Conducting Research Interviews with Bereaved Family Carers: When Do We Ask?

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Abstract

Background: Interviews with bereaved family carers to examine the end-of-life experience of the deceased are important tools for palliative care researchers, but the ethics of approaching the bereaved when they are grieving and vulnerable is often debated.

Objective: The aim of this study was to explore the insights of bereaved family carers about the most appropriate time to be involved in a research interview about the end of life and death of their family member.

Methods: This qualitative study used a social constructionist framework. Twenty-two bereaved family carers of people with motor neurone disease (MND) and cancer were interviewed in Western Australia.

Results: Most family carers (86%) feel comfortable being interviewed about the death of their family member within the first 5 months of bereavement, with 43% reporting they could be interviewed within weeks after death. Family carers reported that recall would be better earlier in bereavement and felt it may be helpful to them to talk about their experiences earlier. They said bereaved people should be allowed to decide for themselves when to be involved in an interview.

Conclusions: These findings indicate that interviews with the bereaved may be most fruitful for researchers and beneficial to family carers when they are allowed to make the choice about timing for themselves, beginning weeks after the death of their family member.

Introduction

RESEARCH THAT SEEKS TO UNDERSTAND the end-of-life experience of patients is hampered by several factors. Inclusion and exclusion criteria reduce the number of potential participants, and only patients who are less impaired, and who are known to relevant services, are approached.^{1–3} Methodological challenges include difficulties predicting decline and prognosis, high attrition rates due to the patient's deterioration, delays due to the patient's fatigue and other physical symptoms, patients moving between community and inpatient settings, and small sample sizes.^{4,5} However, it is ethical concerns about research with the terminally ill that most frequently impede inquiry. Stevens et al.⁶ argue that research in palliative care is characterized by "feelings of protectiveness and caution" (p. 489), which lead to gate-keeping by health professionals, family members, and institutions.^{7,8} Key ethical concerns include people's capacity to consent, particularly due to their frailty and changes in their cognitive functioning^{9,10}; maintaining dignity, safety, and

well-being^{11,12}; and the burden on participants, especially children and the elderly.^{13,14}

Relying on family members' accounts to conduct retrospective research on end-of-life experiences is a valid approach, which can overcome these barriers.^{3,15–17} Family members' interpretations of the patient's dying experience can provide valuable information to improve service delivery and aid decision making about what could work better.¹⁸ There is also an emerging body of evidence that participating in research about a family member's death or the experience of bereavement is not necessarily distressing for participants. Follow-up studies of bereaved participants who had previously been involved in research demonstrate that most people felt positively about their participation, many indicated that it was useful to them personally, and others stated that they were pleased that their participation would help others.^{19,20} A recent study by Eilegard and colleagues²¹ reported that a majority of bereaved siblings found revisiting their sibling's illness and death was a positive experience, and Koffman et al.²² concluded that mortality surveys of bereaved family

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Accepted November 4, 2014.

members about end-of-life care were generally perceived to be positive.

However, regardless of these findings, there is an ever present backdrop of disquiet, and concerns are consistently raised about the ethics of conducting research with family members after bereavement.^{22,23} In their efforts to balance risks and benefits, institutional review boards (IRBs) and human research ethics committees (HRECs) scrutinize research protocols carefully or make approval dependent on strict exclusion criteria.²⁴ However, Emanuel and coworkers²⁵ found that terminally ill patients and their carers experienced little stress when discussing death and dying in an interview and reported that the interview was helpful. The authors argue that IRBs should not restrict research with patients and carers without clear evidence that it will be harmful.

Researchers have to balance the need for reliable information with minimizing participant distress. Asking people earlier in their bereavement is likely to provide more accurate information¹⁵ and better recall.^{26,27} However, a difficult question to answer is, "When do we ask?"^{28,29} Cassarett et al.²⁹ reported that the timing of survey administration after death did not affect distress levels or response rates, even when administered very soon after death. However, there are few studies that ask bereaved people directly about the most appropriate time to participate in a research interview and, as a consequence, there is limited empirical evidence to guide researchers, IRBs, and HRECs.^{22,30,31} This study seeks to fill this gap.

Objective

The aim of this study was to explore the insights of bereaved family carers about the most appropriate time to be involved in a research interview about the end of life and death of their family member.

Methods

Design

This study was part of a larger study exploring the end of life and death of participants' family members. An in-depth qualitative research design was adopted for the larger study using a social constructionist framework. This framework acknowledges that people's unique experiences are valid and explores the ways in which people view the world and construct meaning as they engage in everyday activities.³²

Participants and recruitment

Bereaved family carers of people who died from motor neurone disease (MND) and cancer were recruited. Because MND is a rare condition, family carers of everyone with MND in Western Australia who had died 3 months to 15 months earlier were invited to participate in the study. To provide a demographic match to the MND sample, a random sample of family carers of people with cancer was also recruited with the following inclusion criteria: death occurring 3 to 15 months prior, deceased was between 45 and 80 years old, and three male deceased were recruited for every two females (to match the male to female ratio for people with MND). Ethics approval was granted from a community palliative care service and Curtin University (HR137/2012).

Recruitment materials were sent out from a community palliative care service and a local MND association. Those

wishing to take part were asked to respond directly to the researcher. Twenty-two people were recruited (overall response rate, 23%). The response rate was higher for family carers of people with MND (48%) than for family carers of people with cancer (7%). This could be because a focus of the larger study was improving care for people with MND, or it could be because MND family carers feel an ongoing connection to the local MND association.

Procedure

Audio-recorded semi-structured interviews were conducted by a researcher who is an experienced interviewer with a background in counseling.³³ Interviews focused on experiences at the end of life and death of the family member, the use of services, and satisfaction with support and care. At the conclusion of the interview, participants were asked, "To help us determine when to approach bereaved family members for research, when would be the earliest time you could have told this story as you've told it today?" Prompt questions followed to elicit details such as, "What is your reason for giving that time?" and "How would you have felt if this interview had been conducted earlier/later?" Participants were asked about how they were feeling and whether they had experienced any distress during the interview, and they were also contacted by telephone within 24 to 48 hours to follow-up. If distress was reported, participants were offered counseling support.

Interviews were transcribed verbatim. All data were entered into NVivo 9 software (QSR International Pty. Ltd., Australia) and responses (including responses related to this paper) were coded using thematic analysis.³⁴ Analysis began as soon as possible after each interview and commenced with a process of familiarization. The researcher read and re-read each transcript and listened to the recorded interviews, and a summary of each interview was generated. The key ideas were collapsed into manageable categories, which were grouped together to develop meaningful patterns. Mapping and interpreting these patterns in the data enabled the development of specific themes.^{34,35}

Rigor for the study was ensured through addressing the components of credibility, auditability, and fittingness outlined by Beanland and colleagues.³⁶ Credibility was ensured through continual immersion in the data before and during analysis, both individually and as a team. The research team met regularly throughout data analysis to discuss emerging ideas and to identify alternative interpretations of the text. An audit trail was maintained via summaries and memos to show how data abstraction and reduction were conducted. Fittingness was achieved by reviewing the findings in the light of other research in the area and by using the literature to support or refute the concepts emerging from the data.

Results

Demographics

At the time of the interviews, family carers had been bereaved for 3 to 17 months (mean, 6.7 months). See Table 1 for further demographic information.

Timing

Nine family carers said they could have told their story within weeks of their family member dying, five said 2 to 3

TABLE 1. CHARACTERISTICS OF STUDY PARTICIPANTS

<i>Family carers (n=22)</i>	
Gender	
Male	8
Female	14
Relationship to deceased:	
Spouse/Partner	20
Child	2
Illness of deceased	
MND	12
Cancer	10
Age	
45–49	3
50–59	4
60–69	11
70–79	4
Place of death	
Home	15
Hospital	4
Hospice	2
Residential facility	1
Time from diagnosis to death	
<1 year	7
1–2 years	7
2–3 years	5
3–4 years	1
>4 years	2
Time bereaved	
3–6 months	13
7–12 months	7
12+ months	2

months, four said 4 to 5 months, two said 6 months, and one said 1 year. One person was not able to answer the question.

Themes

The results were collapsed into the following discreet categories: “Better recall if soon after death”; “Not distressing if soon after death”; “Wanting to talk about it so soon after death would be helpful”; “Grief is ongoing so soon after death is fine”; “Need time to reflect so later is better”; and “Just ask: Everyone is different.”

Better recall if soon after death. Family carers who expressed a preference for earlier interviews gave more detailed recall as their main reason, noting that they tried to forget painful details over time.

“Straight after...I would have probably remembered a bit more... You put a lot out of your mind. It’s time to get over it.”
 “A month afterward things would have been clearer...6 months down the track you actually don’t want to remember some of it.”

Not distressing if soon after death. Some family carers said they could be approached at any time because they weren’t susceptible to, or did not experience, distress.

“I’m not a sentimental person as such. And I’m inclined to think, ‘Okay that’s done, gone,’ and I put it out of my mind. I probably would have preferred it a bit earlier.”

“A month, I mean if it had been necessary I could have spoken anytime because I’m a fairly tough sort of person.”
 “Oh, probably almost immediately. I would have been fine.”

Wanting to talk about it so soon after death would be helpful. Several participants mentioned that they found it helpful to talk about their family member’s death, and some mentioned they could not talk with their own families.

“I think I would’ve been quite open to talk about this 2 months after...I find it easier if I talk about things—that helps me.”
 “[Others] they don’t want to talk about it, but I do.”
 “I just think there are some people in this world that would like to talk about it because they don’t want to talk to their family.”

Grief is ongoing so soon after death is fine. Several participants mentioned they were grieving, and would continue to grieve, but it was not a reason to delay sharing their stories.

“I mean, you are going to have to cope with the tears anyway.”
 “I don’t think it will make any difference watching the time...I cry every day.”
 “I think if you had come to me in 6 months’ time, I would have probably lost the plot as well.”

Need time to reflect so later is better. Several participants expressed that it may be important that some amount of time passes before being interviewed in order to gain perspective.

“When you’ve got a bit of distance to reflect on things.”
 “I think perhaps in the first 3 months you’re not quite so able to step back and look a little bit.”

Just ask: Everyone is different. Many participants were mindful that their responses were unique and participants stated that each individual should have the opportunity to make his/her own decision.

“I mean you’ve got to ask them so the choice is theirs.”
 “I think it [would be best] if people are given the opportunity. Ask them, ‘Would you mind answering a few questions?’ I know we’re all different.”

One participant suggested a staged approach would be best whereby people say yes and then get involved at a time that suits them.

“Give people a bit of an option, it goes a bit further out if that’s what they need.”

Discussion

Most people (86%) felt the appropriate time for a research interview was within the first 5 months, with many participants (43%) reporting that they would be willing to be interviewed within weeks of the death. A key reason for the preference for interviews soon after the death was clearer recall of details. At first this appears to be a pragmatic reason, but reflecting on the quotes it is evident that some participants actively try to put thoughts about the death out of their minds and don’t want to remember as time passes. This finding suggests that, at least for some people, there is a preference for recalling details of the death of the family member earlier

rather than waiting until months later to answer questions. This is consistent with findings that indicate better recall of details soon after an event.^{15,26,27} It is also reflective of research on bereavement generally suggesting that people are expected to "move on" and that there are set time periods to grieve^{37,38} and, although it is socially acceptable to talk about a death in the weeks following the death, after a few months it becomes more problematic. Casarett and coworkers²⁹ finding that the timing of survey administration after death did not affect distress levels or response rates, even very soon after death, is also supported.

A further reason given by participants for preferring an interview soon after the death was the desire to talk about their experiences and the experiences of their family member at the end of life. For a few participants, having the opportunity to talk was helpful, supporting findings that the bereaved often experience interview participation as positive.^{20,21,33,39} Participants in a psychological autopsy interview in Central Northern Uganda expressed that the interview helped their personal growth, had a therapeutic effect, encouraged participant empowerment, and afforded a safe opportunity for expression.⁴⁰ For many it may be the first opportunity to talk about their loss,³³ which is particularly relevant in cultures where people are expected to grieve silently and remain stoic.⁴¹

No distress was reported by participants as a result of the interviews in the current study, which adds weight to the emerging body of evidence that suggests participation in research does not necessarily lead to distress,^{19,29,33,39} and supports the challenge to members of IRBs and HRECs to review their guidelines and decision-making processes on the issues, risks, and benefits surrounding bereavement research.⁴²

Some participants in the current study specified that they would prefer to participate in an interview after some time had passed. Interestingly, the main reason given for waiting was time for reflection rather than distress. This mirrors findings from Hynson et al.'s³³ study of bereaved parents, many of whom stated that they would prefer to be interviewed at least 6 months after the death of their family member with some participants preferring 2 years into bereavement. Reasons for these preferences were not explored by the authors.

Finally, and importantly, family carers in this study acknowledged that everyone is different and people should decide about participation for themselves. These findings indicate that interviews with the bereaved may be most fruitful for researchers, and beneficial to participants, when bereaved people are supported to make their own decision beginning weeks after the death of their family member. This supports Hynson et al.'s³³ findings where participants stated that they had some good days and some bad days, and the issue was not so much about timing as how they were feeling when asked. This finding supports recent theoretical positions in the area of grief describing grief as unique and multifaceted. The dual process model articulates that people oscillate between confrontation and avoidance of their loss.⁴³ If we emphasise that grief is nonlinear and may vary from day to day, then it follows that this will affect when, how, and why people decide to participate in an interview. One participant in the current study suggested a staged approach whereby a person could say yes to participation in a research study but be given the opportunity to participate when he/she felt ready. Such an approach would acknowledge the unique needs of individuals.

Participants in Hynson et al.'s³³ study also emphasized the importance of *how* they were approached and highlighted the need for sensitivity. This adds a new dimension to the ethical issue of when to ask and changes the question to, "How do we ask?" Certainly this could be an easier challenge to address; clear guidelines could be developed and used consistently to review ethics applications. Hynson et al.³³ articulate as a starting point the need for trained interviewers, flexibility around interview times and places, and sensitive communication. However, Beck and Konnert¹⁹ caution that any safeguards adopted are in proportion to potential risks, and that a blanket set of guidelines for all bereavement research would be counter-productive.

Conclusion

Family cares can provide valuable information to palliative care services about the end-of-life experiences of their family member, but we need to ensure that gatekeeping does not prevent valuable research from going ahead. IRBs and HRECs need to make informed decisions about the participation of bereaved individuals in research. Currently, there appears to be a universal assumption that bereaved people are vulnerable and need time to grieve before being approached to participate in research interviews. However, the findings from this research suggest that participation in research is not necessarily distressing.

The supposition, particularly by IRBs and HRECs, that a certain amount of time needs to pass before approaching potential participants is also challenged as we found that many participants would prefer to be contacted within weeks of the death of their family member for better recall as details fade over time, and also to tell their stories. The key messages are that people grieve differently, they want to be asked, and they can (and will) say no. How people are approached is a key issue, and this may be where we can develop clear guidelines and protocols.

Acknowledgments

The authors acknowledge the Motor Neurone Disease Association, WA, and Silver Chain Home Hospice, WA, for their help with recruitment, and they wish to thank all the people who took part in this study. This study was supported by a grant (SG12/014) from the Cancer and Palliative Care Research and Evaluation Unit (CaPCREU) at the University of Western Australia.

Author Disclosure Statement

No conflicting financial interests exist.

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