Full Report of Research Activities and Results

Background

One of the fields in which the social and personal implications of the availability of new health technologies are most clearly apparent is that of end-of-life care for now it is possible to alter the manner, timing and place of dying to fit in with a notion of ‘natural’ or ‘good’ death that best suits the preferences of the dying person, their close family and professional carers. However, in spite of the publication of guidelines suggesting that it is good practice to involve dying people and their family caregivers in care decisions (BMA 2001; GMC 2001), we know little about end of life preferences, nor do we fully understand the complexities and risks perceived to surround the doctor – patient or doctor – family relationship during end of life decision making.

Since death is now, in the west, most likely to occur at the end of a long life, it is important to understand the views and values which older people express in relation to these issues. While most older people remain fit and well into advanced old age they are likely to have anxieties about the consequences of future life limiting illness and a heightened awareness of finitude (Munnichs 1966). These fears may make communication about these issues a difficult barrier to cross. Some may have concerns about receiving ‘high’ technology interventions immediately before death that result in prolonged dying, while others may have fears generated by media ‘scandal stories’ suggesting that some older persons have been denied the option of life-sustaining treatments (Winterton 2000).

This project used an innovative methodology developed in partnership with community groups to explore views of these issues expressed by older people living in Sheffield, UK. 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. This is expressed in Illich’s critique that modern medicine has ‘...brought the epoch of natural death to an end’ (1976: 210), while Aries posits the image of medicalised death as an icon of unnatural death: ‘the death of the patient in hospital, covered with tubes, is becoming a more popular image than the transi or skeleton of macabre rhetoric’ (1981:614). The dominance of these ideas has led to a lack of consideration of the ways in which medical technologies are used actively to construct dying and death.

Guidelines published by professional bodies (BMA 2001; GMC 2001) identify two categories of technology for use in end of life care: ‘life prolonging’ treatment and ‘basic care’. The first category refers to ‘all treatments which have the potential to postpone the patient’s death’ (BMA 2001), including cardiopulmonary resuscitation, chemotherapy and artificial nutrition and hydration. The second category refers to ‘those procedures essential to keep an individual comfortable’ (BMA 2001). This 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 older people’s views about these two categories, against a backdrop of: i) empirical evidence that dying older people have their pain and other symptoms inadequately relieved (Ahronheim 1997; Anderson 2002); and, ii) enduring conflicts about the benefits and burdens of life prolonging technologies for older people.

OBJECTIVES

1. To explore the beliefs and understandings older people express about life prolonging (resuscitation and artificial feeding) and basic care (care location; pain relief and comfort) technologies in end of life management.
2. To explore what risks and benefits older people associate with regard to the application of these technologies during end of life care.
3. To explore whether older people are able to express preferences with regard to the use of these technologies during end of life care, and what form these take.
4. To explore whether older people express ideas about natural death and draw distinctions between natural and unnatural technologies.

Overarching these discrete objectives is the issue of decision making. We aimed to explore this in two ways: 1) examining perceptions about how critical decisions about life prolonging and basic care technologies should be made in present time; 2) exploring ideas about preparing for future incapacity through the device of the advance care statement.

We believe that our methodology has enabled us to achieve these objectives, although it should be noted that the study has elicited highly complex, often paradoxical and contextually situated data that need exploration in further research.

**METHODS**

The project took the form of a two-phase exploratory, qualitative study of older people living in Sheffield. The project team had regular meetings and were aided by a steering 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 (see report in appendix 1).

**Phase 1**

Eight focus group discussions were held with 32 participants recruited from six purposively selected community groups representing older people in Sheffield, UK. To ensure a diverse range of participation, eleven community groups were invited to take part. Invited groups fell broadly into the following three categories

1. Groups within the mainstream ‘white’ community which lobby for older people and are organised by older people (11 participants from two groups took part)
2. Groups representing the interests of frail older people and delivering services to them and to their carers (4 participants from one group)
3. Groups representing the interests of older people belonging to different ethnic minority and religious groups (16 participants from three groups)

Participants were invited to take part in a focus group either by being sent a letter on our behalf by a key contact from their group or at a face-to-face meeting.

Phase 1 Participants: nine men; 23 women. One person declined to give any socio-demographic information. Of the remaining 31: four were aged under 60; 27 were aged 60-87 (20 were aged between 65 and 74). 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 were divorced, separated or single. Twenty-three described their health as excellent or very good; eight described their health 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.

Focus group participants were invited to comment on a pictorial ‘aide memoire’ (see appendix 2) in which the key issues relating to selected technologies of end of life care were presented through the medium of a ‘PowerPoint’ (© Microsoft) presentation:

- Where is the best place to be cared for? (Home, hospital, nursing home or hospice).
- Using technology to prolong life (resuscitation and artificial feeding)
- Using technology to give comfort (terminal sedation and morphine)
- Who should decide? (Clinical staff/ patient/ family communications and advance care statements).
Despite concerns that the structure may not have created enough opportunities for participants to raise other issues of importance to them, we believe there were several advantages to our approach: interest in the equipment acted as an icebreaker; the structured approach facilitated data analysis; flexibility was introduced to vary the pace of the discussion, and revisit images or words; and participants said that the slide show was akin to watching television, which they found comfortable and familiar (see Seymour et al, 2002).

**Phase 2**

Two simple ‘vignettes’ were developed from the focus group discussions (see appendix 3) and modified following advice given by phase 1 participants at subsequent meetings.

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 (see below). These data are being used to add interpretative depth to the qualitative data, and to aid comparison of the achieved sample with the health status of the wider population.

Recruitment process

- GPs sent out letters on behalf of the research team to 125 potential participants. One GP practice preferred to hand letters to patients when they visited surgery: this may have affected the resulting sample in terms of health status.
- 44 (35%) returned a card to say they were willing to consider participation and were visited by a researcher.
- 39 (31%) individuals consented to interview, of whom 6 invited a companion to their interview. There were 45 interviewees in total.
- In debriefing questions, some individuals said that they took part because they wanted to help, others because they were interested in the subject or had experiences they wished to talk about.

**Description of interview sample (from SF 36 data)**

**Figure 1: Age and sex of participants**

**Figure 2: Perceived general health by age**
• 38 people lived in their own home; 7 lived in nursing, residential or sheltered accommodation.

• 35 (78%) participants were ‘limited a lot’ in vigorous activities; 16 (36%) were ‘limited a lot’ in moderate activities.

• 24 (55%) felt that their physical and emotional health interfered with their social activities.

• 32 (70%) had experienced moderate to severe bodily pain during the last 4 weeks.

• 15 (33%) expected their health to get worse in the future; 20 (44%) were not sure how their health might change in the future.

• All had experience of one or more significant bereavement.

Interview conduct
Each interview lasted for approximately one hour. The process of explanation prior to the interview, and the process of debriefing after the interview added two or three hours to this.

The vignettes were presented in a random order: some interviewees started their interview with vignette 1, others with vignette 2. The majority of the interviewees were able to work through both vignettes. Vignette 1 was found to be easier to engage with by interviewees, perhaps because they found the scenario more familiar.

Participants reacted to the stories in three ways: 1) Some reflected on the situations that the characters in the stories faced and discussed these; 2) Others described how they thought that characters would respond to the prompt questions posed. Both these groups drew on personal experience as a resource but this was not their primary focus. 3) A third group preferred to talk about their own experiences.

Participants’ responses to these debriefing questions (which were confirmed by those who attended the subsequent discussion day) indicate that most found the use of the third party stories was appropriate and perceived that a more direct technique may have been too difficult and invasive of privacy. Most felt that the length of time taken by the process was about right, and most said that they had found the process interesting and enjoyable.

Data analysis
Both focus group data and interview data were audio taped and transcribed verbatim, and analysed as freestanding data sets. We used NUD*IST to assist the analysis process. Focus group analysis provided an initial coding frame for the analysis of the interview data. Three researchers read the transcripts individually. Notes were then compared for agreement and the key dimensions of the various topics were identified through discussion. Each transcript was then examined in detail, and the coding frame was adapted until no new issues could be identified. Thematic categories were then derived which encompassed similar codes. These were compared to issues highlighted in the published literature. All analysis decisions were made by consensus.

Ethical issues
The research was conducted in line with the ethical standards detailed by the British Sociological Association (1993); an extract is enclosed at Appendix 4. The study had the approval of the North Sheffield Research Ethics Committee.
Focus groups

The perceived sensitivity of the research meant that the preliminary meetings with potential participants had to be managed carefully. Written informed consent was gained when time had been given to consider participation. Procedures to safeguard anonymity were explained and the uses of the tape-recorded material for research purposes explained. Ground rules were established at the beginning of each group regarding confidentiality, and the risks of taking part were also explored including distress that might result from revisiting experiences of loss. Each group had two facilitators with experience of undertaking sensitive research and relevant clinical experience (see Seymour et al 2002).

Interviews

The use of the vignette technique was primarily for ethical reasons of preserving privacy and reducing the chances of distress. Debriefing questions were used to find out what participants thought of the stories; their views about the length of the interview; to check for feelings of distress and to answer any questions. Participants were advised of points of contact from which they might gain bereavement support where desired and were telephoned or visited a few days after their interview by the researcher who interviewed them. If they wished, their GP was told that they had participated in an interview. The follow up telephone calls and visits were reported as helpful by those who attended the discussion day.

Results

For clarity, our analyses to date are organised in relation to perceptions of ‘life prolonging technologies’ and ‘basic care technologies’. We conclude by drawing together a brief summary of overarching perceptions about ‘natural death’. While the individual interviews in phase 2 were used to further explore issues identified during the focus groups in phase 1, there were some differences in content and emphasis and we indicate below where this is apparent.

Life prolonging technologies

Overarching the focus group responses to materials on resuscitation and artificial feeding, was a consensus that the availability of life prolonging interventions should not make their use automatic. Many participants had direct experiences of these technologies but felt that they understood poorly the clinical, ethical and legal framework within which these technologies are used, withheld or withdrawn. This was perceived to threaten opportunities for developing the trusting relationships between patients, carers and clinicians identified as a prerequisite of good quality end of life care. Views about the roles of the family and clinical staff in decision making about life prolonging technologies did not correspond to available guidelines and current law, particularly in relation to participants’ beliefs that family should be able to ‘veto’ particular types of treatment on behalf of older people and, as such, significantly influence the character of the dying trajectory. In spite of this, many participants found it difficult to discuss such issues with their families and had not done so. Addressing these issues through a programme of public education 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 together informed choices about these aspects of care delivery.

We turn now to examine specific issues arising from discussions about resuscitation and artificial feeding.

Resuscitation.

Following analysis of the way in which focus group participants’ responded to material about resuscitation as a technology of life support, subsequent attention in the interviews during phase 2 was directed at understanding participants’ views about the issue of whether decisions about resuscitation should take place between doctors and their seriously ill patients. The first vignette (see
appendix one) was designed to allow exploration of this. Reasons identified for doctors discussing resuscitation, which were expressed by the majority, were because it:

- Reduces uncertainty and gives patients information about their bodies that should be a basic human right.

- Gives information which provides people with the decision making capacity to decide about resuscitation for themselves if they wish.

- Has the potential to open up an opportunity to help patients and their families begin to explore death and dying together.

- Helps the doctor do a ‘good’ job, since the ideal doctor-patient relationship was perceived to be based on respect and mutual understanding.

However, a minority of participants felt strongly that doctors should not discuss resuscitation with patients because they perceived that ill and dying people need protecting from the ‘burdens’ of receiving ‘bad news’ and of assuming responsibility for decision-making. Those taking this position were of the view that dialogue should only occur between the doctor and an informal carer, with the latter seen as adopting the role as a protective advocate or ‘proxy’ for the patient. Our analyses to date suggest participants from the more deprived localities placed emphasis upon the role of family carer standing as ‘proxy’ and ‘protector’ of the ill person, whereas others emphasised instead an individuals’ right to self-determination. We intend to examine this further in subsequent work, and disseminate these findings at forthcoming meetings of clinicians since we are aware of the very high levels of anxiety among health professionals about how to share resuscitation decisions with patients and their family carers.

Artificial feeding

During focus groups, participants were invited to comment on a simple ‘aide memoire’ in which key themes were presented in words and pictures in slides projected on a portable screen. A simple synopsis of the Anthony Bland\(^1\) case was used as a resource to ‘open up’ a discussion about the role of artificial feeding in dying people. All of the focus participants had heard of the case of Tony Bland, and some had strongly negative feelings about the role of artificial feeding in his care. This was valuable insofar as lively debates were generated around a subject that might otherwise have been difficult to discuss. A disadvantage may have been that attitudes to his situation were heavily influenced by recollections of the media coverage of the polarised debates that occurred at that time.

Many participants drew on personal experiences to express complex and sometimes paradoxical understandings of the boundaries between ‘body’ and ‘person’, between ‘life’ and ‘death’, and between ‘artificiality’ and ‘natural’. Much discussion focused on the ‘proper’ roles of, and relationships between families and clinical staff in end of life decisions, and to the expression of expectations about how participants’ families should act to represent them in the event of their serious illness. There was recognition that the application of technological innovations to the management of dying had 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. Participants made clear their views that all parties had to work together to establish the best course of action in impossible circumstances. However it was recognized that, in these new circumstances, families had to be ready to assume a degree of responsibility for representing their

---

\(^1\) A simple synopsis of the Anthony Bland case was used as a resource to ‘open up’ a discussion about the role of artificial feeding in dying people. Anthony Bland was a 19-year-old man crushed in the Hillsborough football disaster of 1989. He remained in a persistent vegetative state until 1994 when, at the request of his parents and following a prolonged legal battle, his feeding tube was withdrawn and he died. The disaster that led his eventual death took place in the city in which the study was located. The case was well remembered by all the study participants.
dying relative, and that new risks were associated with this. Most importantly, participants recognized the difficulties of establishing whether a particular course of action constituted euthanasia or ‘letting go’, and recognized significant threats to the ‘proper’ relationship between family members. Some participants made repeated references to the role of ‘God’ and ‘prayer’ in aiding difficult end of life decisions or in negating the need for human intervention in difficult situations, while others reflected on the meaning of ‘quality of life’ and how this could be assessed.

We designed vignette 2 (see appendix 2) to explore further issues relating to artificial feeding in the individual interviews. Our preliminary analyses suggest that similar issues to those identified by focus group participants are raised, with many interviewees make finely balanced distinctions between ‘living’ and ‘not living’ or ‘just existing’ and ‘quality of life’. They also identify that while artificial feeding may be instituted to help a person or to relieve the anxieties of their family, it may lead to an interruption of the ‘natural day’ or process of dying. Ideas about death with dignity are raised, particularly by some of the oldest participants who voice fears that prolonged artificial feeding could interfere with their desire for dignity during dying. The theme of comfort is visible in these data, with many participants identifying that the sight of a feeding tube would be discomforting for one’s family since it would constitute a bodily invasion which would be difficult to witness. A variety of potential physical or bodily discomforts for the dying person were identified: feelings of choking, soreness and restriction. In connection with the issue of restriction, a few participants draw parallels between artificial feeding and ‘force feeding’.

Basic care technologies

Location of care
Both focus group and interview participants identified home as the preferred place to be cared for at the end of life in ideal circumstances because of its symbolic meanings: the presence of loved ones, independence, familiarity and as a repository of memories. However a range of practical and moral problems associated with care at home were recognised: 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 and as transforming ‘home’ into a form of institutional care setting.

Within the focus group data particularly, themes relating to change over time are highly visible with many of the female discussants exploring how they do not want their daughters to have to engage in caring in the way that they themselves (and their mothers) were once expected to do. In the follow up discussion day of this issue, participants emphasised this issue again and, in so doing, noted that: i) caring for the dying is not necessarily a ‘natural’ skill but rather something that requires a degree of training or is acquired through experience that is lacking in contemporary society; and ii) that the older age of many informal carers means that the issue of ‘care for the caregiver’ is of critical importance. Some participants who were in their mid to late seventies had caring responsibilities for relatives in their nineties.

Attitudes towards receiving care in other settings (we focused upon hospital, hospice and nursing/residential care) were mixed. For example, while many participants were very positive about hospices, few had personal experience of hospice care and there were concerns about their obvious relationship with death. To this extent, hospices were referred to either in highly idealised terms or in highly negative terms. Hospitals were seen to provide high quality technical care, and as such were seen as repositories of specialist care for acute illness and for pain and symptom relief. Some participants identified that the perceived drive to keep older people out of hospital care was potentially denying them such ‘specialist’ attention. However, many participants reported negative experiences of basic care provided within the hospital setting, for example in relation to hand feeding (see also above) and the provision of comfort. Mirroring issues that arose from the discussions about home care, hospitals were also reported as invoking ‘strangeness’ or ‘impersonal’ bodily care from strangers who are paid to do a job.
The provision of pain relief and comfort

The terms ‘comfort’ and ‘love’ were used to describe good care during dying by participants in both the focus groups and the interviews, and participants understood an idealised death to be that in which pain relief and, where necessary, terminal sedation serve to provide dying people with an easy, comfortable and quiet death. In this, bodily symptoms of distress are discreetly controlled and death occurs at an appropriate time and place. Experiences of bereavement were drawn upon by many participants to describe how they understood the role of pain relief and sedation during dying. In these, the distinction was made by many between ‘making the passing as easy as possible’ and hastening death by euthanasia. However, not all participants drew a distinction between the proper use of sedation to ensure comfort during dying in the way that dying people and their families may desire, and an improper hastening of death. Some expressed a lack of understanding about what doctors were permitted to do, and whether or not the provision of pain relief and terminal sedation was actually a form of euthanasia. Many participants were aware that doctors might be worried about causing euthanasia, and a few mentioned the case of Harold Shipman in relation to perceived heightened professional anxieties. Some felt that such anxieties might mean that adequate symptom relief was now harder to obtain.

The experience of pain was seen as making it difficult for dying people to control their own lives and to make choices: in particular, it was seen as leading to an unwanted admission to hospital. While many participants believed that it may be easier to get good pain relief in hospital or in hospices, some were concerned that hospital staff may not listen to them or to their relatives when they were in pain, or that they might find it difficult to ask for pain relief. Some participants’ gave accounts of struggling to get adequate pain relief for their dying relatives which feature perceptions of powerlessness vis a vis clinical staff, and lack of knowledge about pain and symptom control. Dying people with dementia were described as at particular risk of suffering from unrelieved pain: one participant referred to the ‘double jeopardy’ of old age and cognitive impairment.

Advance statements

We explored the issue of advance statements in the focus groups by means of an extract from the Alzheimer’s Society Newsletter and by referring verbally to the BMA guidelines. We attempted to pursue this in the individual interviews by asking interviewees what they thought about the idea of

2 In some circumstances dying people experience what clinicians define as ‘refractory symptoms’ that are unresponsive to therapies normally capable of giving control while not clouding consciousness. Dyspnoea, severe pain, agitation and persistent vomiting have been identified as typical problems which may become unendurable for dying people in the last few days of life. In such circumstances, the practice of ‘terminal sedation’ may be used. By this means dying people in acute and enduring distress are rendered unconscious until death occurs. There is a debate in the clinical literature about this practice, its nomenclature and its risks and benefits.

3 Shipman was a GP in Greater Manchester who was convicted in 2001 of the serial murder of predominantly elderly female patients. His method of killing was by the administration of intravenous diamorphine.

4 A precise definition of advance statements is provided by the British Medical Association publication of 1995; ‘Advance Statements about medical treatment’ pp3-4: ‘A n advance statement (sometimes known as a living will) can be of various types.

- A requesting statement reflecting an individual’s aspirations and preferences...
- A statement of the general beliefs and aspects of life which an individual values
- A statement which names another person who should be consulted at the time a decision has to be made... the named person’s views are not legally binding in England and Wales. In Scotland the powers of a tutor dative may cover such eventualities.
- A clear instruction refusing some or all medical procedures (advance directive). Made by a competent adult, this does, in certain circumstances have legal force.
- A statement which, rather than refusing any particular treatment, specifies a degree of irreversible deterioration (such as diagnosis of persistent vegetative state) after which no life sustaining treatment should be given. For adults, this can have legal force.
- A combination of the above, including requests, refusals and the nomination of a representative. Those sections expressing clear refusal may have legal force in the case of adult patients.
writing down wishes in advance of illness, in relation to the issue of artificial feeding in vignette 2 (see appendix 3). In the latter, a verbal explanation was also given. Very few participants had heard of advance statements however, and this made it difficult for them to express any views. Where participants were able to express beliefs about this issue they perceived advance statements primarily in terms of their potential to aid personal integrity and to help the families of dying people by reducing the perceived ‘burden’ of their decision making. However, concerns were expressed about the perceived link between advance care statements and euthanasia, their future applicability, and the possibility that preferences for care may change. Participants also reported worries and difficulties related to thinking about and discussing death and dying. Trust between doctor and patient, built up over time, was perceived to be important in creating an environment in which the communication necessary to underpin advance care planning could take place. Lastly, participants did not perceive that during dying they would be ready necessarily to adhere to an advance statement and ‘disengage’ from their lives. We conclude that, rather than emphasising the completion of advance statements, it may be preferable to conceptualise advance care planning as a process of discussion and review between clinicians, patients and families.

**Constructing Natural death: some (preliminary) key themes**

- Love, comfort and the relief of suffering
- Meeting family obligations
- Protecting bodily and personal integrity
- Avoiding euthanasia
- Providing support and training for carers
- Identity, independence and ‘home’
- Death at the right time
- Understanding, knowledge and trust

**Activities**

Emergent findings and methodological issues have been selected for presentation at ten conferences in the UK, and at five European meetings to date; two poster prizes have been awarded. The project has been selected to participate in a IHT Programme event on ageing, technology and the built environment (May 29th, 2003).

An exchange fellowship between the Universities of Sheffield and Nijmegen during 2003/4 has been awarded by the IHT programme, focusing on the issue of terminal sedation. We are in receipt of further invitations to talk about the project findings at the University’s of Nottingham and Liverpool.

We designed an email newsletter about the project and sent this out to a data base of ‘users’. This has resulted in a number of enquires: most notably we have been asked to advise (with colleagues) researchers appointed by ‘Help the Aged’ and ‘Age Concern’ to review the state of knowledge in end of life care for older people, and to consider how to open discussions about end of life care with older people. We hope that this will lead to further collaboration.

On March 12th 2003 we held a meeting to provide an opportunity for the older people who had taken part in the research to meet with one another and the research team. A brief outline was presented of some of the main findings of the study. Conference attendees had a chance to comment on these findings and to share with one another their experiences of taking part in a research project. A clear message articulated during the day was the need to open up to wider debate what are the elements of good care and comfort at the end of life, and for recognition of the role that older people have in caring for the dying, and their need for training and support in doing this.
Most notably, the conference demonstrated clearly the capacity and willingness of older research participants to discuss these sensitive matters in a lively and engaged way, and to enjoy the process of doing this.

**Outputs**

- Two data sets (focus groups and interviews) have been offered to the Data Archive.
- Articles published in 'The Guardian' and in the Newsletter of the National Council for Hospice and Specialist Palliative Care. We will be publishing a further article in SAGA magazine on the advice of research participants.
- Five abstracts, two papers in peer reviewed journals and one book chapter have been published. Two further papers are under review, and another two papers are in preparation.
- Providing advice to an education project at the University of Sheffield which aims to improve nurses’ skills in talking to older people about end of life care.
- Two further research projects have been funded which build on aspects of this study:
  - Two other related projects are under review by the PPP Foundation and the British Heart Foundation.

**Impacts**

The impact of the research can be demonstrated in a number of ways:

- Providing new advice and guidelines on palliative and end of life care, especially to nursing and clinical practitioners and to those being trained in the area, and to voluntary sector organisations as they begin to assess the need for action in this field.
- Developing new methodologies for social science for a highly demanding and ethically sensitive field of research.
- Through a highly inclusive research strategy, respondents reported on the immediate value of the project to their own personal care needs.
- Identification of needs for public education and information in ethics at the end of life.
- Drawing together issues previously considered under the largely separate remits of palliative care and gerontology: it suggests important areas of joint action and inquiry.
- Informing discussions about Sheffield’s local strategies for palliative and end of life care through liaison with care providers in the region: the new research bids referred to above have been prepared in collaboration with the latter.
- Contributing to the IHT Programme’s themes on the social management of health, especially in regard to improving our understanding of the locational preferences of terminal care.

**Future research priorities**

This project forms part of a programme of research in palliative and end of life care in which the co-applicants and other colleagues are involved. The methodological approach used in this project
informs a related study examining the views of older Chinese people about cancer and end of life care. The project is also directly linked to a further study in the IHT programme (see above). New research proposals have been submitted for review concerning: 1) the development of a peer education initiative for older people in advance care planning and related issues; and 2) the development of a structured interview template that GPs can use to address issues of prognosis and end of life preferences/ concerns with patients with severe heart failure. We also intend to pursue work in collaboration with colleagues about: place of care preferences at the end of life, and issues surrounding the care of the ‘oldest old’.

References

APPENDIX 1

Article published in the Newsletter of the National Council for Hospice and Specialist Palliative Care, 2003

Technology and ‘Natural’ Death: a study of older people

On March 12th 2003 Sheffield Palliative Care Studies Group, at the University of Sheffield held a conference to mark the end of their 2 year research project. Led by Dr Jane Seymour, the study explored older people’s knowledge, views and risk perceptions regarding the use of health technologies during care at the end of life. The project was funded by the Economic and Social Research Council and the Medical Research Council within the Innovative Health Technologies Programme (IHT) at the University of York: http://www.york.ac.uk/res/iht/. The day provided an opportunity for the older people who had taken part in the research to meet with one another and the research team. A brief outline was presented of some of the main findings of the study. These included views about: place of care at the end of life; making difficult decisions about end of life care; discussion of decisions about resuscitation; and ideas about pain relief and comfort. Conference attendees had a chance to comment on these findings and to share with one another their experiences of taking part in a research project. A small number of researchers, clinicians and others who had expressed an interest in the findings of the study were also invited. A clear message articulated during the day was the need for a ‘back to basics’ approach towards care and comfort at the end of life, and for recognition of the role that older people have in caring for the dying, and their need for training and support in doing this. Most notably, the conference demonstrated clearly the capacity and willingness of older research participants to discuss these sensitive matters in a lively and engaged way, and to enjoy the process of doing this.

Also invited this one day event was Professor Andrew Webster, IHT Programme Director. In his closing remarks he made special reference to the seventy seven older people from Sheffield who took part in the project, thanking them for their participation. Professor Webster said he would be taking a positive message about the conference to the other projects within the Innovative Health Technologies Programme, and recommending that they invited their research participants to similar events.
APPENDIX 3

Two vignettes used in individual interviews.

The main text was put onto large pieces of card and given to the interviewees. Pictures were used (see separate mailed PowerPoint slides). The researcher also read out the text. The prompt questions were used when this was appropriate for each interviewee.

Vignette A.

Frank is 75 years old and has lung cancer. He knows that he has not got long to live, but his doctor says it is impossible to say how long. He lives at home with his wife, Susan, who is also 75. He receives visits from the district nurse several times a week, who comes to see how he is. Frank and Susan also have a home help provided by social services, and get a weekly visit from a volunteer from Age Concern.

- How do you think Frank and Susan feel about all these different people coming into their home?
- In your opinion, what kinds of things are most important in helping Frank to stay at home?
- Is there any help that he and Susan need that they are not receiving?
- Under what circumstances do you think Frank might have to leave home to be looked after somewhere else?
- Do you think it is likely that Frank would ever want to leave home?

One morning, Frank suddenly becomes very breathless. Susan calls for an ambulance and he is admitted to hospital, where he is given oxygen and some fluid is drained from his lung. This makes him feel more comfortable.

That afternoon, a doctor comes to talk to Frank about his treatment. The doctor knows that he should find out Frank’s views about resuscitation in case Frank was to collapse suddenly while in hospital. He tries to explore this issue with Frank.

- Is the doctor right to try to discuss resuscitation with Frank?
- Is there a right way to discuss this?
- Do you think that Frank would want to be resuscitated?
- Is it natural to want to prolong life at all costs?

After a few days, Frank starts to feel a bit better, but he is weak and he is getting a troublesome pain from the cancer in his lung quite often now. A specialist cancer nurse comes with the doctor to visit him on the hospital ward. They discuss with Frank a number of different things that can be done to help his pain.

- Which do you think Frank would prefer if he has a free choice? Why?
- What might be the good or bad things associated with these methods?
- Is it right for the doctor and nurse to discuss pain relief with Frank?

Frank has morphine in a syringe driver and this controls his pain well. He wants to return home although he is offered a place in the local hospice. The hospital arrange for a nurse from the hospice to visit him at home. The hospice nurse helps Frank and Susan by giving them time to talk about things that worry them, and also checks that Frank is comfortable.

- Do you think Frank is right to return home?

Frank gradually starts to worry about what will happen as his life draws to a close. The hospice nurse realises he is worried and they discuss his fears. One of the things they talk about is the use of sedative drugs, which can keep Frank asleep as death approaches. Sedatives are different from pain killers. They are used to reduce anxiety and make people sleepy.
Frank tells the nurse that he wants to die as naturally as possible.

- What do you think Frank will be thinking about when he talks about dying naturally?

Vignette B

Margaret is 75 years old. She has had Alzheimer's disease for five years. She now lives in a nursing home. Margaret cannot communicate very well and often gets confused. Her husband John, who is the same age, visits her frequently. He is fit and healthy. Margaret and John have a daughter, Ann, who lives some distance away. Ann visits when she can.

- How do you think that Ann and John feel about this?
- Do you think the nursing home is the right place for Margaret to be?

One day John gets a call from the nursing home. Margaret, who has been unwell for a few days, has got much worse. Margaret is admitted to hospital with a suspected stroke. When John and Ann visit she appears restless and only semi-conscious. After a few days Margaret's condition improves slightly but she appears more confused than before and cannot eat or drink without choking. She has an intravenous drip up. The doctor responsible for Margaret's care asks to speak to John and Ann to discuss her treatment. He wants to start to feed her through a tube.

- How do you think John and Ann will respond to this?
- What kind of things do you think they will be thinking about?
- What kind of things do you think would contribute to Margaret's quality of life?
- Do you think that this kind of feeding is a natural thing to do?
- Are there any circumstances in which this kind of feeding should be stopped?

Ann and John tell the doctor that Margaret had told them of her fear of being kept alive by tube feeding when she was first given her diagnosis of Alzheimer's disease 5 years ago and on one occasion had said to John she would want to be put to sleep. However, the doctor cannot act on this information because Margaret had never written anything down about this.

- What do you think about people talking about and writing down their wishes about treatment preferences in serious illness?
- What might be the benefits/ disadvantages of doing this?
- How do you think the doctor and Margaret's family should resolve this problem?
- Do you think having this sort of discussion can help people have a 'natural' death?
- If Margaret was able to express an opinion about what was happening to her, what do you think she would say?
- Do you think that she would now want to be treated?
APPENDIX 4

Extract from the British Sociological Association Statement of Ethical Practice
RELATIONSHIPS WITH RESEARCH PARTICIPANTS

[a] Sociologists have a responsibility to ensure that the physical, social and psychological well-being of research participants is not adversely affected by the research. They should strive to protect the rights of those they study, their interests, sensitivities and privacy, while recognising the difficulty of balancing potentially conflicting interests. Because sociologists study the relatively powerless as well as those more powerful than themselves, research relationships are frequently characterised by disparities of power and status. Despite this, research relationships should be characterised, whenever possible, by trust. In some cases, where the public interest dictates otherwise and particularly where power is being abused, obligations of trust and protection may weigh less heavily. Nevertheless, these obligations should not be discarded lightly.

[b] As far as possible sociological research should be based on the freely given informed consent of those studied. This implies a responsibility on the sociologist to explain as fully as possible, and in terms meaningful to participants, what the research is about, who is undertaking and financing it, why it is being undertaken, and how it is to be promoted.

(i) Research participants should be aware of their right to refuse participation whenever and for whatever reason they wish. They should also not be under the impression that they are required to participate.

(ii) Research participants should understand how far they will be afforded anonymity and confidentiality and should be able to reject the use of data-gathering devices such as tape recorders and video cameras.

(iii) Where there is a likelihood that data may be shared with other researchers, the potential uses to which the data might be put may need to be discussed with research participants.

(iv) When filming or recording for research purposes, sociologists should make clear to research participants the purpose of the filming or recording, and, as precisely as possible, to whom it will be communicated. Sociologists should be careful, on the one hand, not to give unrealistic guarantees of confidentiality and, on the other, not to permit communication of research films or records to audiences other than those to which the research participants have agreed.

(v) It should also be borne in mind that in some research contexts, especially those involving field research, it may be necessary for the obtaining of consent to be regarded, not as a once-and-for-all prior event, but as a process, subject to re-negotiation over time. In addition, particular care may need to be taken during periods of prolonged fieldwork where it is easy for research participants to forget that they are being studied.

(vi) In some situations access to a research setting is gained via a ‘gatekeeper’. In these situations members should adhere to the principle of obtaining informed consent directly from the research participants to whom access is required, while at the same time taking account of the gatekeepers’ interest. Since the relationship between the research participant and the gatekeeper will continue long after the sociologist has left the research setting, care should be taken not to inadvertently disturb that relationship unduly.

[c] It is incumbent upon members to be aware of the possible consequences of their work. Wherever possible they should attempt to anticipate, and to guard against, consequences for research participants which can be predicted to be harmful. Members are not absolved from this responsibility by the consent given by research participants.

[d] In many of its guises, social research intrudes into the lives of those studied. While some participants in sociological research may find the experience a positive and welcome one, for others, the experience may be disturbing. Even if not exposed to harm, those studied may feel wronged by aspects of the research process. This can be particularly so if they perceive apparent intrusions into their private and personal worlds, or where research gives rise to false hopes, uncalled for self-knowledge, or unnecessary anxiety. Members should consider carefully the possibility that the research experience may be a disturbing one and, normally, should attempt to minimise disturbance to those participating in research. It should be borne in mind that decisions made on the basis of research may have effects on individuals as members of a group, even if individual research participants are protected by confidentiality and anonymity.