected, despite awareness that potential participants were not afforded the opportunity to make an informed decision.

Timing and Location of Interviews

Successful interviewing requires meticulous planning, and the location of interviews needs careful consideration. It is important for participants to feel safe, comfortable, and at ease during interviews (Elmir et al., 2011). The environment should be private and free from interruptions, particularly when discussing sensitive issues. Interviews should always be conducted at a place and time selected by the participant (Doody & Noonan, 2013). Interviews in participants' homes and give researchers entry into a private part of participants' lives (Dickson-Swift et al., 2007) but also place the participant in a position of some control (Doody & Noonan, 2013).

Time dependence burden of caregiving is significant and influenced by the degree of impairment and caregiving involvement (Hoskins, Coleman & McNeely, 2005). This was true for carers for persons with end-stage dementia. A plethora of evidence exists on caregiver burden (Van Vliet et al., 2010; Flynn & Mulcahy, 2013; Hawkins et al., 2013) and its impact on family carers. Etters, Goodall, and Harrison (2008) attributed depression, ill health, and decreased quality of life to caregiving, and lack of social support and isolation are among risk factors of this role (Flynn & Mulcahy, 2013).

Participants in this study were offered the opportunity to be interviewed at any location suited to them, and all participants opted to be interviewed at home. Reasons were varied; most participants were current carers who did not have an abundance of free time and were not in a position to leave the home or their caring duties. Some did not have other family members or supports to facilitate social outings. Former carers also selected to be interviewed at home.

When carers made contact with the researcher by text message or telephone to consent to be interviewed, they typically requested that the interview take place the following day or within a few days of this first contact. A great degree of flexibility was required to organize interviews with participants who were current carers. By virtue of their ongoing and intense caring role, these participants often were not in a position to plan very far in advance. Therefore, interviews had to occur within a day or two of the first contact. Initially, this required a great deal of reorganization of the researcher's work schedule to facilitate these requests. The researcher had to prioritize interviews over other work and block off periods of free time over a number of days, to ensure that participants had a choice of days and times for the interview.

Rapport & Relationship-Building

Researchers enter other people's lives, often at a time of crisis and stress, and ask them to discuss their experiences (Liamputtong, 2007). This can be for an extended period of time, such as with repeat interviewing or as a one-off event. The process of conducting qualitative research may be complex, personal, and intense. Interviewing people considered vulnerable about sensitive topics makes the establishment of a trusting relationship with the researcher especially important (Murray, 2003). Investigation of a sensitive topic may precipitate participants' intense emotions. Researchers must consider the vulnerability of their participants and devise a plan to provide appropriate support when required. Ensuring researchers have a good understanding of the appropriate boundaries of the researcher-participant relationship and the ethical issues that may arise will lead to a mutually beneficial experience to both parties (Murray).

Paramount to building an effective research relationship is initiating a rapport-building process from the outset, which will facilitate access to a participant's narrative (Dickson-Swift et al., 2007) by helping participants feel at ease to disclose intimate and sensitive information. A strategy to ensure that the researcher – participant relationship is non-hierarchical is reciprocal sharing of personal stories by both participant and researcher (Liamputtong, 2007). This creation of a level playing field enhances rapport as well as showing respect for participants and validating their stories. In research on sensitive topics, the frequency and intensity of researcher disclosure may differ (Lee, 1993; Renzetti & Lee, 1993) and has the potential to make researchers feel vulnerable (Fontana & Frey, 2005).

When questions are posed to researchers with a healthcare background, a role conflict arises (Ashton, 2014). Although the researcher is there as data collector, it is difficult to shed nursing knowledge and experience and enter the field with a blank curriculum vitae (Johnson & Macleod Clarke, 2003). In such cases, sustaining an impartial data gatherer role is difficult, and nurses with experience and training will act on instinct and answer clinical questions, discuss concerns with participants, and refer on if required. While according to Jack (2008), information provided by nurse-researchers has the potential to influence participants' responses or discourage the participant from openly sharing more information, refusing to answer health-related questions also may adversely affect the interview. Britten (1995) advocated deferring requests for answers or information until the end of the interview, and, if a need for further intervention is identified, referring the participant to another health care professional.

While researchers must be empathic to the participants' needs, they should remember that they are researchers and not counselors (Hennink, Hutter & Bailey, 2011). Murray (2003) advocated retaining clear boundaries with participants, to prevent nurse researchers from becoming nurse therapists. Empathic distance is required to engage with participants without becoming too involved (Valentine, 2007). Nonetheless, nurse researchers can draw on experience to spot signs of distress (Ashton, 2014). Dowling (2006) highlighted the difficulties in separating the nurse from the researcher and contended that participants may consent to partake in research studies as a result of being a healthcare user, or in this case, the carer for a healthcare user. Dowling found it unjustifiable to use the role of the nurse to recruit participants and then abandon this identity once the study commences.

Etherington (2004) affirmed that researchers are intimately involved in both the process and the product of research, but to maintain credibility and objectivity, the researcher is required to be reflexive and aware of influences on the researcher's internal and external responses as well as the relationship to participants and the research topic. The researcher is obliged to self-reflect (Carolan, 2003) or to self-critique, explaining how his/her own experiences, values, beliefs, and perceptions have or have not influenced the research process (Koch & Harrington, 1998).

Carers in this study asked the first author about her feelings on end-of-life care and about the dementia disease trajectory. They were aware that the researcher was a registered nurse, based on information provided in the information letter. On occasion, the first author was asked medical questions with the belief that, *"well you are a nurse so you understand."* One participant was discussing a dilemma of whether or not to allow administration of antibiotic therapy to her mother with end-stage dementia. The participant asked the researcher, *"What would you do if you were in my situation?"* The researcher responded by saying, *"That is a very difficult situation to be in, and one that I would find hard making a decision. Perhaps we can discuss this further when the interview has finished?"* This response acknowledged the difficulty faced by the participant and showed empathy. However, the researcher was aware that engaging in a discussion about this topic could change the interview's focus.

Therapeutic Interviewing

Any interview is sensitive because disclosing information about the self makes the respondent vulnerable to emotional turmoil (Drury, Francis & Chapman, 2007). Qualitative researchers encourage participants to provide rich data by eliciting underlying emotions and listening

intently to participants' utterances. Despite the potential for participants' upset or distress, cathartic disclosure can be a revelation or prompt a new understanding of past or recent events (Birch & Miller, 2000). The researcher should create a space in which a participant can relive difficult emotions, providing relief and reinforcement of participants experiences (Ashton, 2014).

Although therapy is not the purpose, and even researchers from a healthcare background may not be trained counselors or therapists (Ashton, 2014; Valentine, 2007) Holloway and Wheeler (1995) suggested that research interviews can be therapeutic. Birch and Miller (2000) used the term therapeutic to represent a process (which is sometimes emotional) by which an individual reflects on and comes to understand previous experiences in different ways, promoting a changed sense of self with new understandings. Both qualitative interviews and therapeutic practice involve disclosing aspects of the self, revealing intimate personal experiences in the presence of an effective listener.

The endeavor to create a successful interview can be likened to the work of counselors and therapists involved in therapeutic practice. Allowing participants the space to reflect on, re-order, and give new meanings to past experiences is the essence of much therapeutic work (Sammot Scerri et al., 2012). Social theorists have highlighted the merits of therapeutic or expressive culture, appreciating the value of expressing feelings and not keeping them bottled up (McLeod, 1997). Therapeutic change, according to Rose (1991), requires the resolution and release of repressed emotions. A therapeutic relationship is founded on empathic listening, witnessing the expression of emotions and the disclosure of a more private self, and acknowledging the participant's experience of self-determination and self-worth (Shamai, 2003).

In this study, having developed an interview schedule prior to data collection allowed the first author to anticipate the likelihood of emotional responses and to adequately prepare for them. This gave rise to the creation of a distress protocol (Table 2), which could be implemented to protect participants in the event that upset did occur. Indeed, some participants did become upset, but all agreed to continue and found being able to express emotion and discuss their role as carer as cathartic. One participant spoke about agreeing to participate in the research, as it was a chance for her to talk about herself: “ *This is the first time anybody has ever actually asked me about me, because any time anybody comes in the door it's 'how is your Mum,' but nobody has ever said 'how are you, Elizabeth'?* ”

How researchers deal with distress and emotional situations is based on personal style. Much has been written on how researchers should deal with such events (Ashton, 2014; Hewitt, 2007; Walls et al., 2010). Roulston, deMarrais, and Lewis (2003) advised that if researchers become uncomfortable dealing with participant emotions, changing topic can be a useful tactic, but they cautioned that this may be a lost opportunity for knowledge to be gained. In one case, the first author acknowledged a participant's upset by saying, "*I see that you are upset, would you like to take a break from the interview for a while?*" Mitchell (2011), however, encouraged acknowledging the participant's upset by maintaining eye contact, and attempting to talk through the issue. Emotions expressed during an interview enhance our understanding of the participant's experience and are as epistemologically beneficial as other data, allowing the researcher to enter into the life-world of that person. Hofmann (2007) advocated for a greater emphasis on reporting, expressing and understanding of emotions during interviews, to increase sensitivity to such situations and yield more meaningful interpretations of data.

Table 2. Distress Protocol

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| Distress Protocol | This procedural protocol ensures that research participant's wellbeing and rights are protected. The steps outlined below are for participants benefit in the event that they become distressed while being interviewed. |
| <p>The interview will be terminated if:</p> <p>The researcher will intervene if the participant is:</p> <p>The researcher will, with the participants consent:</p> | <ul style="list-style-type: none"> • The participant decides to terminate the interview. • The participant decides to participate in the interview at another time or place. • Experiencing anxiety or distress during the interview. The participant should be asked if they would like to take a break and if they wish for the audio-recorder to be switched off. • Continuing to show signs of upset. The participant will be asked if they would like the interview to end and if they would like the researcher to call someone to spend time with them, such as a family member or friend. • Unduly distressed. The researcher will remain with the participant until they are calm and composed. The participant may then decide to continue with the interview or not. • Refer to others if they request. • Gain permission to call them later in the day or the following day to ensure they are no longer distressed. Alternatively, the researcher may ask if they would like a family member or someone from the local community to call them to offer support. • Contact details of useful numbers and support groups will be offered to the participant if they require them. |

Concluding the Interview

After an interview, Ashton (2014) advised allowing participants time to regain composure and to allow for feedback and discussion. Emotional interviews also can affect the researchers' physical and emotional health (Dunn, 1991) and leave them emotionally drained and burned out (Geerish, 2011). Hammersley and Atkinson (1995) noted that researchers conducting sensitive interviews rarely leave the field unscathed. Preparation and planning for such events is imperative. Researchers should plan for self-care and informal support networks (Hallowell, Lawton & Gregory, 2004).

Disengaging from the research field may be more of a process than a single event, particularly if the study involves repeat interviews with participants. Participants' involvement in research may have lasting effects on them, particularly after discussing sensitive topics. In addition, participants and researchers may become close through the passage of time. Researchers attempt to construct a social relationship of reciprocity, friendship, and shared understandings, in an effort to uncover a deep meaning of the topic under investigation (Birch & Miller, 2000). A blurring of boundaries may occur, whereby participants may see the researcher as a friend, which may be a reason for concern. Burns (2000) suggested withdrawing gradually, returning to participants during the write-up and analysis stages to recheck and clarify points before finally concluding the research relationship.

Corbin and Morse (2003) reported that no evidence had emerged that participants have suffered negative long-term effects or have been referred for counseling as a result of being interviewed, and that anecdotal evidence suggests that interviews are more beneficial than harmful. That being said, participants should be afforded the opportunity for feedback and discussion of their feelings on completion of an interview (Murray, 2003), spending time discussing the interview experience and the impact it may have had on them. Sammut Scerri et al. (2012, p. 107) also advocated debriefing with participants on completion of sensitive interviews, to "help the participant back to a normal state of arousal from the intensity of the interview." The researcher is responsible to identify additional support needs and provide contact details on sources of support as required.

In the present study, one of the final questions asked during interviews was, "*What is good about being a carer for someone dying with dementia?*" Interviews conducted on this topic have the potential to focus only on the negative aspects of being a carer, and refocusing on the positive aspects of their caring role allowed for a positive ending to the interview. Not

all participants identified many/any positives, but the majority did identify good points, such as feeling good about being able to fulfill a promise to care for their loved one at home, having the opportunity to get to know their family member better, and doing what felt right by them and for them in their time of need.

Ethical Considerations

Topics studied using IPA or other qualitative approaches include those central to the unique life experiences of individuals and may be classified as sensitive areas of investigation, due to the potential for intrusion into people's private lives. Even talking about sensitive issues to participants may constitute harm for them.

In addition to ethical approval from institutional ethics committees, qualitative research also requires sustained reflection and review (Smith et al., 2009). Researchers are obliged to uphold beneficence and non-maleficence, or doing good and avoiding harm to participants. In an effort to protect a participant's identity, transcripts of interviews should only be viewed by the research team, and data for wider use such as for publication should be carefully edited for anonymity. Smith et al. (2009) contended that anonymity is all that qualitative researchers can offer; by saying that something is confidential is to say that no other individual will see it, which is not the case. Researchers can represent participants and make their voices heard within an academic or professional forum, but this should not be achieved at the cost of anonymity. Because total anonymity is impossible in a face-to-face interview, data must be stored and reported in a way that the source is unidentifiable. This is ensured through coding personal data to protect participants' identity and storing data securely.

Risk assessment is important when conducting research on sensitive topics. Despite efforts to predict risks at the outset of a study, researchers cannot know what an interview will uncover. A risk assessment should be completed and a distress protocol developed prior to data collection in sensitive contexts (Sammut Scerri et al., 2012) to ensure that researchers consider any potential distress participants may experience during the course of the study and develop strategies to deal with upset if it occurs. Researchers should ask themselves questions such as, is this study likely to cause any discomfort or distress, either physically or emotionally? If the answer is yes, then the researcher should estimate the degree and likelihood of discomfort or distress and the precautions needed to minimize them. Participants should be provided with access to appropriate supports in the event of becoming upset during an interview.

Researchers may have feelings of guilt related to the interview process, the effects of the research on the participants, or the data collected (Dickson-Swift et al., 2007). Researchers do not set out to exploit or use participants (Edwards, 2009), but researchers may feel simultaneously excited and guilty about the data (Dickson-Swift, 2007; Sammut Scerri et al., 2012). Lofland and Lofland (1995) referred to this as an ethical hangover. Qualitative researchers must acknowledge the power granted to them when participants trust them to report and disseminate their personal narratives with the wider public (Shamai, 2003). Research supervisors or team members can be of great help in dealing with feelings of guilt, upset, or vulnerability. Supervision and self-care are important to deal with the stress and strain of sensitive interviews (Mitchell, 2011).

Any qualitative researcher is challenged to explore how their experiences and assumptions influence the development of knowledge. Bracketing is advocated by Smith et al. (2009) for researchers employing IPA as a methodology. Bracketing, which originates from Husserl's descriptive phenomenology, prompts researchers to set aside their own understandings and assumptions in an effort to allow the phenomenon under investigation to speak (Crotty, 1996). Bracketing interviews, in which the researcher is interviewed on the topic of study, can uncover the researcher's personal and professional experiences during data collection and analysis. Bracketing allows the researcher to "hold the tension of the dialectic process of investigating the nature of the participant's experience, at the same time as holding her own experience" (Rolls & Relf, 2006, p.286). According to Myerhoff and Ruby (1992), bracketing requires an ability to reflect on oneself, the supportive environment and reflective skills, and Ahern (1999) suggested reflective diaries and journals to aid this process.

A great degree of reflexivity and bracketing of assumptions was required of the first author, who was a registered general nurse with knowledge of the dementia disease trajectory and of palliative care. Bracketing assisted the researcher to objectively explore any hidden or blind assumptions, so that data were collected and analyzed in ways that did not prejudice the subject matter (Crotty, 1996). Field notes and reflections were detailed immediately after each interview, with the intention to document initial thoughts and feelings for discussion with the research team.

Conclusions

The framework presented here may assist researchers in conducting sensitive interviews with vulnerable groups, by directing focus to the participant's needs as well as points for researchers

to consider before embarking on their data collection journey. In this paper, we detailed the experiences of a novice researcher conducting sensitive interviews with vulnerable participants and examined the complexities of negotiating access to these participants. The role of a defined interview schedule, the importance of developing relationships, and the issues arising when discussing the sensitive area of the end of life with participants also were explored. While adhering to the ethical principles of beneficence and non-maleficence, researchers must acknowledge that all qualitative interviews have the potential to cause distress, and even talking about sensitive issues to participants may constitute harm for them. Researchers are advised to conduct a risk assessment and devise a distress protocol prior to data collection in sensitive contexts. Assessing participants for signs of distress during research of a sensitive nature and identifying strategies for minimizing discomfort are fundamental to good ethical practice (Walker, 2007). While avoiding entering into the role of nurse counselor, nurse researchers can draw on experience in an effort to spot signs of distress (Ashton, 2014).

The framework will require further use to evaluate its effectiveness as a tool for novice researchers in particular when planning for and interviewing on sensitive topics. Moreover, further implementation of the framework will need to be carefully evaluated to determine actual application of the model and acceptability in practice by researchers. Meanwhile, incorporating these essential elements may improve the effectiveness of sensitive interviewing with vulnerable groups and avoid loss of critical information.

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