

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.⁶⁻¹⁰ 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. 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. The researchers were from a range of disciplines and 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. 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.

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FH conducted interviews by telephone or face to face and 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, adopting an interpretive approach and using 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.

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.

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.

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.

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. 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.

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).

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

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.

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).

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 is 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).

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 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.

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.^{3 4 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 literature,^{4 6 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}

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.

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- 1 Clark J. Patient centred death. *BMJ* 2003;327:174-5.
- 2 Bowling A. Research on dying is scant. *BMJ* 2000;320:1205.
- 3 Riley J, Ross JR. Research into care at the end of life. *Lancet* 2005;365:735-7.
- 4 Addington-Hall J. Research sensitivities to palliative care patients. *Eur J Cancer Care* 2002;11:220-4.
- 5 Entwistle V, Titterton J, Calnan M. Researching experiences of cancer: the importance of methodology. *Eur J Cancer Care* 2002;11:232-7.
- 6 Lawton J. Gaining and maintaining consent: ethical concerns raised in a study of dying patients. *Qual Health Res* 2001;11:693-705.

- 7 Rowling L. Being in, being out, being with: affect and the qualitative researcher in loss and grief research. *Mortality* 1999;14:167-81.
- 8 Seymour J, Skilbeck J. Ethical considerations in researching user views. *Eur J Cancer Care* 2002;11:215-9.
- 9 Beaver K, Luker K, Woods S. Conducting research with the terminally ill: challenges and considerations. *Int J Palliat Nurs* 1999;5:13-17.
- 10 Seymour J, Ingleton C. Ethical issues in qualitative research at the end of life. *Int J Palliat Nurs* 2005;11:138-46.
- 11 Harris F, Kendall M, Murray SA, Worth A, Boyd K, Brown D, et al. *What are the best ways to seek the views of people affected by cancer about end-of-life issues?* London: Macmillan Cancer Relief, 2005.
- 12 Rose K, Webb C. Analyzing data: maintaining rigor in a qualitative study. *Qual Health Res* 1998;8:556-62.
- 13 Cook AM, Finlay AG, Butler-Keating RJ. Recruiting into palliative care trials: lessons learnt from a feasibility study. *Palliat Med* 2002;16:163-5.
- 14 Krishnasamy M. Perceptions of health care need in lung cancer. Can prospective surveys provide nationally representative data? *Palliat Med* 2000;14:410-8.
- 15 Gray R, Sinding C, Ivonoffski V, Fitch M, Hampson A, Greenberg M. The use of research-based theatre in a project related to metastatic breast cancer. *Health Expect* 2000;3:137-44.
- 16 Gray RE. Performing on and off the stage: the place(s) of performance in arts-based approaches to qualitative inquiry. *Qual Inq* 2003;9:254.
- 17 Lee RM. *Doing research on sensitive topics*. London: Sage, 1993.
- 18 Seamark DA, Gilbert J, Williams S. Are postbereavement research interviews distressing to carers? Lessons learned from palliative care research. *Palliat Med* 2000;14:55-6.
- 19 Woods S, Beaver K, Luker K. Users' views on palliative care services: ethical implications. *Nurs Ethics* 2000;7:314-26.
- 20 British Sociological Association. Statement of ethical practice. www.britisoc.co.uk/equality/63.htm.
- 21 Association of Social Anthropologists. Ethical guidelines for good research practice. www.theasa.org/ethics/ethics_guidelines.htm.
- 22 Seale C. *Constructing death: the sociology of dying and bereavement*. Cambridge: Cambridge University Press, 1998.

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Sex ratio and time to pregnancy: analysis of four large European population surveys

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ABSTRACT

Objective To test whether the secondary sex ratio (proportion of male births) is associated with time to pregnancy, a marker of fertility.

Design Analysis of four large population surveys.

Setting Denmark and the United Kingdom.

Participants 49 506 pregnancies.

Main outcome measure Secondary sex ratio.

Results No association was found between the sex ratio and time to pregnancy and no discernible trend was found for sex ratio with time to pregnancy, either within individual datasets or in the pooled analysis. The odds ratios were 0.97 (95% confidence interval 0.90 to 1.04) for contraceptive failures, 1.01 (0.96 to 1.05) for time to pregnancy of 2-4 months, 1.02 (0.97 to 1.08) for 5-10 months, 0.98 (0.93 to 1.03) for 11 months or more, and 0.88 (0.74 to 1.06) for fertility treatment, with 0-1 months as the reference category.

Conclusion No association was found between the secondary sex ratio and time to pregnancy.

INTRODUCTION

Evidence exists of a decline in semen quality over

recent decades and a deterioration in the reproductive health of males, with an increase in the incidence of testicular cancer and probably of hypospadias and cryptorchidism—the “testicular dysgenesis syndrome.” One possible cause is endocrine disruption due to environmental agents with oestrogenic or antiandrogenic effects, although direct evidence is lacking and other mechanisms are possible.¹ Other things being equal, a decline in semen quality is expected to be followed by a declining trend in fertility, although during the same period no such decline—as measured by the time to pregnancy—has been observed.²

In parallel, during the same period the proportion of male offspring (the secondary sex ratio) has been declining in many countries, including the United States and Canada and in several European countries.^{3,4}

Exposure to certain substances, such as the nematocide dibromochloropropane,⁵ has been found to affect both the secondary sex ratio and male fertility. This parallelism of trend together with shared chemical determinants raises the question of whether the probability of conceiving a male child is linked to the parents' fertility. We tested the hypothesis that the secondary sex ratio