



## Technology and Natural Death: A Study of Older People

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# RESEARCH FINDINGS

### KEY FINDINGS

This study explored older people's knowledge, views and risk perceptions about health technologies used during care at the end of life. It explored:

- the beliefs and understandings older people express about life prolonging and basic care technologies in end of life management.
- what risks and benefits older people associate with regard to the application of these technologies.
- whether older people express preferences with regard to the use of these technologies during end of life care, and what form these take.
- whether older people express ideas about natural death and draw distinctions between natural and unnatural technologies.

- Participants felt they had a poor understanding of clinical, ethical and legal issues relating to end of life care and did not know where they could gain information.
- Patients, clinicians and their families were perceived to be caught in a shared dilemma imposed by medicalisation.
- Trust and good communication were seen as essential prerequisites of good quality end of life care.
- New risks linked primarily to matters of family obligation were perceived during end of life decision making
- Many participants believed that in the dying situation family members should be able to give consent on behalf of older people
- Home care during dying was perceived as an ideal, but was associated with a range of practical and moral problems.
- Concerns were expressed about the perceived link between advance care statements and euthanasia, their future applicability, and difficulties in thinking about and discussing death and dying.

#### RESEARCH TEAM

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Guidelines published by professional bodies identify two categories of technology for use in end of life care: 'life prolonging' treatment and 'basic care'. The first category refers to treatments which have the potential to postpone the patient's death, including cardiopulmonary resuscitation, chemotherapy and artificial nutrition and hydration. The second category refers to those procedures essential to keep an individual comfortable, and includes pain relief and the management of distressing symptoms as well as warmth, shelter, hygiene and the offer of oral hydration and nutrition. We were concerned to explore views about these two categories of technology expressed by older people living in Sheffield, UK, against a backdrop of: i) empirical evidence that dying older people have their pain and other symptoms inadequately relieved and, ii) enduring conflicts about the benefits and burdens of life prolonging technologies for older people. The concept of 'natural death' and, specifically, how ideas about this are fashioned in relation to new health technologies, was employed as a theoretical framework. The study took place as policy momentum gathered in the UK to examine issues relating to quality of end of life care and as evidence was being collected to underpin the Mental Capacity Act and the review of Assisted Dying.

Study participants reported that they found our methods of research (we used story boards and media extracts in focus groups and interviews) acceptable and that they enjoyed the process of participating in the study, in spite of some initial reservations about the topics covered.

In their reflections on the role of life prolonging and basic care technologies in end of life care participants communicated complex and sometimes paradoxical

understandings of the boundaries between 'body' and 'person', between 'life' and 'death', and between the 'artificial' and the 'natural'. It was perceived that the application of new technologies to the management of dying transformed a social order of dying in which 'doctor knows best' to one in which patients, clinicians and their families were caught in a shared dilemma imposed by medicalisation. Trust and good communication, and the ability to weigh up *in collaboration with* clinicians the risks and benefits of particular courses of action with regard to the use of these technologies, were seen as essential prerequisites of good quality end of life care. It was recognized that, in these new circumstances, families had to be ready to assume a degree of responsibility for representing their dying relative, and new risks linked primarily to matters of family obligation were associated with this. Some participants placed emphasis upon the role of family carer standing as 'proxy' for the ill person, whereas others emphasised instead an individual's right to self-determination.

Some key issues raised by participants about individual technologies are as follows:

#### *Life prolonging technologies*

- Participants felt they had a poor understanding of the clinical, ethical and legal framework within which life prolonging technologies are employed.
- A role for family 'veto' in decision making was perceived, with many participants believing that in the dying situation family members should be able to give consent on behalf of older people (this does not correspond to available guidelines and current law).

## Basic care technologies

- Home was seen, ideally, as the preferred place to be cared for at the end of life because of its symbolic meanings: the presence of loved ones, independence, familiarity and the repository of memories.
- However, a range of problems was associated with care at home, including: fears of dying alone; worries about being a 'burden' to family; and concerns about the caring skills of family carers and the risk of receiving inadequate symptom relief. The presence of professional carers in the home, and the need to accommodate technologies to aid caring, was regarded by some as compromising the public /private boundary.
- The terms 'comfort' and 'love' were used to describe good care during dying and an idealised death was perceived to be that in which pain relief and sedation are used carefully to provide an easy, comfortable and quiet death.
- Concerns raised about pain relief and sedation focused on understanding of permissible clinical actions and the risks of exclusion from good pain relief.

## Advance statements

- Advance statements were understood in terms of their potential to aid personal integrity and to help families by reducing the perceived 'burden' of their decision making.
- Concerns were expressed about the perceived link between advance care statements and euthanasia, their future applicability, and difficulties in thinking about and discussing death and dying.

- Participants did not perceive that they would be ready necessarily to adhere to an advance statement and 'disengage' from their lives.
- We conclude that advance care planning would be better understood as a process of discussion and review between clinicians, patients and families, rather than the completion of an advance statement.

## Conclusions

Our findings indicate a need to ensure that life prolonging and basic care technologies are provided in ways that respect and support a variety of understandings about love, comfort, obligation and burden during dying. The study highlights: the role that older people have in caring for the dying and their related needs for support and training; the need to address information needs about issues of end of life care ethics, clinical practice and advance care planning; and the capacity and willingness of older research participants to discuss these matters and to enjoy the process of so doing. Developing a programme of public education and information was identified by some participants as an issue which should be addressed urgently if older people and their family carers are to be better equipped to make informed choices about these aspects of care delivery. Since completion of the study, we have been able to develop and pilot some peer education materials for advance care planning with funding from the Health Foundation. We have also conducted a related study using the same design with older Chinese people in Sheffield and Manchester (funded by the Health Foundation) and have completed a detailed report commissioned by Help the Aged about older adults and end of life care.

# About the Project

The project took the form of a two-phase exploratory, qualitative study of 77 older people living in Sheffield. In phase one, 8 focus group discussions were held with 32 participants recruited from six purposively selected community groups representing older people. To ensure a diverse range of participation, eleven community groups were invited to take part. Pictures and media extracts were used to facilitate discussion in the focus groups, and the data were used to design two third party story boards or 'vignettes' that were employed in interviews with 45 older adults living at home in phase 2. Three general practices in different localities within Sheffield were asked to draw a sample of patients in the age categories: 65-74 years, 75-84 years and over 85 years. The sample was checked by GPs to ensure the inclusion of people of different marital status and place of residence. Exclusion criteria were: inability to give informed consent, experience of close bereavement in the last year, recent diagnosis of a life limiting illness. Health status was examined using the SF-36, revealing that many participants were in frail health. The project team were aided by an advisory group, including participants from phase 1, which met on four occasions to discuss matters of research conduct, data analysis, dissemination and research outcomes. Thirty-five participants attended a 'discussion day' at the end of the project and provided invaluable feedback about the methods we employed and preliminary findings.

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