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Key challenges and ways forward in researching the “good death”: qualitative in-depth interview and focus group study

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ABSTRACT

Objective To understand key challenges in researching end of life issues and identify ways of overcoming these.

Design Qualitative study involving in-depth interviews with researchers and focus groups with people affected by cancer.

Participants An international sample of 32 researchers; seven patients with experience of cancer; and four carers in south east Scotland.

Results Researchers highlighted the difficulty of defining the end of life, overprotective gatekeeping by ethics committees and clinical staff, the need to factor in high attrition rates associated with deterioration or death, and managing the emotions of participants and research staff. People affected by cancer and researchers suggested that many people nearing the end of life do want to be offered the chance to participate in research, provided it is conducted sensitively. Although such research can be demanding, most researchers believed it to be no more problematic than many other areas of research and that the challenges identified can be overcome.

Conclusions The continuing taboos around death and dying act as barriers to the commissioning and conduct of end of life research. Some people facing death, however, may want to participate in research and should be allowed to do so. Ethics committees and clinical staff must balance understandable concern about non-maleficence with the right of people with advanced illness to participate in research. Despite the inherent difficulties, end of life research can be conducted with ethical and methodological rigour. Adequate psychological support must be provided for participants, researchers, and transcribers.

INTRODUCTION

When an editorial in the *BMJ* posed the question, “What is a good death?”¹ contributors concluded that we cannot answer this as we lack the necessary evidence from research, especially from the perspective of patients and carers.² Achieving a comfortable and dignified death requires research that supports the development of end of life care as an evidence based

specialty.^{1,3} It was in direct response to the *BMJ* good death theme issue that Macmillan Cancer Relief commissioned us to explore the reasons behind this lack of research evidence in end of life care.

Practical, ethical, methodological, and emotional difficulties are experienced by those conducting research into the end of life.⁴⁻⁹ Clark called for more qualitative research with patients and families, cross cultural research, longitudinal studies that can identify the changing needs of patients and families, and the use of innovative methods that examine the difficulties of research in palliative care settings.¹ With some notable exceptions, however, few researchers have written specifically about the challenges involved with conducting end of life research.^{6,8-10} This was confirmed by a systematic literature review in which we identified only small numbers of publications related to the practicalities of conducting such research.¹¹

METHODS

Methodological approach

We used qualitative methods to learn about the experiences, perceptions, and practice of relevant researchers and the views of people approaching the end of life and their carers. We defined end of life broadly as the months before the death of patients with advanced illness, whether or not they were receiving palliative care. We explored issues relating to research conducted with people in the last months to the last days of life and in bereavement.

Sampling and data generation

We identified a purposive sample of 34 researchers and completed interviews with 32 (table 1). One person declined for personal reasons, and another was unavailable during the period of the study. Initially the researchers were identified from our systematic literature review,¹¹ which aimed to determine what methods are being used in cancer studies and how best to include the views of patients in the development of services. We included papers on research methods published in 1980-2004 that sought the views of people

Table 1 | Main research methods used, disciplinary backgrounds, and locations of researchers interviewed in end of life research

Methods	No of participants
Interviews/focus groups	11
Participant observation	4
Arts/drama	4
Quality of life tools/surveys	3
Storytelling	2
Narratives/diaries	2
Mixed methods	6
Not specified	6
Discipline:	
Psychology/psycho-oncology	9
Nursing/medicine	7
Medical sociology	5
Social work	3
Medical anthropology	2
Creative arts	1
Not specified	5
Location:	
United Kingdom	25
Canada	3
United States	1
Sweden	1
Netherlands	1
Australia	1

affected by cancer about end of life issues. This enabled us to identify researchers from a range of disciplines who were using diverse approaches to conducting end of life research. Some were researchers of international standing, who were asked to reflect on their own research experience and give an overview as managers of many projects; others were comparatively junior researchers with more current “hands-on” experience. Many had also worked on non-cancer research. To follow up themes emerging from early interviews and to include more non-cancer work, we interviewed two transcribers and researchers with experience of working in specialties such as HIV/AIDS, dementia, and education, thus enabling us to learn from research methods in other sensitive subjects.

To complement the researchers’ perspectives and to include the experience of patients and carers we held four focus groups that explored a range of users’ views of the best ways to conduct research. Day hospice staff recruited a group of four patients with advanced cancer. They met on two occasions, firstly to discuss ways of conducting research and then to validate the researcher’s interpretation of the discussion. The second group, of three patients specifically interested in research, was recruited from a cancer network database. The third group, consisting of four carers, was recruited through a community palliative care team (table 2).

FH conducted the interviews by telephone or face to face and also facilitated the service user focus groups

(see appendix on bmj.com for interview and focus group schedules).

Data analysis

The interviews with researchers and the focus group discussions were recorded, fully transcribed with accompanying field notes, and entered into NVivo version 2. We integrated, coded, and thematically analysed both datasets using an interpretive approach and a coding scheme derived both from the research questions and from issues that emerged during data generation and early analysis.¹² An anthropologist (FH) led the analysis with the ongoing involvement and input of two members of the research team with backgrounds in sociology and nursing and extensive experience of end of life research (MK and AW). We all regularly discussed emerging themes to include multidisciplinary perspectives (including patients, palliative medicine, and primary care) and further strengthen and develop the analysis. We agreed on four major themes.

RESULTS

Most researchers with experience in both end of life and other research specialties thought end of life research should not be seen as a special case as the challenges were equally relevant in other topics of biomedical and social research. They cited the need for sensitivity, caution, and respect for the physical and emotional wellbeing of participants in any research.

The interviews with researchers and the discussions in user groups highlighted these issues for consideration in conducting end of life research: the design of end of life studies, recruiting participants, ethical conduct, and the emotional challenges faced by participants, researchers, and transcribers.

Designing end of life studies

Defining end of life

All the researchers discussed the ambiguities around the concept of end of life, which one health professional might define as the last 48 hours but others might use to refer to the last six months or even longer. In addition, the uncertainty surrounding any individual patient’s prognosis and the fact that he or she may be unaware of their status as “terminally ill” or receiving “palliative care” render it difficult to identify and recruit patients who clearly have a limited life expectancy. Problems with defining and standardising the research numerator and denominator of people

Table 2 | Location and participants of focus groups

	Location	Participants
Focus group 1	St Columba’s Hospice, Edinburgh	4 men aged ≥65 with advanced cancer
Focus group 2	University of Edinburgh	3 women with experience of cancer (aged 45-55)
Focus group 3	St John’s Hospital, Livingstone	3 women and 1 man: spouses of people with advanced cancer

facing death has led many researchers to gather proxy views after death from informal and professional carers.

Methodological options

End of life researchers were using a range of established social science methods, each with its own strengths and weaknesses. Most researchers thought that a range of approaches and methods was needed, given the variety of issues and groups to be investigated. We found considerable interest in the combining of methods and approaches:

“Well at the moment the project we are doing . . . we are using a mixture of quantitative and qualitative methods to get at different issues and that actually seems to be working really well because it gives us a sort of broad overview of the experiences of lots of different people” (researcher 29).

While some discussed the importance of “innovative methods” such as arts based research involving drama or poetry or using story boards, few had ventured beyond the mainstream methods. One senior researcher said that lack of support from funding bodies was a barrier to using more innovative research techniques. Several researchers suggested that approaches and methods from other sensitive issues, such as long term disability or domestic abuse, could be useful in end of life research.

Most participants in the focus groups expressed a preference for qualitative methods. Providing that the research is conducted sensitively, these methods allow people to raise and contextualise issues important to them:

“Let the patient introduce the subject, rather than the researcher asking questions that might not be to their liking” (participant in focus group 1).

Recruitment of participants

Gatekeepers

Researchers recognised the need to recruit sensitively, and most sought advice from health professionals on the suitability of participants. Some, however, reported that health professionals acted as overzealous gatekeepers, blocking recruitment or introducing a selection bias. This problem, they suggested, could be ameliorated by careful wording of patients’ participation letters and by establishing good relationships with health professionals and keeping them fully informed.

All researchers agreed that research should be scrutinised and conducted ethically but also found the bureaucracy and time involved in submissions to ethics and research committees increasingly burdensome. Many spoke of the paternalism of ethics committees, which added to the access barrier imposed by clinicians acting as gatekeepers for perceived “vulnerable” patients, rather than seeing them as individuals capable of making their own decisions:

“I think patients and family members are people, human beings in their own rights, citizens of the world and they can make decisions whether or not they want to take part in research” (researcher 14).

Inclusive approaches

Difficulties in including people from various ethnic communities were repeatedly highlighted, these recruitment problems reflecting demographic and language barriers and the fact that few people from minority groups access specialist palliative care. Given the recruitment difficulties within the majority population, it is not surprising that many studies fail to engage with people from these small populations. Many researchers, however, thought that greater efforts should be made to include these perspectives to ensure that culturally appropriate care is developed. Successful recruitment strategies included exploring what could be offered in return for participation (for example, information sessions about a particular issue, a social event, or art based activities); gaining the approval of community leaders; and considering issues from the perspective of service users to ensure the study design, research materials, and methods of dissemination are culturally appropriate.

Other hard to reach groups identified included people with physical, sensory, and cognitive impairment; those from socially deprived areas; children and young people; and all those with non-malignant conditions. Many researchers and members of the user focus groups suggested that there is a need for more inclusive approaches and methods and a greater commitment to recruiting from these groups:

“We are all largely middle class, middle aged, you know. We are not representative. We are people who are articulate and can speak out” (participant in focus group 2).

Do people facing the end of life want to participate in research?

Participants in the user focus groups confirmed the researchers’ views that many people with advanced illness still want to participate in research. They thought that the perspectives of patients and carers must be included in research to develop suitable and effective services and support. The researchers reported that many people see their participation as an opportunity to “give something back” in return for the care they, or their loved ones, have received or as an opportunity to try to improve services and support for people in the future. Participants in two of the focus groups spoke at length about the personal benefit of taking part in research:

“When I spoke to [researcher’s name] it really helped me. Because I felt that it was somebody listening, and I know it helped me” (participant in focus group 2).

Some participants in focus groups raised concerns about the real value of participating in research, feeling that the efforts made were sometimes a token gesture as no feedback was received and no change resulted:

“We are speaking, we are saying our piece, and we go away feeling better, but years down the line you think, ‘Well, did it make any difference?’” (participant in focus group 2).

Researchers also pointed out that research may not result in changes to patient services, and that participants should be made aware of this.

Maintaining ethical conduct

Talking about death

As some potential participants may not understand, or wish to be confronted with, their prognosis, researchers advised proceeding as if people do not know they are dying, unless there is an explicit acknowledgment to the contrary. Many researchers emphasised that this should be borne in mind in the design of information sheets and questionnaires for patients, as well as during interviews – for example, not using the phrase “end of life” in information sheets:

“It’s very difficult as a researcher, you are trying to ask questions and ascertain what this person knows about their illness and how they feel about it before you go a step further” (researcher 3).

Researchers emphasised the need to respond to cues given by people about their willingness to discuss end of life issues and cautioned against asking direct questions about death and dying. These ethical concerns were overlaid by more general societal taboos surrounding death and dying, sometimes leading to a lack of confidence in researchers in approaching such discussions.

Researchers reported difficulties in giving feedback, such as copies of project reports, to participants without confronting them with information about end of life issues that some might prefer to avoid:

“How do you identify people who actually are dying and how do you write it up so that you don’t upset some people because they still think they’re going to get better?” (researcher 25).

Informed consent

Researching end of life issues necessarily means engaging with people (both patients and their families) who may be in extremely poor health and experiencing exhaustion, depression, or high levels of stress and anxiety. For this reason, researchers emphasised the importance of distinguishing between informed and valid consent. While it is good practice to ensure that research participants are fully informed about their role in a study (balanced with the need to ensure that they are not presented with information that may upset them), researchers underlined the importance of ensuring that, particularly in longitudinal research, once consent is given, its validity is regularly reconfirmed. Participants should be given several opportunities to withdraw, up until, and even during, interviews or focus groups.

Emotional challenges for participants, researchers, and transcribers

Some researchers, many of whom had also worked on non-cancer studies, considered the emotional challenges of conducting end of life research to be no greater than those in research with other groups such

as people with long term disabilities or threatened with domestic violence or child abuse:

“I started off doing research with stroke patients and I couldn’t have continued with that type of work because that was, you know, just some of the things that those people were going through, living with disability, wasn’t going to get any better, it was going to get worse and the stress on their carers. Whereas dying is something that is going to happen to all of us and so in that sense it’s not a problem for me” (researcher 7).

Some senior researchers thought it important to recruit experienced researchers for these studies, emphasising that often the most important factors are the skills and personal qualities of the researcher:

“Much of it comes down to the skills and the personality of the people who are collecting the data, that you really do need people who are skilled, who are able and who make it a positive interaction for the people concerned” (researcher 18).

Research managers often expressed concerns that end of life research placed heavy demands on junior researchers, who should be offered formal counselling sessions as well as informal debriefing and peer support. They also identified a lack of career structure, which made it difficult to retain skilled researchers.

Many researchers identified end of life research as demanding, but most also spoke of satisfaction gained. Witnessing enduring relationships restored faith in the human capacity to receive and give love and support. It inspired researchers to re-evaluate their own lives in more positive ways and, in some cases, face their own mortality:

“It is, I think, a terrifically important field. It’s important that we do begin to talk more about end of life care . . . so the reward for me is knowing that perhaps one is contributing in a small way to changing social attitudes and culture around end of life care” (researcher 13).

We questioned staff who transcribed end of life interviews because researchers had raised concerns about the emotional demands placed on them. The transcribers explained that events in their own lives could affect their reactions:

“A very close friend of ours died just about this time last year with cancer and for a while whenever I was typing I couldn’t stop thinking about him and it made you look at it very differently” (transcriber 1).

Several researchers warned of the harm that can be caused by not paying attention to the emotional state of interviewees. They indicated the importance of knowing how to bring the interview to an end in a manner that left the interviewee in a safe emotional state and of ensuring access to external support if needed.

DISCUSSION

The evidence from our study indicates that some people with advanced illness may want to take part in research. Researchers with experience in the specialty consider that end of life research is not essentially different from other types of research and not too difficult

Table 3 | Barriers to researching end of life care and possible solutions

Barriers	Possible solutions
Difficulties in designing studies	
Lack of agreed definitions of palliative care, terminal care, and end of life	Researchers to provide definitions to recruiters as part of study documentation
Difficulties of specifying/determining prognosis (or difficulty recognising/defining end of life)	Use specific instruments or prognostic guides, or recruit at a stage in illness trajectory not at defined prognosis
Variable levels of awareness of diagnosis and prognosis in patients and carers	Explore participants' understanding and language they use to describe the illness, and talk with them at that level
Uncertainty about suitable methods	Match methods to research aims, resources, and local context. Consider mixed methods and innovative approaches from other specialties
Funding bodies tend to support only tried and tested methods	Encourage researchers from other specialties/methods who have published successfully to participate in palliative care research groups. Researchers should argue case for innovative methods to examine problems associated with traditional research approaches, particularly in relation to hard to reach groups
Ethical issues	
Staff gatekeeping/ethics committee procedures and attitudes	Work closely with staff and keep them well informed. Clarify that issues around living with illness will be discussed, and sensitive issues will be examined only if patient gives cues. Involve clinical staff in research steering groups
Maintaining informed consent in longitudinal studies	Regularly check willingness to maintain consent
Doubts among clinicians, ethics committees, and carers about willingness of people at end of life to participate in research	Provide evidence that people want to participate and can do so without harm. Include users in research development and project management
Challenges in recruiting participants	
Difficulties in recruiting representative range of people at end of life	Use range of recruitment techniques – for example, local media and community groups, health professionals, and innovative methods
High attrition rates	Factor in attrition rates of 30-50% for longitudinal studies
Emotional challenges	
Researchers	Employ experienced researchers; offer training in advanced communication, palliative care induction. Plan interview workload (three a week). Provide debriefing and peer support sessions. Budget for external support and supervision
Transcribers	Include debriefing and support sessions as required

to conduct. Nevertheless, there is a dearth of research on the views of patients and carers on the good death. Some barriers are practical and methodological: uncertainty about defining end of life, patients lacking awareness of their prognosis, and overly protective gatekeepers hindering recruitment. Although they may be necessary, imaginative and inclusive methods are rarely used, reflecting the challenges in attracting funding for these approaches. More insidious barriers may lie in the societal taboos surrounding death and dying that affect such research.

Strengths of this study

We sampled the views of a broad international group of researchers to determine the reasons for the lack of research in this specialty. Our approach allowed us to include the views of researchers and patients and carers. The qualitative approach enabled an in-depth exploration of the key challenges in end of life research across a range of disciplines and methodological approaches. Many of the findings relate to both quantitative and qualitative research.

Limitations of this study

As we used a systematic review to identify researchers, our sample comprised those who had conducted and published research on key issues in end of life study. Consequently the sample reflects the preponderance of qualitative methods in such published research. Researchers using quantitative methods, however,

were also represented, and approaches with mixed methods were popular. Most researchers we identified were from the United Kingdom, perhaps reflecting a more established research programme, although work in other countries is growing.

This is also the case for the dominance of published work concerned with cancer, rather than other non-malignant conditions, and with earlier stages in the progression of cancer.

As only a small number of people with advanced cancer and their carers participated in our user focus group, we must be cautious in generalising their views. Participants were encouraged to express their views frankly, and their perceptions provided valuable insights in addition to the data from interviews with researchers.

Main findings in the context of the existing literature

Gatekeeping by health professionals and ethics committees has previously been identified as a barrier to end of life research.^{34 13 14} From our study, however, it is clear that many people at the end of their life would welcome the opportunity to participate in research. Many researchers suggested broadening and deepening our understanding of end of life research by developing innovative approaches and methods able to capture the perspectives of a wider range of people, conditions, and settings.¹⁵⁻¹⁷

Researchers were articulate about the professional and personal challenges faced, as revealed in previous

WHAT IS ALREADY KNOWN ON THIS TOPIC

There is little research evidence from patients and carers on what constitutes a good death
This problem is most acute in relation to marginalised populations

WHAT THIS STUDY ADDS

Many people facing death may want to contribute by being included in research
Standard research approaches can be effective, but greater inclusion might be achieved by adopting and developing innovative methods from other specialties
Researchers consider that end of life research is no more challenging than many other areas of health and social research
Barriers to end of life research arise not only from ethical, practical, methodological, and emotional challenges but also from societal attitudes to ageing and death

literature,^{46 8 17-19} but many, especially those who had worked in other types of research, challenged the idea that end of life research is a special case, more difficult or sensitive than many other areas of social research.^{20 21} We summarise the barriers to researching end of life care and possible solutions in table 3.

The personal and societal taboos surrounding death and dying present a major challenge, and funding bodies, ethics committees, and researchers are also affected by them. The concept of social death is well established in the literature: people can suffer a social death before their physical death as society turns away from the dying.²² Some people's desire to participate in research at the end of life may itself be an example of resistance to social death, an opportunity to be an active and participating citizen again rather than an invalid or patient.

CONCLUSIONS

The lack of openness in society about death and dying acts as a barrier to end of life research, yet such research is essential. It must, however, be conducted with ethical and methodological rigour and in ways that support patients, their relatives, transcribers, and researchers. A range of methods and approaches is needed, drawing on work from many specialties, to make the research effective and more inclusive. Ethics committees and clinicians must balance concern about non-maleficence with the autonomy of people to participate if they want. By not letting them, we mark them as "different" and deny them the opportunity to decide for themselves.

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Contributors: All authors designed the study and met as a steering group throughout to help interpret and analyse the data. FH undertook the lead in data analysis together with MK and AW, and all authors wrote the paper. MK is the guarantor.

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