

Methods forum

Using focus groups to explore older people's attitudes to end of life care

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ABSTRACT

This paper reports on the methodological and ethical issues that were encountered when using focus groups to explore older people's knowledge, beliefs and risk perceptions about the use of innovative health technologies in end of life care. Older people drawn from community organisations in Sheffield, England, took part in discussions about the application of 'life prolonging' and 'comfort care' technologies during serious illness and impending death. The paper offers a reflective account of the management of recruitment and informed consent, and of the issues that arose when facilitating group discussions of potentially distressing material. It concludes with a brief account of the steps that were taken to enhance the 'credibility' of the data.

KEY WORDS – focus groups, qualitative research, methodology, end-of-life care, attitudes, research ethics.

Background

Little research in Britain has examined older people's views and experiences of end of life care. The perceived sensitivity of the subjects of death and dying, together with the problems of gaining access to the views of older people, especially those who are very frail or sick, poses special barriers to this type of research. The few published studies make clear, however, that older people face many difficulties during the dying process in achieving a balance between their desire for independence and the need for care and support (Young and Cullen 1996). It is also clear that older people's views about end of life care depend not only upon their attitudinal stance (Schiff *et al.* 2000), but

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also on individual circumstances and prior death-related experiences (Finch 1987; Williams 1990; Corr 1993). It is unlikely, therefore, that a conventional approach to attitudinal research, that uses attitude scales or categorical questioning to reveal an underlying structure of beliefs, will successfully lead to an understanding of their attitudes to end of life care. What is required is an approach that allows access to the informants' broad 'referential structure' (Denk *et al.* 1997: 113), while at the same time allowing room for the expression of biographical and contextual details.

In this paper we reflect on the use of focus groups in a study that is exploring older people's knowledge, beliefs and risk perceptions regarding the use of innovative health technologies during care at the end of life. We examine the difficulties that arose in connection with recruitment, informed consent, and the group discussion of potentially distressing material, and conclude with a discussion of the steps undertaken to enhance the 'credibility' of the data (Lincoln and Guba 1985). The paper aims to inform the work of other researchers in this field, and to contribute to methodological debates about the ethics and conduct of qualitative research.

The use of focus groups

Focus groups possess elements of participant observation and individual interviews (Madriz 2000), and are primarily a means of listening to people's views on a specific area of inquiry in a non-threatening setting (Morgan 1988). Focus groups are a popular method for accessing understandings of illness and for examining people's experiences of health and health services (Duncan and Morgan 1994). They are recommended as a useful means of engaging with users in developing health care policy and practice (Thornton 1996; Owen 2001). The origins of focus groups are generally ascribed to opinion gathering in market or political research, where speed, low cost and flexibility often take precedence over representativeness or rigour. As Reed and Payton (1997) point out, however, focus groups have also long been employed in anthropology, ethnography and qualitative social science. In this tradition, focus groups are used explicitly to study the role of social interaction and conversation in opinion formation, especially where the subject of study is little understood (by researchers) or infrequently discussed in day-to-day life. The aim is less to uncover stable 'facts' about opinions and attitudes, and more to facilitate 'the process of developing a group perspective or position among a particular set of

people ... [even if] people come to a focus group with particular ideas and [views] (Reed and Payton 1997: 770).

Focus groups may then be an effective method for exploring sensitive issues such as end of life care. The group process should enable participants to explore the issues in their own terms, to formulate questions, and to make their views and priorities explicit. These insights and questions can then be incorporated in subsequent research (Kitzinger 1995). Where groups 'naturally occur' (Morgan 1997), *i.e.* when members are already known to each other by dint of some allegiance or membership of an established organisation or association, then focus groups serve two purposes, of providing a familiar and supportive environment for the participants, and of introducing the researcher to the cultural values of the organisation. In this way, carefully conducted focus groups provide an important means of accessing groups that are otherwise neglected by research, and of opening up sensitive topics that are rarely discussed and about which the researchers have little understanding.

There are few reports in the medical and health care literature of the special considerations involved in conducting focus groups on sensitive topics with older and very frail participants. Studies in education (Keller *et al.* 1987) and nutrition (Crockett *et al.* 1990) have however shown that focus groups with older people can be successful, providing that steps are taken to ameliorate sensory, physical and mental impairments. Reporting on the use of focus groups with vulnerable clients, Owen (2001) emphasises the importance of experienced facilitators, who can manage the consequences of personal disclosure and support the participants, and notes that the method is time consuming. Focus groups in the United States that have explored the meaning of 'good death' with patients, families and service providers (Steinhauser *et al.* 2000), and others that have considered end of life decision making with older women and minority ethnic groups (Morrow 1997), confirmed the need for small group size, carefully designed and explained ground rules, and attention to clarity – alongside the widely recognised standard requirements of at least two facilitators with experience of sensitive issues, and carefully worded probe questions.

Recruitment and informed consent

We now turn to reflect on some of the challenges of using focus groups as a means of exploring older people's attitudes to end of life care. Eight

focus group discussions were held with 32 participants¹ recruited from six purposively selected community associations that either represent or comprise older people in Sheffield. The participants included members of three types of organisations:

1. Mainstream 'white' community associations that lobby for older people or are organised by older people (11 participants from two organisations);
2. Those representing the interests of frail older people by way of delivering services to them and their carers (four participants from one organisation);
3. Those representing the interests of older people belonging to different ethnic minority and religious groups (16 participants from three organisations).

The sensitivity of the research topics meant that the preliminary meetings had to be managed carefully. We (JS, GB and MG)² began by giving information about our backgrounds as nurses and researchers in palliative care, which served gradually to open up the issues of interest. It was found important to make it clear that we did not assume that serious illness and dying was inevitably and only associated with older people, so we emphasised the many problems of discovering the views of older people about serious illness and dying, and the special difficulties when people are unwell or frail. The very process of inviting people to participate in a focus group context encouraged impromptu discussion of the issues, often in animated and engaged ways, while others clearly tried to disengage themselves from a subject that they considered distasteful. In these situations, we tried to close the conversation by pointing out that the topics were exactly those to be covered in the discussion group.

Using a clinical background as an identity was valuable for setting our research in context and for building rapport and trust with potential participants, but caused some difficulties. Some people clearly regarded us (JS and GB) as potential care-givers. This was particularly the case among frail older people, some of whom were clearly very lonely. When one very elderly woman at an Age Concern day care centre was approached with a view to participating in the discussions, she asked, 'Do you do home visits on this project because I'd like to talk to you on your own'. Researchers must clearly not only recognise the possibility of misunderstanding and incorrect expectations, particularly among people with few social relationships or who are lonely, and should actively counter the effect.

This woman, and another who expressed interest in taking part, were advised by their care workers to 'go away and think about it'.

The care workers were clearly worried about the risk of exploitation, and they later reported that the older women's participation would be 'too much of a commitment'. We perceived that some care-workers were more uneasy about the study topics than the older people whom we invited, and suspect that there was subtle encouragement not to take part.

Some invited people felt 'over researched', particularly among the Age Concern day care group attenders. One woman who was approached in mid-June said that she was already taking part in a 'clinical' research project. She reported her experience of answering a structured questionnaire: '[it has] good questions because you either know the answer or you don't: I don't have to think. In your study, I think I might have to think, and I'm not sure that I want to do that. In any case, winter is coming on'.

In spite of these problems, the participation of frail older people was achieved and strong connections with their associations were established. A flexible approach was found essential, especially when trying to work with older people from ethnic minorities. It became clear, for example, that among the members of Sheffield's Somali-origin community that we approached, it would not be acceptable to convene a focus group, although some individual older people were willing to be interviewed. At an initial meeting with members of Sheffield's Afro-Caribbean community, the key contact believed that we would probably not be acceptable as facilitators for an older women's group. We therefore suggested that a discussion group be held in our absence, using our materials but facilitated by an Afro-Caribbean worker. In the event, this did not happen, because when we attended one of the regular support meetings of older Afro-Caribbean women, they raised no objections. In the case of an Asian-origin community, the gatekeeper's opinion was that as white researchers, we (JS and GB) had no possibility of engaging older Asian people with our subject. Useful comments were however received about our discussion group materials, which will inform future work with the community.

Managing focus group discussion of distressing topics

In facilitating the focus groups, a balance was sought between the expression of individual views and coverage of the topics of interest. We wanted people to be able to distance themselves from the material if they wished, but also to allow space and time for the personal stories that participants wished to relate. Two crucial elements were to allow

people to maintain their sense of privacy, and to provide sufficient material for a general discussion if that was preferred.

From our interest in new health technologies, we knew that visual presentations are an effective and interesting way of communicating with most audiences. We needed to ensure that participants had enough information and knowledge to discuss the issues, and also that we had a means of 'bringing back' the discussion if it became out of hand. A computer-based Power Point™ 'slide show' was the obvious choice, and provided a simple pictorial aide-mémoire with the following key themes:

- Where is the best place to be cared for? (home, hospital, nursing home or hospice).
- The use of technology to prolong life (resuscitation and artificial feeding).
- The use of technology to give comfort (terminal sedation and morphine).
- Who should decide? (clinical staff, patient or relative, with material on communications and advanced care planning).

While this fairly structured approach may limit the opportunities for participants to raise other issues, it had several important advantages. First, the computer and projection equipment generated interest and discussion and was a useful ice-breaker. Second, the structured approach enhanced our understanding of both the groups' response to the introduction of a topic, and the development of their expressions during the conversation and through the interaction. The participants often asked questions, either of the researchers or of each other, and then reached a shared understanding. This sequence was most evident when participants had little direct experience of the topic, or had had few previous opportunities to think through their opinions. Third, the approach facilitated data analysis and the use of the groups' responses in the development of an aide-mémoire for later personal interviews. Fourth, the material gave valuable flexibility with which to vary the pace of the discussion, and to revisit or skip over particular images or words. It also provided useful markers of the end of a topic: on the occasions when the discussion became deeply personal, it was sometimes necessary to take a break – the slides made this easier.

Unexpectedly but importantly, we realised that the participants viewed the slide show as similar to watching television. Most people are comfortable and familiar with television, and many of us sometimes watch programmes that include taboo or 'risky' material. By showing such material in this way, it may be de-personalised, and it clearly generates a lot of interest. The participants asked many questions,

which we tried to answer in informed and clear ways. They were most revealing, and gave us insights into the types of needs that people have for information about end of life care. Sometimes the participants told stories that revealed a need for immediate information and for further discussion.

One of the most difficult stories to respond to was when a woman participant said, 'I've done euthanasia', and then recounted a harrowing story from 18 years before. She had cared for her mother who died a lingering death from cancer, and had been left with morphine syrup to give her mother but with next to no guidance as to its use. Our direct response to this account was to discuss the meaning of euthanasia and the differences between the relief of suffering and the intention to kill.

At the end of each group we informally 'debriefed' the participants, often over lunch, and asked them what they thought of the way in which we had handled the discussion. We offered follow-up discussion of anything that had been raised in the group, and to answer their questions during the subsequent days and weeks. The names and addresses of bereavement care organisations were provided. One respondent subsequently telephoned with questions, and we organised a follow-up meeting with each association some weeks after the initial discussions.

Credibility of the data

For Lincoln and Guba (1985: 314), 'the most crucial technique for establishing the 'credibility' of research data is through 'member checks', in which those who participate in research are invited to comment on the interpretation made by the researchers. To do this effectively, we wrote a summary report for each participating community association, and invited each group to meet us to discuss the validity and implications of our analyses with the participants. The reports were welcomed by the participants and generated much interest and discussion. They were judged to be good summaries of each focus group discussion, and enabled the participants to compare the views of their group with the others'. This debriefing exercise gave the participants opportunities to raise several issues about which they wanted more information, and has generated valuable ideas both for the research and for local dissemination and development work.

Conclusions

Several methodological lessons were learnt from this project. Recruiting black and minority ethnic older people proved difficult, partly because of the topics of the study, but also because a willingness to be flexible about the form of interview or discussion group helped raise participation. Similarly, the recruitment of frail older people has been difficult, partly we believe because of the anxieties of care workers about possible exploitation or distress. The issue of consent to participate is far from straightforward. We became aware, for example, of offers to participate that appeared to be motivated more by loneliness than by an informed agreement to discuss the study topics. Some frail older people may have been unable to decide whether or not to participate since they were not used to making choices. In spite of this, we were able to involve frail older people, but achieving informed consent required several methods of communication, since the older people that we met had various comprehension and decision making difficulties.

To run focus groups on difficult subjects, we learnt that careful planning is an essential prerequisite of a sensitive exploration of older people's views about death and dying. Using television-like technology to present potentially risky material put people at their ease and provided a structure or 'frame' for the ensuing discussions. Moreover, the material and the mode of presentation seemed to enable the participants to talk and discuss freely without having to draw on personal experiences of illness, loss and bereavement. This meant that privacy could be and was preserved. When personal experiences were recounted, the structure and format of the groups meant that participants appeared to gain comfort and reassurance from the empathy of others. Small group size, plenty of time, and at least two facilitators are essential. Ideally, participants should know one another, since they then have a natural opportunity for peer support. Such familiarity could of course be inhibiting, but we believe that providing the opportunity for peer support outweighs this disadvantage. Our tentative conclusion is that many of the participants found the discussions interesting, informative and enjoyable.

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NOTES

- ¹ Nine men and 23 women participated. One person declined to give any socio-demographic information. Of the remaining 31: four were aged less than 60 years, and 27 were 60–87 years of age (20 were 65–74 years). Twenty-six identified their ethnicity as white; two as Irish; two as Black Caribbean and one as Black British. Fourteen were married; 13 widowed; and four divorced, separated or single. Twenty-three described their health as excellent or very good, and eight as fair or poor. Twenty-one said they had strong religious beliefs. Analysis of social class was based on last reported occupation and showed an equal distribution across five categories.
- ² JS has a background as an intensive care nurse, and GB as a mental health nurse. MG is a gerontologist with experience in palliative care research.

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