Gatekeepers, Process Consent and Real Names: Ethical aspects of writing vivid stories based on qualitative research in palliative care

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Abstract

Palliative care research is often described as difficult and challenging. This is largely due to ethical issues that arise in dealing with vulnerable patients and families, who are likely to be emotionally and physically burdened by their situation. Gatekeepers who control access to palliative care clients have a reputation for being reluctant to let them be further troubled by requests to take part in research activities. This means that getting a research proposal approved by an ethics committee, or convincing nurses to distribute invitations to participate, may require persuasive arguments as well as careful construction of an ethically defensible research protocol.

My proposed palliative care research will be based on solicited reflective diaries and semi-structured interviews with home-based family carers, and forms part of study toward a PhD in the area of creative nonfiction writing. This paper discusses the ethical issues that were considered in preparing an application for the Human Research Ethics Committees of Hunter New England Health and the University of New England. The discussion of strategies for approaching gatekeepers, ensuring beneficence, and negotiating consent will offer insights for the conduct of any research involving a vulnerable population and a sensitive topic. A dual consent process and giving participants the choice of real names rather than pseudonyms in publications are interesting and distinctive features of my research project.

Introduction

Palliative care involves the provision of specialised, multidisciplinary health care services, when it is recognised that a person has an active, progressive illness with little prospect of cure, and the primary treatment goal is the best possible quality of life for patient and family (Masso et al. 2004). In Australia, palliative care units based in hospitals focus on providing beds for those patients with symptoms requiring treatment or stabilisation, or those needing temporary respite care or end-of-life care. Consequently, whilst families may be receiving services and resources through linkage with a palliative care unit, there is an increasing trend for caregiving to take place at home, and for this to involve a considerable commitment from a family member or friend (Hudson 2003a). Writing about the lived experience of fulfilling this commitment will be the focus of my doctoral studies.

Preparing an ethics application for a topic in palliative care is fraught with many challenges. After discussing how I came to be researching this subject, despite not having a background in health studies, I present the various ethical issues that I had to think about in writing my application for the University of New England and the Hunter New England Human Research Ethics Committees (HRECs). I discuss general concepts such as gatekeeping, beneficence, and obtaining consent, with particular emphasis on how they related to my research, and the strategies I employed in dealing with them. I also explain why I needed to have a dual consent process and why I decided to offer participants the seemingly radical option of having their real names appear in publications.

Background

My interest in home-based palliative care sprang from the experience of helping to look after my mother when she was bedridden with advanced breast cancer. Caring

for the dying is not a subject that is easily broached in Australian society, and so, like most people, I came to the task completely unprepared for the overwhelming physical, emotional and psychological challenges it entailed. I decided to make writing about these challenges, in a way that would engage and inform a general audience, the focus of my PhD. It will involve researching and writing a thesis comprising a book-length manuscript and an exegesis, about the experiences of family carers who are providing at-home care for a loved one in the final stages of a life-threatening illness.

The research will be located within the interpretive paradigm because the goal is to study meaningful social action from the perspectives of the participants (Neuman 2000). A biographical approach will inform the construction of the character portraits, providing necessary background information about the carers, their family situations, and how they came to take on the role of palliative caregiver. The research will also draw upon phenomenography as a tool for mapping participants' reflections about their lived experiences (Barnard, McCosker & Gerber 1999). To elicit the detailed descriptive and reflective information required by both the biographical and the phenomenographical approaches, the diary:diary interview method will be used (Zimmerman & Wieder 1977). Participants will be asked to record thoughts, feelings and anecdotes about their daily life as a carer, and talk to me about what they have written. The information gathered, plus my own diary-recorded reflections about my experiences as an informal carer, will underpin creative nonfiction narratives about home-based palliative caregiving. Creative nonfiction is factual writing that employs devices typical of fiction, such as scene-setting, characterisation, dialogue and figurative language (Gutkind 1997).

If published, I hope that A Hospital Bed at Home: Stories of palliative caregiving by Australian families will be a supportive resource for carers, depicting and validating common elements in their experiences and feelings, while sensitively exploring the issues they face. Such an 'insider's account' should also serve to increase understanding and empathy about informal palliative caregiving amongst the general community. I also envisage that my research will be useful for health professionals, promoting sensitivity in their dealings with informal carers and respect for their role as 'co-workers'; as well as for policy makers, informing support programs for informal carers.

The first hurdle to be faced in undertaking my research was to obtain ethics approval from the University as well as from the local area health service, Hunter New England Health. I needed the approval of the health service because I was hoping that the community palliative care nurses who visited patients at home would help me get in touch with potential participants. The Human Research Ethics Committees and the Community Health nurses were, therefore, the people holding keys to the gates that needed to be opened before my research could proceed.

Gatekeeping

Gatekeepers are people with the authority, formal or informal, to control access to a research setting (Neuman 2000). Gatekeeping is a well-recognised problem in palliative care research. Major projects have been subjected to lengthy delays due to difficulties in obtaining HREC approval (Masso et al. 2004). Researchers have reported that attempts to recruit participants were stymied by health professionals, who either

failed to distribute invitations to participate or cautioned potential participants against involvement (Fulton 1998; Hudson 2003b).

The desire to spare burdened families further stress may be well-intentioned, but this paternalistic attitude serves to deny people the right to make an informed decision about participation in such research (Hudson 2003b). Lee and Kristjanson (2003) argue that over-protectiveness regarding palliative care research is based on an outmoded view of patients as 'dying' rather than 'living with a terminal illness' and involves the belief that, in the words of a lay member of an ethics committee, 'dying people should just be left alone'(Lee & Kristjanson 2003:14). However, one of the goals of the modern palliative care movement is to help people live as actively as possible until they die, which may include voluntary involvement in research aiming to increase knowledge and bring benefit to future patients and families (Lee & Kristjanson 2003). Interestingly, the recently updated National Statement on Ethical Conduct in Research Involving Humans now contains explicit acknowledgement of 'the entitlement of those receiving palliative care to participate [in terminal care research]' (National Health and Medical Research Council 2007:62).

An excellent resource for aspiring palliative care researchers is a booklet funded by the National Palliative Care Program called Ethical research in palliative care: a guide through the Human Research Ethics Committee process. It warns researchers that HREC committees assessing palliative care research proposals may exaggerate psychological risks in a way that overemphasises burdens relative to benefits. To counter this possibility, the booklet suggests that applications should cite studies demonstrating that participants do not experience the type of research being proposed as burdensome, and substantiate claims about potential benefits by referring to studies demonstrating that such benefits have been obtained (Masso et al. 2004).

In writing my ethics application I followed this advice by discussing empirical evidence indicating that most participants in palliative care research find the experience to be a positive one. Some people appreciate the opportunity research provides to reflect upon, finding meaning in, and come to terms with a major life event; and being able to contribute information that may be used to help others can be a source of pride. A follow-up survey of participants who had been involved in longitudinal research whilst caring for a relative dying of cancer, found that almost three quarters experienced direct and indirect benefits and the majority (88.9%) cited no negative aspects associated with research participation (Hudson 2003b). Grinyer (2004) asked parental caregivers of terminally-ill young adults to contribute narrative accounts of their experiences and subsequently asked how their participation had affected them. Results showed that the parents valued their involvement, and many had found the process of writing therapeutic. Their feelings of isolation had been reduced, and overall, they believed they had benefited from contributing.

The second, and perhaps more insidious, issue to consider with respect to gatekeeping is one that can surface after HREC approval to conduct the research has been obtained. Palliative care research often relies upon medical professionals such as nurses to distribute invitations to participate. An intermediary who has regular contact with potential participants can introduce the research with less risk of provoking distress and anxiety than would a formal approach by a stranger (Beaver, Luker & Woods 1999). However, this means that the intermediaries are in a position to act as a filter. Broback and Bertero (2003) noted that recruitment for their study of informal carers in Sweden had been impeded because district nurses felt uncomfortable with using the term 'palliative care' when talking to patients and next of kin, unless the patient was terminally ill and bedridden. Fulton (1998) reported an extreme case of

covert opposition from domiciliary nurses in his PhD study on the influences of discourse on illness experience. Despite a pool of 2,200 potential participants receiving nursing care from a particular service, only one person, who had been given an invitation by a relief nurse, approached him to volunteer for the research. She later withdrew when her regular nurse advised her that the research was 'of little value to patients' (Fulton 1998:103).

These examples illustrate the importance of convincing intermediaries that the research about which they are distributing information serves a useful purpose and participation may be beneficial. How the intermediaries are introduced to the project's aims and methods, and the advice they receive about the type of language to use when telling potential participants about it, can have a large impact on how enthusiastically they engage with their recruitment role (Daniels & Exley 2001). Rather than assuming that health managers will convey all the right messages about the research to the people on the ground, it may be better to speak personally to everybody charged with distributing invitations to participate and address any concerns they may have. However, given the 'scattered, small service provision' characterising palliative care in Australia (Lee & Kristjanson 2003:15), where each nurse in a district may only visit a handful of clients, personal contact with many individual nurses may pose a methodological challenge.

As my research is qualitative and does not require the recruitment of a large number of participants, I do plan to speak to all the nurses who will be distributing my invitations to participate, either at group meetings or individually by telephone. This direct contact will have an additional benefit in terms of implementing purposive sampling. I need recruitment to be a staggered process, in order to give me time to gather diary entries from each person, conduct and transcribe multiple interviews with them, and write first drafts of stories about their experiences. It would be unfair on participants to sign them all up in one large batch, given that the loved one may die before I am ready to begin research activities with a particular carer.

Therefore, to control the pace of recruitment, there will be a progressive rollout of the study across different areas within Hunter New England. Nurses will receive information about the research and invitations to distribute when it is time to recruit participants in their area. This staggered process means that recruitment will be able to vary in focus over time, in order to include a range of people from diverse backgrounds. For example, if the participants recruited from Armidale were all women living in town, I could ask the nurses in Walcha to hand their invitations to men or people living on rural properties.

The staggered recruitment process will be advantageous for me and the participants too. Seeking to avoid causing disappointment, by not leaving too long a gap between when a person opts to participate in palliative care research and the time that the researcher is ready to accept his or her contribution, is an example of planning how to do the research in a way that maximises beneficence.

Beneficence

The principle of beneficence relates to conducting research in ways that protects participant's welfare, minimises risk of harm to them and respects their privacy (Masso et al. 2004). A threat to beneficence in research that encourages people to talk about painful topics is the risk of provoking emotional distress. The standard precaution is to indicate this possibility on the Information Statement for Participants and provide contact details for counselling services. However, it has been claimed that there is no evidence that the level of emotional distress caused by talking about painful topics in a

research interview is greater than in everyday life or that it requires follow-up (Corbin & Morse 2003). Also, individuals have reported that they appreciated the opportunity to tell their story to an attentive listener, even if they became upset whilst doing so (Dyregrov 2004).

Another risk for participants in palliative care research is that of being confronted with information that they are psychologically unprepared to handle (Haley 2002). In writing my Invitation to Participate and Information Statement for Participants, I had to think carefully about what words to use to describe the health status of the patient. It is common to see the term 'life-limiting illness' used in preference to 'terminal illness'. This struck me as euphemistic jargon likely to be understood only by health-professionals, so I chose to use 'life-threatening illness' instead.

Although families involved in this type of research should know that they are receiving palliative care services, this does not necessarily mean that they accept the premise of palliative care: that their loved one is going to die. People can live in parallel realities, simultaneously understanding the terminal nature of the illness and yet still believing in the possibility of a miraculous cure (Kirk, Kirk & Kristjanson 2004). I know from my own experience that caregivers may deeply resent statements loaded with assumptions about the inevitable trajectory of their loved one's disease. My aunts never stopped thinking that somehow my mother would be saved. A nurse who tried to engage them in practical discussion of what the family would be facing 'further down the track' received a coldly hostile response. Therefore, in any discussions with caregivers that touch upon the sensitive issue of prognosis, I will 'respect the need for hope' (Kirk, Kirk & Kristjanson 2004) and let questions be guided by the attitude they express in their diaries.

It is recognised that participants in palliative care research may be vulnerable to unrealistic perceptions of benefits (National Health and Medical Research Council 2007). Careful communication is required to manage expectations in order to avoid disappointment later. It is likely that I will find, as did Grinyer (2004), that family caregivers will invest a great deal of significance in the idea of a book that memorialises their loved one. However, I might not be able to use all the material they give me, or they might not like what I do with it. Also, there is no guarantee that the book will be published. I felt it was important to be clear and upfront about this in the information sheet and so I included the following warning:

> You need to understand that I cannot promise that the book manuscript will be published. Nor can I promise that all the information that I collect will be included in the book or any other publication. Responsibility for the final form of the written products of this research rests with me and selection and editing of material will be necessary. However, ownership of the diary and interview information remains yours and if you are not happy with what I have written, you have the right to request changes or ask that your material be withdrawn.

Obtaining Consent

A sense of desperation and obligation may impel palliative care patients to sign up for research. Believing it represents their last chance to try a new cure, give something back to society or invest their situation with a redeeming meaning, they may agree to participate even if it is burdensome (Masso et al. 2004). Family caregivers may share this attitude. Research involvement of families receiving palliative care services must

be continually up for renegotiation as their circumstances and feelings will be volatile. The way to implement this is via process consent:

> Process consent allows consent to be renegotiated at different stages of the interaction between the researcher and the participant. It is suitable for longitudinal approaches where participants are contacted on a number of occasions and consent needs to be re-established and renegotiated
>
> Beaver, Luker & Woods 1999:15

My research protocol is deliberately designed so that caregivers' accounts of their thoughts and feelings are being gathered whilst they are actively engaged with the situation. Almost all previous writing on this topic, both academic and general, has used retrospective data. I believe that information gathered whilst the caregiving is taking place, rather than after the death of the loved one, will be richer, livelier and more honestly "gritty", as distortions from hazy recollection and sentimental reframing may be lessened. However, this makes it even more important for me, as the researcher, to stress the non-binding nature of the agreement to participate and to be sensitive to any signs that a participant does not wish to continue (Masso et al. 2004). In the information sheet, after the list of things participants would be expected to do, I included the following caveat:

> The best interests of your family are more important than the demands of this research, and you should feel free to stop, postpone or cancel your involvement in research activities at any time.

Another issue related to contemporaneous data collection that I had to think about was what to do if the person the carer was looking after died during the data collection period. It would be rather brutal to "sack" the participant if they wished to continue! I decided I would have to resolve this on an individual basis, depending on the wishes of the carer and how much data we had to work with.

Dual Consent

In addition to being sensitive to the possibility that participants might wish to renegotiate their involvement in the research, I also had to consider that patients might not like the idea of their carer talking to me about their health situation. The Hunter New England Health Ethics Officer advised that my research would require two different information sheets and two consent forms, as the patient would have to agree to their carer's participation. In implementing dual consent, I had to decide whether the patient should have all the same rights as the carer. Should the patient (as well as the carer) be given the opportunity to review transcripts of interviews and edit/delete sections? This might inhibit the carer from speaking freely and would compromise the confidentiality of the diary entries and interviews. Should the patient (as well as the carer) be asked to read pre-publication narratives and sign a release form? Depending on the patient's state of health, this might be perceived as an onerous task. In the end I distinguished between those "participating" – the carers, and those "involved" – the patients, and the only thing patients were asked to do was read the information sheet and sign a form consenting to their carer's involvement. I left it up to the carer to decide whether or not to talk to the patient about what they had told me or show them the pre-publication narratives.

Choice of real names instead of pseudonyms

Conventionally, researchers protect the anonymity of participants and the confidentiality of their information by disguising personal identities in publications (Neuman 2000). Consent forms often include a statement like the following: "I agree to publications based on the research data, provided that my real name is not used." However, as the purpose of my data collection was to produce vivid, true-to-life creative nonfiction stories, rich in potentially identifying detail, I felt strongly that it would be impossible to guarantee that someone who knew the family being written about would not recognise them, even if names and places were changed. The new section on qualitative research in the National Statement makes it clear that just promising to use pseudonyms may no longer be sufficient:

Participants are often easily identifiable… and the information they provide may be sensitive. For these reasons, care should be taken that participants are not identifiable by the information they provide, unless they have agreed to be identified… participants should be informed about any potential to be identified in the results of research even if identifiers, such as name and address, are removed (National Health and Medical Research Council 2007:28)

Hunter New England Health HREC application guidelines state that prior to publication of material containing potentially identifying information, participants need to sight the intended use of their data and sign a release form (Hunter New England NSW Health 2005). Therefore, my information sheet said:

Given the descriptive and detailed nature of the stories I will be writing, I cannot give you assurances of confidentiality or anonymity. I can disguise names, dates and locations, but cannot guarantee that someone who knows your family circumstances will not be able to recognise you in the stories. You will be given the opportunity to review any writing for publication containing quotations or material that may directly or indirectly identify you. Your explicit consent on a Release form will be required prior to publication. If you want real names to appear with your material in the publication you will have to nominate this option on the Release form, otherwise pseudonyms will be used.

Note that the last sentence in this excerpt from the information sheet mentions that participants can elect to have their real names used, rather than pseudonyms. Some research participants prefer to waive anonymity in order to "give voice" to their personal experience (Giordano, O'Reilly, Taylor & Dogra 2007). They may feel that they 'lose their ownership of the data' when they are anonymised (Grinyer 2002). Three quarters of the thirty participants in Grinyer's study – parents who contributed narratives about the experience of caring for an adult child with cancer – opted to have their real names published, and spoke of the book as a lasting memorial to their son or daughter (Grinyer 2002, 2004). It is possible that participants in my study will have similar feelings.

Conclusion

For some research projects, writing an ethics application is a fairly straightforward process. This is not the case for topics relating to palliative care. I found that careful consideration of how to handle gatekeeping, beneficence, consent and anonymity became a fascinating exercise in applied ethics, one that fundamentally shaped the design of the entire project. In this paper, I have used my own HREC application to anchor discussion of these concepts. This is appropriate because ethical principles cannot be applied mechanically: so much depends on particular circumstances and

context. That said, I believe the strategies presented here could provide a useful starting point for any research involving a vulnerable population and a sensitive topic. Finally, I am pleased to report that my research protocol was approved by the University of New England HREC on first submission; and was approved by Hunter New England Health upon receipt of minor amendments and clarifications.

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