

# Place of Death in the Morecambe Bay Area

Patterns of  
and preferences  
for place of final  
care and death  
among terminally  
ill cancer patients  
and their carers

An end of  
project report

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# Executive summary

## 1. Objectives

- 1.1 This project set out to answer four research questions:
- Where do cancer patients die in the Morecambe Bay area (MBA) – at home, in hospice, in hospital, or elsewhere?
  - Why do they die in these locations?
  - What are patient and carer preferences for place of death in the MBA?
  - Does the place of death match patient and carer preferences?

In answering these questions, an understanding was developed of: i) the nature of patient and carer preferences for place of death in the MBA, ii) the factors that shape these preferences, and iii) the factors that influence the actual locations of patient deaths.

## 2. Study Setting and Methods

- 2.1 **Study site:** The area formerly served by Morecambe Bay Health Authority, comprising Barrow-in-Furness and Ulverston, South Lakes and Kendal, Lancaster and Morecambe.

2.2 **Methods:**

Actual place of death patterns were identified through data collection and analysis as follows:

- Area and individual level statistical analysis of the location of 6,900 cancer deaths in the MBA (data from ONS mortality data files, 1993-2000).
- Semi-structured interviews (n=16) with health professionals and associated workers involved in the delivery of palliative services in the MBA, to establish the scope of specialist palliative care service provision.
- Patient (n=41) and carer (n=18) interview series on the circumstances surrounding end of life care and actual place of death for a cohort of 41 terminally ill cancer patients located across the MBA.

Patient and carer place of death preferences were identified through the analysis of the two interview data sets to:

- establish patients' preferences and preparations for end of life care in the context of illness management, social circumstances and informal care arrangements, and service use and evaluation.
- establish professionals' knowledge about, and perspectives on, patient and carer preferences, and to identify professionals' views concerning the 'ideal' place of death arrangements for cancer patients.

## 3. Principal findings

3.1 **Actual place of death**

The proportion of cancer deaths that occur at home in the MBA (24% among interviewed patients; 22% of 6,900 cancer deaths occurring between 1993 and 2000) is close to that found nationally (26%). The marked difference between MBA and national place of death patterns is found in the low proportion of patients who die in hospital

(35% vs. 55%) and the high proportion that die in hospice (33% vs. 17%). In combination, the average home death rate, the above average hospice death rate, and the below average hospital death rate in the MBA mean that MB cancer patients have a greater opportunity to die *in hospice rather than in hospital* than is the case nationally. This is associated with Morecambe Bay's unusually high number of hospice beds per capita, although this is skewed markedly in favour of the Lancaster locality (St John's Hospice).

### **3.2 Preference for place of death**

It is now a conventional wisdom that most cancer patients would prefer to die at home, and this is reflected in the push towards the greater facilitation of deaths at home in current palliative care policies at national and local Cancer Network levels. Findings from our patient interviews support this: the greatest single preference was for a home death (36%). However, as a sole preference, this home preference is lower than would be expected from other studies. What differentiates this study more notably, however, are the findings that an additional 32% of interviewed patients held an equal preference for a home *or* hospice death, and that no patient wished to die in hospital. *Thus, patient preferences in this study were overwhelmingly in favour of either a home or a hospice death.* We would have to qualify any endorsement of a strong policy push towards home deaths by pointing to an almost equal preference for death in hospice.

### **3.3 Do preferences for place of death match outcomes?**

Among interviewed patients, not all of those who wished to die at home were able to do so (interpretative caution is required given the small sample size). In contrast, all patients who wished to die in hospice were able to do so. If a patient had an equal preference for a home or hospice death their preference could be met in all cases, but these deaths were overwhelmingly accommodated in hospice rather than at home. Despite not wanting to die in hospital, a fifth of patients did end their lives in one of the three hospitals in the MB area.

The chances of dying in hospital vary across the MBA. The statistical analysis of 6,900 cancer deaths found that patients living in the Barrow area were 84% *more* likely to die in hospital, while those in the Kendal district were 68% *more* likely to do so, than those living in the Lancaster district. Conversely, patients living *outside* the Lancaster district were between 36% and 51% *less* likely to die in a hospice than those living within the Lancaster district.

### **3.4 Do place of death patterns in the MBA suggest social inequality in place of death options?**

This study did not find an association between the proportion of deaths at home and patients' socio-economic status (as measured by ward affluence/deprivation). A positive association was found between the proportion of deaths in hospital and deprivation, and there was an inverse relationship between the proportion of deaths in nursing homes and deprivation. In common with other studies, associations between gender and age and place of death were found. Men are more likely to die at home but gender has no effect on the likelihood of death in hospice. Women are more likely to die in nursing homes. Younger patients are more likely to die at home or in a hospice, while older cancer patients are more likely to die in hospital. Thus there is evidence of social inequality in place of death options for cancer patients.

### **3.5 Factors that influence actual place of death**

The analysis of data from the three data sources has produced a list of factors that influence the place of death of cancer patients in the MBA. In headline form, these factors are as follows:

<b>Factors influencing actual place of death</b>
Service provision and usage, including proximity to services.*
Carer's capacity to care.*
Changes in hospice services (towards day-care and higher patient throughput).
Symptom management.
Patient's social circumstances.
Patient and carer attitudes to death and dying, and the strength of their place of death preference.
Patient gender.
Patient age.
Patient socio-economic status.
Tumour type.
The historical trend towards an increased proportion of patients with complex needs.

\* Factors of greatest influence.

### 3.6 *Factors that influence preference for place of death*

The analysis of data from two of the data sources (professionals' interviews, patient and carer interviews) has produced a second list of factors associated with patient and carer preference for place of death in the MBA. The identification of these factors adds considerably to current knowledge in this field. In headline form, these factors are as follows:

<b>Factors associated with patient and carer preference for place of death</b>
Patient concern for the welfare of the carer/family.
Patient's assessment of the carer's capacity to care.
Patient's fear of loss of dignity
Symptom management.
Patient's social circumstances.
Patient and carer perceptions of the reliability of services, and the degree of 'safety' they offer.
Patient's attitude to a hospice
Patient's knowledge and experience of hospitals.
Patient's knowledge and experience of community services.
Patient's attitude to nursing homes.
Patient's attitude to, and outlook on, death and dying, including their religious faith.
Previous personal experience of death and dying.
Carer's attitudes and willingness to care.

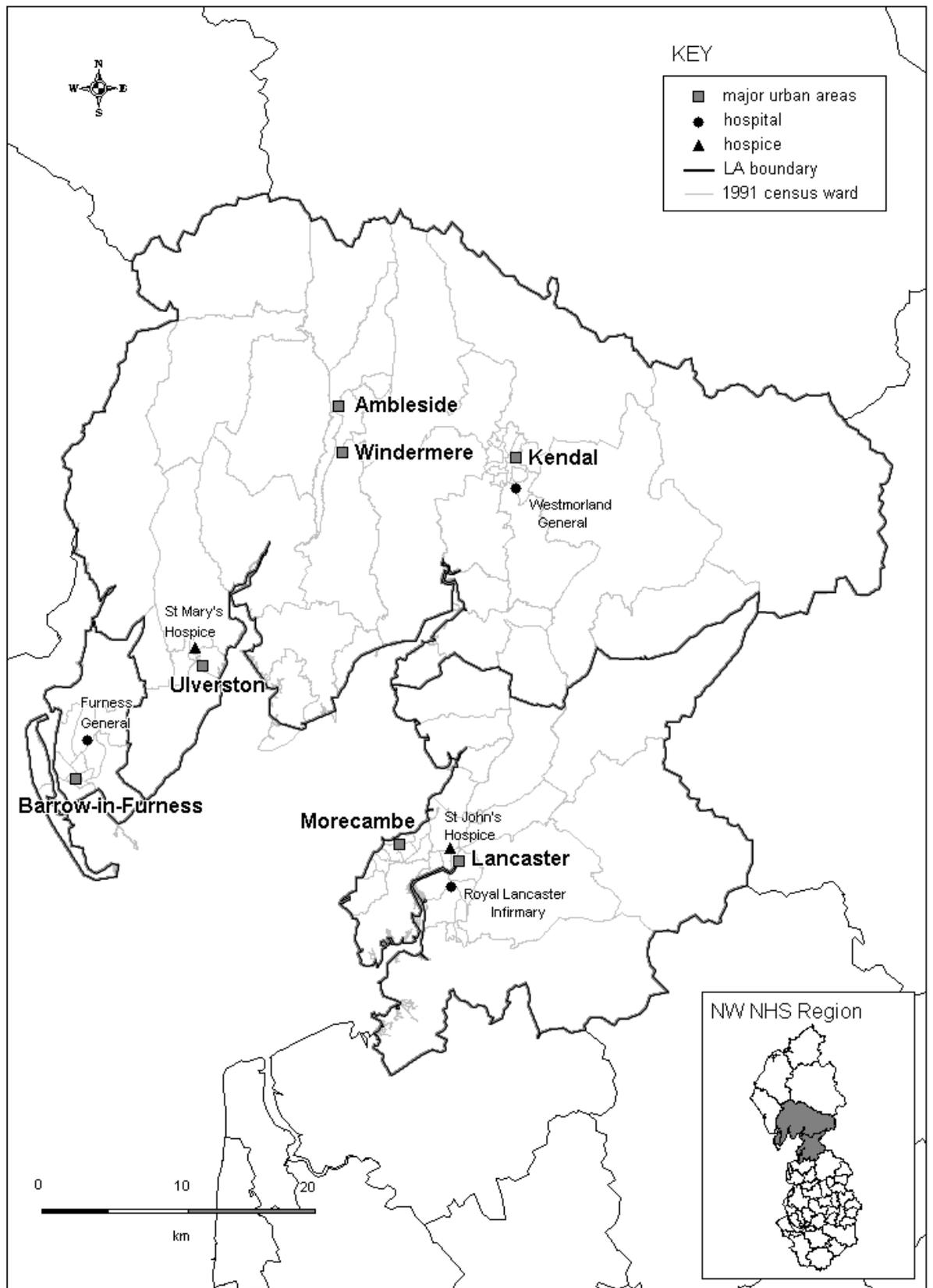
## 4. Recommendations

Most of these recommendations are formulated for service commissioners and providers in the Morecambe Bay area. However, they will also be of interest and relevance to a wider audience of professionals, academics and lay people involved with palliative care services.

- 4.1 Service commissioners and providers in the MBA should note that it is not generally the case that the MB hospices re-direct patients from home as a place of death to hospice, but that the re-direction is from hospital to hospice.
- 4.2 In the main, cancer patients in the MBA would prefer to die either at home or in hospice. Services should be in place to accommodate these preferences.
- 4.3 If patients' place of death preferences are to be met, specialist and non-specialist palliative care services in all parts of the MB area will require development and reconfiguration so that patients are enabled to die at home in greater number, and are

- supported in avoiding a hospital death (unless that is their preference). This would begin to reverse the long-term trend away from home deaths.
- 4.4 The community services in greatest need of development are: 24-hour district nursing services; out-of-hours on-call specialist palliative care services; all-week Marie Curie night sitting services; more comprehensive Social Services support.
- 4.5 The high level of preference for a hospice death found in this study indicates that the current level of hospice bed provision in the MB area should be sustained. Thus, the development of community based services to support a greater number of home deaths as recommended above should not be at the expense of hospice beds.
- 4.6 The geographically skewed nature of hospice bed provision within the MB area is problematic, resulting in an increased chance of dying in hospital as one moves from Lancaster, through Kendal and westward to Barrow. Service commissioners and providers should examine the possibilities for equalising access to hospice beds across the MB area.
- 4.7 Support for informal carers should be maximized so that carers can, in turn, support a home death, if that is the patient and carer preference.
- 4.8 In assessing the patient's need for formal health care and Social Services, health and social care professionals should gain a full understanding of the contours and dynamics of the social relationships involved in the patient's social setting. The informal care resource has to be assessed (and re-assessed over time) so that it can be worked with to optimal effect. This would be of benefit to both patients and carers.
- 4.9 Professionals should be responsive to the particular needs of a carer dealing with a patient with high levels of emotional distress and/or cognitive deterioration.
- 4.10 Professionals working with patients should seek to identify and understand the preference for place of death that both patients and carers hold, and should be alert to tracking any change in preference. In doing this, it should be recognised that patients take many considerations into account, and that preferences are formed in the light of patients' personal histories and current social relational contexts.
- 4.11 In the MBA, home and hospice deaths are not differentially patterned by socio-economic status. However, deaths in hospitals and nursing homes do show such variations. These and other social variations found in place of death (gender, age, proximity to services) should be addressed because some of them amount to health care inequalities in the face of the overwhelming patient preference for either a home or hospice death.
- 4.12 In developing services, commissioners and providers should take account of the full range of factors that influence actual place of death, detailed in the study Report.
- 4.13 In developing services commissioners and providers should take account of the full range of factors that influence patient and carer preferences for place of death, detailed in the study Report.
- 4.14 Increased opportunities and incentives for training in palliative care should be made available to GPs in the MBA.
- 4.15 Out-of-hours services in the MBA should receive assistance in developing their palliative care capacity (especially: training of staff, availability of specialist drugs).
- 4.16 Hospital services in the MBA should be assisted in improving the quality of end of life care.
- 4.17 Professionals in close contact with patients should be aware that many patients want, but are unlikely to ask for, more explicit and detailed information about the course of their disease, about the symptoms that are likely to occur, and about the signs that indicate that death is fast approaching. Professionals may need support/training in identifying and responding to this need.
- 4.18 Service commissioners and providers in the MBA should give full consideration to extending specialist palliative care services so that patients with non-malignant conditions have an equal opportunity to access these excellent services.

# The Morecambe Bay Area



## Acknowledgements

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# Chapter 1

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## Introduction

This study has taken place at a time of rapid change and development in specialist palliative care service policy and planning frameworks, both nationally and locally. As well as attempting to retain our focus on place of death matters in the Morecambe Bay area (MBA) (the area covered by the former Morecambe Bay Health Authority (MBHA)<sup>1</sup>), we have tried to keep abreast of both the surrounding re-configuration of health service structures (PCTs, Strategic Health Authorities, Cancer Networks and so forth) and the new national policies and priorities for palliative care provision that have issued forth. The project proposal first began to take shape in 1998, with the backing of Morecambe Bay Health Authority, but by the time the project team had secured funding and commenced the study in October 2000, change in the statutory health service landscape was already underway. These contextual points are significant because one of the key study objectives was ‘to assist in the development of a palliative care strategy by MBHA’. We now find ourselves producing a final Report for a local audience of service commissioners and practitioners who are located in, or relate to, new organisational structures with new priorities. With this in mind, we have attempted to produce a Report that is of utility to the re-configured local audience. And, as was always our intention, we present findings that will be of interest and relevance to a much wider audience of policy makers and practitioners in UK specialist palliative care arenas.

The project set out to address four research questions:

- Where do cancer patients die in the MBA – at home, in hospice, in hospital, or elsewhere?
- Why do they die in these locations?
- What are patient and carer preferences for place of death?
- Does the place of death match patient and carer preferences?

The stimulus for this examination of place of death patterns and preferences was the recognition by MBHA<sup>2,3</sup> in 1998 that there were marked variations in where cancer deaths occurred across the district, and that the district’s place of death profile differed notably from that for England and Wales. MBHA<sup>2</sup> reported that:

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<sup>1</sup> Morecambe Bay Health Authority (MBHA) ceased to exist in April 2002 following the re-configuration of English Health Authorities. MBHA merged with other HAs to form a new Strategic Health Authority for Cumbria and Lancashire. We shall refer in this report to the area formerly covered by MBHA as the Morecambe Bay area (MBA).

<sup>2</sup> MBHA (1998)a Strategy for the development of palliative care services. Kendal: MBHA

<sup>3</sup> MBHA (1998)b Palliative Care. Kendal: MBHA

- Nationally, 55% of cancer patients die in hospital, 17% in hospice, and 26% at home (1993 E&W).
- In MBHA in 1996: 34% of cancer deaths occurred in hospital, 36% in hospice, and less than 20% at home.
- Of those dying of cancer in MBHA (1996), hospice deaths accounted for: 23% of deaths in Furness and South Lakes; 28% in Kendal, and 48% in Lancaster. Only 10% died at home in Morecambe, compared with 16% in Kendal, 19% in Lancaster, 29% in South Lakes, and 24% in Furness.

The relatively high proportion of hospice deaths among cancer patients in Lancaster and Kendal stood out (there are two hospices in the MBA, one in Ulverston and one in Lancaster). MBHA noted that ‘The reasons for these differences need to be understood before any major service changes are planned.... These figures show that the number of patients dying at home is lower than national averages. This may be the result of patient preferences and may reflect the development of hospice services’.<sup>2</sup> So, did the high proportion of hospice deaths in parts of the district reflect patient preferences for place of death? Or would patients prefer greater opportunity to receive specialist community based services that could sustain them at home through to the end of life? These and associated concerns led a team of independent academic researchers at Lancaster University to draw up proposals for the current research project<sup>4</sup>.

<b>Project objectives – as set out in the original research proposal</b>
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In summary, the project objectives outlined in the research proposal were as follows (see Appendix 1 for full proposal):

## **Objectives**

### **Immediate objectives:**

- 1) To gain an understanding of the unusual (compared with the E&W) profile of ‘place of death’ patterns for cancer patients in the MBHA area.
- 2) To describe and explain how decisions, events and circumstances interact to determine actual place of death for cancer patients in the MBHA area.

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<sup>4</sup> We were delighted that Professor David Clark of Sheffield University, a leading researcher and writer in the palliative care field, was able to join our research team, as were three local specialist palliative care nurses, a local consultant oncologist, and a former member of MBHA staff who had been involved in the Authority’s palliative care service planning (see names on title page).

3) To identify the preferences of adult terminally ill cancer patients and their informal carers in the MBHA area regarding the place of palliative/final care and the place of death

**Longer term objectives:**

4) To provide information which can assist in the further development of a palliative care strategy by MBHA

5) To contribute to health services research in the rapidly changing field of palliative care.

These objectives informed a study design that had three key elements:

- i) geo-epidemiological study of place of death data;
- ii) the study of patterns of service development together with the views and preferences of professionals and associated workers;
- iii) the study of adult patient and carer preferences concerning place of final care and death.

This required us to:

- i) Model place of death in the MBA using data from the Public Health Mortality File.
- ii) Describe the development of palliative care services in the MBA involving interviews with selected key health and social care professionals and voluntary sector workers (around 20 interviews)
- iii) Conduct a similar prospective study to Townsend et al,<sup>5</sup> involving interviews with a sample of patients (c. 50) diagnosed as terminally ill with cancer, and their carers. Patients to be distributed across the MB area.

The study design and methods are detailed in Chapter 3 of this Report.

An unplanned but welcome feature of the study, facilitated by the involvement of Professor David Clark, was the linking of our research with the national Hospice Histories Project (HHP) during our first year (see Appendix 3 for details of the HHP). This meant that a proportion of our interviews with health professionals involved an additional interview (conducted back-to-

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<sup>5</sup> Townsend, J. et al (1990) Terminal cancer care and patients' preference for place of death: a prospective study. *BMJ*, 301:415-17.

back with our own project interview) to be archived with the HHP (interview details are given in Chapter 3). The HHP interviews provided useful additional data for our project.

### Project objectives revisited

For the purposes of this Report, it is helpful to present the research objectives in the form of key research questions (noted earlier), and to reformulate the elements of the study design in line with these questions. This should give the reader a closer understanding of what we have been attempting to uncover:

#### **Key research questions:**

- Where do cancer patients die in the MB area – at home, in hospice, in hospital, or elsewhere?
- Why do they die in these locations?
- What are patient and carer preferences for place of death?
- Does the place of death match patient and carer preferences?

Answering these questions has required us to:

- Seek explanations for place of death outcomes.
- Attempt to identify patient and carer place of death preferences.

**Seeking explanations** has been undertaken through data collection and analysis at aggregate and individual levels:

- Aggregate and individual level analysis (MBA) of the location of *all* cancer deaths in a specified period (1993-2000).
- Individual level analysis of accounts of the scope of specialist palliative care service provision in the MB area, and thus on place of death options (semi-structured interviews with health professionals and associated workers and documentary review).
- And, individual level analysis of the circumstances surrounding the actual place of death of a cohort of terminally ill cancer patients located across the MB area.

The **identification of patient and carer place of death preferences** has been undertaken through data collection and analysis as follows:

- Attempting to engage in a series of discussions with patients and carers who constituted the cohort of terminally ill patients whose cases were followed, about matters of service use and evaluation, forward planning, preparations for the end of life, and preference for end of life care.

- Exploring, through semi-structured interviews, professionals' and associated workers' knowledge about and perspectives on patient and carer preferences (frequently referred to in this Report as the 'health professionals interviews' for brevity). In addition, the views of these professionals on the 'ideal' place of death arrangements for cancer patients have also been captured.

By these means we have attempted to understand i) the nature of patient and carer preferences, ii) the factors that shape these preferences, and iii) the factors that influence the actual locations of patient deaths in the MB area.

## **Ethical considerations**

There is no question that we were undertaking particularly sensitive and ethically demanding research. We had the benefit of a track record of research with cancer patients that stood us in good stead in this regard (Thomas et al, 2001). Permission for the study was sought and obtained from the two Ethics Committees that existed in the MBHA area in 1999.

It was of concern to us, and to the local ethics committees, that patients who did not fully comprehend their prognosis should not be caused the distress of its revelation through their involvement in the research process. Townsend et al (1990) found that only a small proportion of their sample did not know their diagnosis or prognosis, and this proved true for our research also. However, we needed to safeguard our potentially vulnerable sample. To this end, all interviews were undertaken by interviewers with experience in interviewing the dying and bereaved (most were undertaken by the project Research Associate, a few were undertaken by the three specialist palliative care nurses working with the academic team, and who were already in contact with the patient).

To ensure that the patients' informed consent was gained as a 'process', a two-stage patient recruitment scheme was devised (described in Chapter 3). And repeated checks were made during data gathering to ensure that participants were willing to continue. Note was taken of ethical insights in the palliative care literature (for example Seymour & Ingleton 1999; Aranda 1995; Beaver, Luker & Woods 1999).

## **Structure of the Report**

Following this introductory chapter, Chapter 2 reviews the literature on i) place of cancer deaths, and ii) cancer patients' preferences for place of death. Chapter 3 outlines the study design and methods. The characteristics of the interview samples are reported in Chapter 4, as

are response rates and the outcome of the patient referral process. The last section of Chapter 4 moves into the presentation of study findings, reporting place of death outcomes for the patient cohort and considering their match with the patients' preferences for place of death. Chapters 5 to 9 concentrate on different dimensions of the study findings. Chapter 5 reports the results of the geo-epidemiological analysis of 6,900 cancer deaths in the MBA. Chapter 6 provides a detailed account of the perspectives of health professionals and associated workers on the nature of palliative care services in the MBA, together with their views on the nature of patient preferences and on the factors that led to deaths occurring in particular places. Chapters 7, 8 and 9 set out the findings of our interviews with patients and carers, focusing respectively on the following themes: C7 - 'body matters' (symptoms and other bodily-related concerns), C8 - 'social matters' (the social networks and informal care relationships in which the patients were embedded), and C9 - 'service matters' (patients' and carers' contact with, and experience of, health and social services in the palliative phase of illness). The study's four key research questions will be referred to throughout, and are used to structure Chapter 10, the final chapter, which attempts to summarise the findings and comment upon the new knowledge generated by this study. Some recommendations are also presented. The reader can make reference to the study documentation and related materials in the Appendices (these are sign-posted throughout).

## Chapter 2

### Background literature and the features of our approach

This chapter reviews, in brief, the literature that informed the research proposal and the broader body of literature that has been consulted during the lifetime of the project. By discussing the research of others, we can clarify the conceptual approach taken in this study.

The project's four key research questions have required an engagement with several domains of literature in the fields of palliative care and cancer studies, as set out below.

Our research questions	Types of literature
Where do cancer patients die in the MB area – at home, in hospice, in hospital, or elsewhere?	Literature on: <ul style="list-style-type: none"><li>• Place of cancer deaths: internationally, nationally, locally.</li><li>• Trends in place of cancer deaths.</li></ul>
Why do cancer patients die in these locations?	Literature on: <ul style="list-style-type: none"><li>• Factors that are associated with or predict where cancer patients die.</li></ul>
What are patient and carer preferences for place of death?  Does the place of death match patient and carer preferences?	Literature on: <ul style="list-style-type: none"><li>• The nature of 'preference' for place of death.</li><li>• Place of death preferences of cancer patients.</li><li>• Factors that are associated with or predict place of death preferences.</li><li>• Factors that are associated with or predict changes in place of death preferences.</li></ul>

The discussion that follows considers these research questions and their associated literatures in turn.

#### Where do cancer patients die?

The broad context for this study lies in the Calman-Hine report, prepared for the Chief Medical Officer of England and Wales in 1995 (Expert Advisory Group on Cancer, 1995). The focus of this was on improving the quality of cancer services, following concerns about unacceptable variation in service delivery and performance. More recently, the NHS National Cancer Plan, produced in 2000, gives considerable prominence to the reduction in cancer-related health inequalities. It proposes standards for improving cancer services in a number of respects, including better access to treatment and, most important from our perspective, improvements in

access to specialist palliative care. Such palliative care comprises a range of possible services, including: specialist care provided in the community settings, hospices and day centres, and specialist care delivered in hospital settings.

One dimension of variation in service delivery and of health inequality concerns the opportunities that terminally ill cancer patients have to die in their preferred setting. To explore this, we need to start out with some knowledge of current patterns for place of cancer deaths. Within cancer epidemiology, there is a research tradition in England and Wales that has considered social and geographical variation in cancer mortality and incidence (Quinn et al, 2000) and survival (Coleman et al, 1999). Place of death research is a more recent phenomena, focusing on the predictors of place of death among those with cancer (Higginson et al, 1998; Higginson et al, 1999).

Over the last century there has been a general trend whereby fewer cancer deaths occur at home and a higher proportion take place in hospitals. It was not until the last third of the 20<sup>th</sup> century that a growing hospice movement began to claim its share of cancer deaths. This is summarised below:

<b>Place of death of people with cancer (UK) 1885-1992</b>				
	<b>Hospital</b>	<b>Hospice</b>	<b>Home</b>	<b>Other</b>
<b>1885</b>	3%	-	89%	8%
<b>1956</b>	45%	-	50%	5%
<b>1974</b>	59%	5%	31%	5%
<b>1992</b>	51%	18%	25%	6%

*Source: Inaugural Lecture, Professor Michael Richards, 14 March 1996*

Between 1969 and 1987 the proportion of cancer patients in England dying in institutions increased from 46% to 50% (hospitals), and 5% to 18% (hospices and other institutions). Also during this period, deaths at home decreased from 42% to 24% (Cartwright, 1991).

Between 1985 and 1994 the percentage of cancer patients who died in a NHS hospital or nursing home fell gradually from 58% to 47.3%. Death in non-NHS hospitals or voluntary hospices increased from 9.8% to 20.9%. The main change in this 10 year period was a move from deaths in NHS hospitals and nursing homes to hospices. However, in 1997 NHS hospices accounted for 18% of hospice beds in the UK and Higginson et al (1999) extrapolate to suggest that the true percentage of cancer deaths in hospices would be 16.7%, with 44.3% of cancer patients dying in hospitals and nursing homes. During this period there was only a very slight increase in the proportion of home deaths, 25.5% in 1992 up to 26.6% in 1994 (Higginson et al 1999).

The Hospice Information survey reports that approximately 155,000 people die of cancer per year in the UK, and that in 2000/01 25% of these died at home and 19% in a palliative care unit (Hospice Information 2001).

A cancer registry study of cancer deaths between 1989 and 1996 in Yorkshire found falling rates of hospital deaths (46%-43%) and home deaths (33%-28%), while the proportion of hospice deaths increased (Amir et al 2000). They also noted significant differences in hospice deaths in the Region's seven Health Authorities, clearly indicating a correlation between availability of beds and the trend to die in hospices. Differences are also noted in this study's Region, the North-West. Data (1990-94) from the Hospice Information Service (Higginson, 1999) indicate that, in North-West England, there is considerable geographical variation in the proportion of deaths occurring at home, ranging from 33 per cent in South Lancashire to 22 per cent in Morecambe Bay. There is a striking inverse relationship at electoral ward (small area) level, between the proportion of home deaths and socio-economic deprivation, both across England as a whole, and in particular regions (Higginson et al, 1999).

#### Why do cancer patients die in these locations?

Attention has been given in recent years to the predictors of place of death among those with cancer (Higginson et al, 1998; Higginson et al, 1999). Given compelling evidence that up to 70 per cent of people with cancer prefer to die at home (Grande et al, 1998; Karlsen & Addington-Hall, 1998; Higginson & Sen-Gupta, 2000) research has focused upon finding those factors which best predict cancer death at home.

Low rates of home deaths may be due to a number of factors, including perhaps the relatively good provision, in some parts of a district, of hospice care. However, an examination solely of home deaths, in the absence of data on the availability of provision in other settings, may give a misleading picture. Small areas that have low proportions of home deaths may have either a hospital or a hospice close by, affording an alternative place of death. We cannot hope for a full explanation of variation in home death without taking account of these geographical determinants. As Higginson and her colleagues (1999) observe, 'analysis of supply effects, such as available palliative care services, social services and GP community hospitals, is needed to investigate the variation further'. Others too (Grande et al, 1998) argue that distance to services needs to be taken into account. We do this in our study by using Geographical Information Systems (GIS) (see Chapter 5).

What follows is a listing of factors that have been identified as associated with, or predicting, place of death in a range of studies.

## Factors associated with, or predicting, place of death for cancer patients

### 1. Service provision

- Users of community based home care services (as opposed to those attached to an inpatient facility) are more likely to die at home than other patients (Grande et al, 1998). Service availability greatly effects place of death, more so than patient characteristics. ‘Patients with certain characteristics may therefore be more likely to die at home by virtue of being more likely to access services which improve their chances of dying at home’ (Grande et al, 1998: 573).
- Grande et al (1999) did not find any significant difference in the percentage of home deaths between patients allocated to ‘hospital at home’ and a control group. However, of those that were actually admitted to hospital at home, significantly more died at home.
- Higginson (1996) indicates that when community palliative care nurses are involved with patients, approximately 50% of deaths occur at home, just over 25% in palliative care units and slightly fewer in hospital.
- In an editorial, Higginson (2000) reports on unpublished data, which found that 90% of patients who received care from a Marie Curie nurse did achieve a home death (Higginson & Wilkinson, 1999). She contends that more home deaths can be achieved if adequate community based resources are available.
- Having special equipment was associated with an increased likelihood of dying at home, but using social and health services for social care was associated with a decreased likelihood of dying at home. (Karlsen & Addington-Hall, 1998).
- In a Norwegian study (Jordhoy et al 2000) an intervention to support people at home was compared with conventional care. Of the 395 deaths, significantly more of the intervention patients were enabled to die at home.
- An Italian study (Costantini, et al 1993), using a population-based sample of all cancer deaths in a 4-year period, reports that the provision of palliative home care was the strongest predictor of home death.

### 2. Carers: their capacity to support the patient through to the end of life

- Patients with informal carer support were more likely to die at home and to access palliative home care (Grande et al, 1998).
- Wilkes (1984) found that the difficulties of the carers were more often a cause for admission to hospital than the difficulties of patients themselves.

- Doyle (1980) found that in 90% of cases, hospital admission became necessary because of stress on relatives, lack of night sitters, and lack of equipment.
- Herd (1990) found that 45% of hospital admissions were of people whose carer was unable to continue, or in 22% of cases because there was no carer
- Thorpe (1993) looked at the reasons for admission to hospital in the terminal care phase, and a subsequent hospital death. These included: poorly controlled symptoms, excessive nursing demands, crisis (e.g. severe pain), and the sudden illness of main carer.
- Cantwell et al (2000) studied predictors of home death in 90 cancer patients. Among their findings was that the presence of more than one carer was predictive of a home death.
- Open awareness of dying where the patients and carers both know and can discuss the options, has been shown to increase the odds of dying at home or in a hospice and not dying in a hospital (Seale, Addington-Hall & McCarthy 1997)
- In an Italian study (De Conno et al, 1996) a home care programme was evaluated, but it was found that the only factor associated with home death was a higher degree of family support.
- In an editorial, Higginson (2000) suggests that the needs of carers and interventions to assist them are little studied and exciting opportunities exist for collaborative work with carers to rectify this situation.

### **3. The management of symptoms**

- Thorpe (1993) looked at the reasons for admission to hospital in the terminal care phase, and a subsequent hospital death. These included: poorly controlled symptoms, excessive nursing demands, crisis (e.g. severe pain), and the sudden illness of main carer.
- Addington-Hall & McCartney (1995) found that for both cancer and non-cancer deaths there had been continued problems of unrelieved pain and other symptoms such that hospital admission in times of crisis was common.
- Seamark et al (1998) found that pain and symptom control were the more frequent, and terminal nursing care the less frequent, reason for admission to a hospice.
- Hunt (1996) reports that in Australia the proportion of patients who remained at home decreased steadily in the last three weeks of life as functional status decreased.
- A Belgian study of 40 patients (Van den Eynden, 2000) reported that both emotional and somatic factors played a part in the determination of place of death.

### **4. Distance to services**

- Herd (1990) found that a higher percentage of cancer patients in a semi-rural area died at home (53%) than the average for metropolitan areas, and that those living further from a hospital were more likely to be cared for at home at the end of life.

- There are also indications in a study comparing community hospitals and hospice that distance from a facility may influence patterns of service use (Seamark et al 1998).

#### **4. Gender and age**

- Women are less likely to die at home than men (Higginson et al, 1998; Grande et al, 1998). Younger women may be more likely to access home care (Grande et al, 1998).
- A Spanish study (Izquierdo-Porrera et al, 2001) examining elderly patients (65 and older) found that factors predicting death in the hospital were different for men and women. For men the predictive factors were related to their medical condition, whereas the predictive factors for women were mainly related to functional dependency and social support.
- Older people are less likely to die at home (Higginson et al, 1998).
- Older patients are less likely to die at home and access home care (Grande et al, 1998).

#### **5. Socio-economic variation**

- There is a striking inverse relationship at electoral ward (small area) level between the proportion of home deaths and socio-economic deprivation, both across England as a whole, and in particular regions (Higginson et al, 1999).
- Cancer patients in higher socio-economic groups are more likely to die at home and to access home care (Grande et al, 1998).
- People from more deprived areas or of lower social class are less likely to die in their own homes (Higginson et al, 1994).
- Sims et al (1997) found that place of death is associated with social class, highlighting issues of equity of access to services.

#### **6. The strength and visibility of patient and carer preference/desire for a particular place of death**

- Stating a preference for place of death was associated with an increased likelihood of dying at home (Karlsen & Addington-Hall, 1998).
- Cantwell et al (2000) studied predictors of home death in 90 Canadian cancer patients. The main predictor of a home death was patient and carer desire for home death.
- In a retrospective case-control chart review, McWhinney et al (1995) matched 75 patients who received the services of the home support team and who died at home with 75 patients who received the same services but died in hospital. Factors significantly associated with dying at home were the patient's preference for dying at home recorded at the time of the initial assessment, a family member other than the spouse involved in the patient's care, and the use of private shift nursing. The patient's preference for dying at home was not met if the caregiver could not cope or if symptoms were uncontrolled. The patient's preference for

dying in hospital was not met if his or her condition deteriorated rapidly or if the patient died suddenly.

## 7. The patient's tumour type

- People with cancers of the lung, colorectum, respiratory organs, bone or connective tissue and lip, oral cavity and pharynx were more likely to die at home than patients with breast, lymphatic or haematological cancers (Higginson et al, 1998).
- Haematological patients are less likely to die at home (Hunt, 1996)

### What are cancer patient preferences for place of death?

It has been said that a 'good death' is one in which patients' wants and needs are met (Samarel, 1991). Policy documents are replete with statements that services must reflect users' preferences and accommodate choice, but what is known about preferences with regard to place of final care and death?

Higginson & Sen-Gupta (2000) recently conducted a systematic review of literature on the place of death preferences of patients with advanced cancer. They identified 18 studies, half of which were conducted in the UK, with four American studies and one each from Israel, Italy, Australia, Singapore and Canada. These studies included five surveys of the general public, with the remaining 13 obtaining the views of patients and carers who were dealing with advanced cancer. Although Higginson & Sen-Gupta indicate that half the studies were flawed in design or reporting, they conclude that home care is the most common preference (over 50% among patients), with inpatient hospice care as second preference for those with advanced cancer. However, preference for care at home tended to be higher than for death at home. They suggest that: "No consistent conceptualisation of the factors that determine preferences for place of terminal care of patients with cancer emerged from the studies reviewed and this should be the focus for future work" (2000: 299). It is just such a conceptualisation that we attempt in this study.

Several studies of preference were conducted in the UK in the 1990s and found similar patterns. We report the key findings:

- In their review, Higginson & Sen-Gupta (2000: 297) state that 'If we consider only the three higher quality studies – grade B or above, that directly asked patients [about their preference] and had a higher than 60% response rate – the preferences for home care [n.b. home care] were 81% (Gilbar & Steiner, 1996), 90% (declining to 50% later) (Hinton,

1995), and 67% (in ideal circumstances, but reducing to 49% in existing circumstances near death) (Townsend et al 1990)'.

- The Townsend et al (1990) study, which we drew upon in the design of this study (see Chapter 3), found that of the 59 patients (from a sample of 84) with terminal cancer who stated a preference for place of death (in existing circumstances), 34 (58%) chose home, 12 (20%) hospital and 12 (20%) hospice (1 for 'other'). Preference for home death decreased slightly during care (58% to 49%), with slight increases in preference for hospital (20% to 24%) and hospice (20% to 24%) as death approached (Higginson et al 2000: 295).
- Hinton (1995) also found initial patient preferences for home care (*sic*) decreased as death approached (90% to 50%), replaced by preference for hospice care (10% to 40%).
- In a larger study (Dunlop 1989) of 160 patients referred to a hospital support team, of the 90 who could express a preference the majority chose home (48, 53%), with 26 (29%) preferring hospice, 13 (14%) hospital and 3 (3%) a nursing home.
- Symptoms: Butow et al (1997) studied change in preferences for information, involvement and support in 80 cancer patients. They concluded that situational factors, such as change in disease status, may alter a patient's preferences for information and involvement. Patients whose condition had recently worsened were more likely to want progressively less involvement in decision-making.
- Butow et al (1997) studied change in preferences for information, involvement and support in cancer patients. Gender was predictive of patient preferences. Having a religious faith was also predictive of patient preferences.
- Charlton (1991) found a higher preference for hospice care in a general population of GP attendees who indicated they had close personal experience of death and dying.
- In their review, Higginson & Sen-Gupta (2000: 299) note that 'Preference for care at home appeared to be higher than for death at home'. They also suggest that people's preferences change with their options and are strongly influenced by the services provided. They state:  
A preference for home care or death may be an empowered expression of wishes or an aversion from the perceived disadvantages of hospital care. A preference for hospital or hospice care may indicate a resigned acceptance of the inevitability of inpatient care, a desire to save relatives and close friends from the burden of caring at home, a belief in better care being provided, or a refusal to admit that a cure is not possible. Many other interpretations are possible.... (Higginson & Sen-Gupta, 2000: 299).

Further:

More work is needed to understand the preferences of patients in different age groups, gender, culture and economic circumstances (ibid: 299).

Our study can address some of these lacunae, particularly the conceptualisation of the factors that determine preferences.

Much palliative care research has used a post-bereavement sample of carers (for example, Addington-Hall & McCarthy, 1995). Proxies are an important source of information given that the majority of patients can not be interviewed in the last week of life (Fowler, Coppola & Teno, 1999). However, questions of validity are raised in using proxies and these have been discussed in the literature (Fowler, Coppola & Teno, 1999; Addington-Hall & McPherson, 2001). It seems that family members tend to underestimate functioning and over-report symptoms in comparison with patients (Ahmedzai et al, 1988; Higginson et al, 1994). However, there are indications of good agreement between patients and carers on aspects relating to service provision and communication (Higginson et al, 1994; Hinton, 1996). The other main issue raised in the literature is that of recall, and the extent to which grief affects evaluation of events. We summarise the findings of a few of these studies:

- Addington Hall (1991) asked 80 bereaved carers about their satisfaction with place of death of the person cared for. Where the patient had died at home, 30 of 31 were satisfied with place of death, compared with just over half where the patient had died in hospital.
- An Australian study (Wakefield & Ashby, 1993) also reported that carers of patients dying in hospital were less likely to consider that this site was the right place for the death to have occurred.
- However, Seale (1991), in a comparative study of 171 bereaved cancer carers, found no difference in dissatisfaction with the site of death between hospice and conventional hospital care, although hospice staff were more highly praised than hospital staff.
- Karlsden & Addington-Hall (1998) found that 38% of all patients were reported by bereaved carers to have expressed a preference for place of death, and 73% of patients had wanted to die at home. Of those who had expressed a preference for a home death, only 58% had achieved this.

Our prospective research design involving a series of interviews with patients and carers aims to provide data of a different kind to post-bereavement studies. Our focus is on the context and the differing perspectives of the parties involved, and not just on the patients themselves. We deliberately chose to explore the carer experience in conjunction with that of the patient, recognising that cancer deaths do not occur in isolation, but that all parties are affected and have preferences. Although we employ a post bereavement element, our carers are not just proxies; throughout we asked them to reflect on *their own* experience, as well as try to elucidate the events surrounding death at post bereavement. As with our last study (Thomas et al, 2001), however, carers often have to be coaxed and reminded to speak of and for themselves, rather than speak of the patient. Their tendency to be ambivalent about their own needs and opinions

in the cancer scenario is also documented in other studies (Harding & Higginson 2001; Meissner et al 1990; Toseland et al 1995; Ward & Cavanagh 1997; Krishnasamy 2001).

### A note on our perspective on the nature of preference

One might think from the above review that eliciting patient preferences for place of death is a matter of uncovering something that exists as a 'pure' type, a clearly definable entity, that can be categorised. The research endeavour of identifying patient preferences is presented by many authors as a sensitive (certainly) but fairly straightforward procedure; once patients have spoken on the matter, boxes on research instruments can be ticked: 'home', 'hospice', 'hospital', 'other', 'no preference'.

From the start, we were somewhat sceptical about what constituted 'a preference' and about how *certain* recorded preferences actually are. Put another way, much of the research on preference for place of death has been undertaken within a positivistic philosophical framework, and we were coming at the issues more phenomenologically, utilising qualitative research methods. For us, preferences for place of final care are not likely to be simple choices. Indeed, to anticipate our findings here, in the interviews with patients and carers, preferences were rarely stated categorically, but tended to take the form of a leaning in one direction, qualified by speculations about how things might change with events. Patients and carers spoke about the important contextual factors in their lives, and expressed a lot of uncertainty about how 'things will go'. Our impression is that it is hard for patients to talk of preferences without embedding their discourse in accounts of their personal contexts: of symptoms, physical limitations, relationships with the carer/carers, relationships with the health services and health personnel. Preference for place of final care and death was **not** presented as something that could be considered in the abstract. People tended to take a pragmatic view, one that was contingent on the various, and changing, factors in their lives that they saw as playing a part.

### Literature on research ethics, with some reflection on our interviewing experience

Apart from the methodological and practical problems, moral questions are raised in interviewing people close to death. Some writers have argued that interviewing may be exhausting for patients in the later stages of disease, and others have suggested that it is unfair to burden people with research at a time when they are already dealing with emotive issues in their lives (de Raeve, 1994). In contrast, others have argued that it is morally important to support people in voicing their experience at the end of life, that there may be some element of

therapy in the research interview, or that people may benefit through feeling they are able to make a contribution that improves the experiences of others. As Aranda (1995:46) suggests, 'many people attach importance to being able to help someone else at a time when their usefulness in society is being challenged'. Participants in our study often suggested that they wanted to help in order to 'repay' the help they had received from health personnel.

In a study of cancer patients by Montazeri, Milroy & McEwan (1996) 96% of patients indicated that being interviewed was acceptable, because the interview was not disturbing; they felt relaxed, they liked to talk, the interview was conversational. Our aim was also to keep the interview as relaxed and informal as possible. There were also indications that for a proportion of the interviewees, especially women who lived alone, it was just good to have someone come to the house. There were some who prefaced discussions about interview arrangements with remarks about not being able to get out and about easily any more and thus being happy to see the interviewer at any time. While the benefit is small for these patients, these hints suggest that interviews are not as burdensome as might be expected, given the sample population. In some interviews, participants expressed emotion through crying, and when this happened the researcher offered to stop. However, none of these people wanted to end the interview, and all expressed a willingness to carry on, either through their tears, or after a moment's pause to gather their words together again.

Barnett (2001) gained feedback from her participants, a sample of 85 patients with advanced cancer, about the interviews she conducted, and reports that none of them wished they had not taken part; 66% were glad they had participated and the remaining 34% were neutral. She concludes that research with terminally ill patients can be both valuable and ethical, and that it is paternalistic to exclude them from discussions of issues that concern them.

## Chapter 3

### Study design and methods of data collection

This chapter opens with a brief summary of the study setting then presents, in turn, the three key elements of the study design introduced in Chapter 1:

- iv) geo-epidemiological study of place of death data;
- v) the study of patterns of service development together with the views and preferences of professionals and other stake-holders;
- vi) the study of adult patient and carer preferences concerning place of final care and death.

The chapter closes with a discussion of the interview data analysis techniques utilised.

#### Study Setting

The research took place in the north west of England in the area covered by the former Morecambe Bay Health Authority (MBHA). Data collection required the recruitment to the study of cancer patients and their main informal carers via services across the MBA: community services, two hospices and one hospital out-patient clinic. With one exception, the health and social care professionals who participated in interviews were also drawn from the MBA.

#### 1. The geo-epidemiological study of place of death data: data and analysis

A preliminary assessment of place of death, by locality, had already been undertaken in MBHA (MBHA, 1998a, 1998b), leading the Authority to call for further research into the determinants of place of death. Our first objective was to model place of death data using Geographical Information Systems (GIS). We attempted to explain variation in the place of cancer deaths within the MBA by using two scales of analysis: first, among small areas (electoral wards), and second, among individuals. We use a range of possible predictors, both socio-demographic and geographical.

Anonymised patient data were provided by the Health Authority, and comprised the Death Extract File (1993-1997) and the Public Health Mortality File (1998-2000), as supplied by the Office of National Statistics (ONS). Data fields included: age at death; sex; year of death; postcode of home address; electoral ward of residence; place of death (home, hospital, hospice, nursing/retirement home, or elsewhere); and cancer site (tumour type). We removed from the file those deaths that occurred outside the study area. This yielded 6900 individuals, all with home addresses within 89 electoral wards of Morecambe Bay.

We added to the file the Carstairs deprivation index (Morris and Carstairs 1991) for each electoral ward, based on 1991 Census data. Using a postcode look-up table, relating postcode to Ordnance Survey grid reference, and digital road network data (from Bartholomews Ltd) we calculated travel distances by road from postcode of home address to the nearest hospital and hospice. We also constructed a notional hospital 'catchment area', based on travel distance to the nearest hospital; this served to distinguish between wards in the three main geographical areas: Lancaster/Morecambe; Barrow/Ulverston (Furness); and Kendal/South Lakeland.

For the ward-level analysis we fit binomial regression models, using the GLIM (generalised linear modelling) package, modelling the observed proportion of deaths in each setting and using the total number of deaths as the binomial denominator (the sample size). We look first at the effect of deprivation but then control for possible proximity effects by including travel distance from ward centroid to nearest hospital and nearest hospice as predictor variables. We also see if the general relationship holds across all areas; does catchment area have any effect? We take the Lancaster/Morecambe area as the reference 'catchment'.

In the individual-level analysis we use binary logistic regression models, where we consider a death to be: at home (or elsewhere); in hospital (or elsewhere); and so on. These models are estimated using the SPSS package. Backward elimination with a 5 per cent significance level is used in both analyses to determine the best model. In the binomial regression models, goodness of fit is measured by 'scaled deviance'; for a well-fitting model the scaled deviance should not be much larger than the residual degrees of freedom. For the binary logistic regression models we express results in terms of odds ratios and 95 per cent confidence intervals. A variable is taken to be a good predictor if the confidence interval does not include unity. Lancaster-Morecambe is again taken as the reference area. Breast cancer is used as the reference category for tumour type, and male for gender. In the absence of any information on socio-economic status for individuals we have attached the ward-level Carstairs index to each patient; while crude, this provides one means of describing the areas within which patients live.

## 2. The study of patterns of service development together with the views and preferences of professionals and associated workers

To describe the development of specialist palliative care services in the MB area, and thus to uncover the place of death options currently available, we used two methods, paying attention to the differences in Lancaster/Morecambe, Kendal/South Lakes and Furness. First, a picture of local service provision was gained through the use of readily available (though limited) documentary evidence (see Appendix 2 for a list of documents) and, second, new data was

generated through semi-structured interviews with selected health and social care professionals and voluntary sector workers (the ‘health professionals interviews’ for short).

## Interviews

Health professionals to be approached for interview were identified through ‘snowball’ or ‘reputational’ sampling techniques. We sought out personnel who were closely involved in palliative care in the MBA, and had been working in this field for some years. Names were initially identified through consultation with members of the project steering group, and then those whom we interviewed suggested further names. Potential interviewees were contacted, the project explained and interviews requested.

In addition to participating in our semi-structured project interview (the place of death (POD) interview), some respondents were also invited to participate (on the same interview occasion) in a second interview for the Hospice History Project (HHP, see Chapter 1, and Appendix 3 for a description of the HHP project). Participants were fully informed about the differing natures of the two interviews.

- *The HHP interview* involved a longer and more personal interview for those who felt they could contribute to the aims of the HHP. It was explained that this interview would be in the public domain, but that a transcript of the interview and a copy of the summary (to be posted on the HHP web site along with their name and photograph) would be sent to them for approval prior to entering the HHP files. A formal consent form was signed and returned to the HHP.
- *The POD interview* was shorter and more specific to the aims of our project. We discussed anonymity with each participant, and explained that this would not be fully possible due to the small numbers of palliative specialists in the locality. We also explained that transcripts would be returned for approval if requested.

The interview schedules for the two types of interview are in Appendices 4 and 5. These provided guidelines for the interviews, but were modified to suit the occupational perspective of the interviewee.

In addition to enabling us to gather data on service developments and patterns of provision, the semi-structured interviews generated a rich picture, from a professional standpoint, of how decisions, events and circumstances interacted to shape actual place of death. The interviewees also gave another perspective on the place of death preferences held by patients and carers, and allowed professionals to outline their own ideal model of end-of-life care. The HHP interview transcripts have been used as sources of data for this project in addition to the POD transcripts since the former contained valuable additional information of relevance.

### 3. The study of patient and carer preferences concerning place of final care and death.

How were patient and informal carer preferences about where the death should occur to be identified? At the project proposal stage, the best option appeared to be to conduct a similar prospective study to that undertaken by Townsend et al (1990). The Townsend et al research involved a longitudinal study of randomly selected patients with cancer from hospital and community settings who were identified by haematology, pathology and cytology departments in one hospital. Eighty-four patients expected to live less than two months were interviewed every two weeks until death, while patients with a longer life expectancy (up to a year) were interviewed every month until fortnightly interviews began at the 'two months remaining' point. The interviews involved a researcher-administered questionnaire on preferences for place of death, covering preferences in a) existing circumstances and b) ideal circumstances. The main informal carer was interviewed three months after the death to compare actual with preferred place of death.

What we proposed to replicate from this study was its longitudinal engagement with a randomly selected group of terminally ill cancer patients, around 50 in total,<sup>6</sup> and their resident carers, with a focus on place of death preferences. However, it was always our intention to go beyond the parameters of the Townsend et al's interview/questionnaire encounter with patients (this was one of the reasons for identifying a smaller sample size: 50 compared with Townsend et al's 84). We wanted to conduct qualitative interviews, at least in the first instance (while patients were well enough), so that we could gain a deeper understanding of the nature of 'preference', and the factors influencing preference, by considering patients' and carers' lived experience of the illness, their knowledge of available services, and their wider social circumstances. We wanted to look at preferences in the context of personal and service situations.

Thus our original intention was to draw a random sample (stratified by area of residence to ensure coverage of the MB area) of cancer patients whom we could approach for interview at an appropriate time (two to three months from expected time of death) from a comprehensive list of eligible patients (patients whom consultants thought likely to live for less than a year) referred to our study by health professionals across the MB area. As we describe below, this

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<sup>6</sup> In response to the comments of one of the project proposal peer reviewers, we indicated that we would try to increase the number of patients interviewed. Before the commencement of the study it appeared likely that the three specialist nurses working with the academic team would be able to each undertake a number of interviews (with appropriate training and support from the academic team), thus taking the total number of patient respondents beyond 50. However, as fieldwork proceeded it became evident that these nurses' ongoing service commitments meant that they were only able to undertake one or two interviews each. This interview experience was, nevertheless, highly valued by the nurses, and contributed significantly to their research capability building. In fact, the total number of patients interviewed was 41.

plan could not be executed for a number of reasons. Difficulties with this sampling strategy surfaced in the pilot study.

### **The pilot study**

A small pilot study was undertaken at the end of 2000. This involved the design and trial (with a single specialist nurse) of a referral form to be used by health professionals assisting us with patient recruitment. This resulted in the rewording of a section of the referral form, and the division of the question about 'who is helping' into 'family and friends' and health professionals' (see Appendix 6 for the referral form). Two practice interviews with willing patients were also undertaken. These were useful in providing a 'feel' for the subject matter, enabling the testing out the interview schedule and procedures. The importance of the interviewee's social context was highlighted. We were fortunate in interviewing two people in very different circumstances and with differing ways of communicating about their care preferences, which helped us to reflect on ways of handling the sensitive nature of the subject matter.

The pilot study assisted in firming up our intention to conduct initial interviews at a time when the patient was estimated to have three months left to live. The referral form made reference to this and asked the referrer to indicate whether contact should be made:

- 1) Not at all;
- 2) As soon as possible;
- 3) Within a month;
- 4) Between 1 and 2 months;
- 5) Longer than 2 months.

A series of communications by letter, telephone and face-to-face discussion with potential referrers began in the pilot study phase. This involved approaching health and social care professionals involved in the treatment and care of terminally ill cancer patients, located in two hospitals, two hospices and a number of community based services. It became clear that, despite genuine support for the project in the locality, only a minority of health care professionals were willing or able to serve as patient referrers to the project. These difficulties in patient recruitment are now discussed in some detail.

### **Patient Recruitment**

The referral of patients to the study took place from February to December 2001. The difficulties in securing patient referrals are considered under two headings associated with i) the willingness of health and social care professionals to refer, and ii) ethical practices.

*i) Finding professionals willing to refer:* Unlike Townsend et al (1990), we did not have the benefit of a ‘captive’ patient population served by one hospital, nor of accessing patients who could be routinely referred to the research team by staff in hospital departments. Rather, we had to persuade health and social care professionals in key positions vis-à-vis terminally ill cancer patients, but who were scattered across the MB area, to refer patients to us.

We approached 19 such professionals for assistance (consultants, specialist nurses, district nurses, and nursing home managers). Two declined to participate at this stage. Visits were made to those expressing a willingness to consider participation to explain the project and its referral form. Written notes about the referral form (Appendix 6), pre-paid envelopes, and copies of the Information Sheet for patients and carers (Appendix 7) were left with prospective referrers. However, in the event, some of those who agreed to help, and appeared willing, either did not refer any patients, or only a very small number. We received referrals from 13 professionals (79 patients in total, only 62 of whom could be contacted for reasons discussed below and in the following chapter)<sup>7</sup>, the majority of whom were specialist and district nurses (see Table 1). Those who agreed to help but did not refer comprised 3 consultants (*cf* Jordhøy et al, 1999) and 2 specialist nurses.

**Table 1: Sources of referral**

Sources of referral	No. of personnel involved	No. of patients referred
Specialist palliative care nurses	7	56
Consultants	3	11
District nurses	2	10
Nursing home managers	1	2
Total	13	79

Thus despite the considerable effort made by members of the team to secure the participation of key health personnel across the area, referrals were neither great in number nor comprehensive in their coverage of terminally ill cancer patients in the MB area. The total number did not enable us to sample meaningfully. Instead, we have followed up all of the patients who could be contacted from among the 79 referred to the study.

The reasons for the rather disappointing pattern of referrals from health professionals are unclear – but certainly time constraints were a factor. Professionals’ pressing alternative priorities are likely to have played their part in our recruitment experience as they have in other

<sup>7</sup> There are approximately 860 cancer deaths each year in the MB area. Thus, the number of patients referred to the study for interview represents only 9% of the total number of terminally ill cancer patients.

studies (Wilson-Barnett & Griffiths, 2002: 365). On following up potential referrers with gentle reminders, some low recruiters admitted they just forgot to think about the potentiality for patient referral in the busy clinical setting (see also Brown, Long & Milliken, 2002 on such 'forgetting').

Another factor that may have discouraged referral, and one which was often anticipated when we explained the project to health personnel, was the difficulty of gauging the appropriate timing of referral. The disease trajectory was felt to be somewhat unpredictable, and every patient unique. This difficulty did manifest itself in the actual referral and interview process, where we found that a proportion of the patients referred were too ill or close to death to be contacted. Another indication of this difficulty is the fact that some of the patients referred outlived their estimated three months of life; indeed, 7 were still alive at the close of the project on 30 September 2002. It has been suggested that doctors are frequently inaccurate in 'time remaining' prognoses for terminally ill patients. A literature review by Viganò et al (2000) found low rates of association between clinical estimation and survival time, with particularly low rates where studies looked at case-by-case survival prognosis rather than aggregate predictions. In addition, errors in estimating survival time are usually found to be consistently optimistic (Christakis & Lamont, 2000).

We are not alone in having difficulty recruiting a large pool of potential respondents in this field of study (see, for example, Rinck et al, 1997; McWhinney, Bass & Donner, 1994). Rinck et al (1997) found that in 10 of the 11 studies they reviewed, recruitment was a problem. An editorial in the *International Journal of Nursing Studies* (Wilson-Barnett & Griffiths, 2002) notes that in clinical research inadequacy of patient numbers is a common barrier to study completion. One reason suggested for this concerns staff turnover. In our study there were several changes to the specialist nursing personnel in one setting, due to promotion, retirement and maternity leave. While these changes did not compromise the project, they may have reduced patient referrals.

*ii) Ethical practices that served to limit patient referral:* In the Townsend et al (1990) study, patient names appear to have been referred to the research team without the patients' knowledge or permission. Our study design placed ethical considerations at the forefront (see Aranda's (1995: 41) claim that "the context of the dying person's life is one of ethics"). This meant that we insisted on informed patient consent from the start. This required referrers to explain our research project to patients (in line with the Patient and Carer Information Sheet) and to ask patients if they were willing for their name to be forwarded to our Research Associate. If patients refused, we asked referrers to complete the same form but to omit the patient's name, address and phone number (Appendix 6). In this way we hoped to have some demographic information for assessing non-response (see the following chapter).

Thus there was a two stage approach to patients. First, patients were asked by a professional with whom they were in contact whether they would be willing to participate in the study and could be referred to the Research Associate. Referrers gave patients who indicated a willingness to be referred a copy of the Patient and Carer Information Sheet (Appendix 7), which could be read at home, and which contained a clear indication that the patient could refuse to participate at any stage. Second, the Research Associate made contact with patients if, and when, this was recommended on the referral form. Where a time scale longer than three months was involved, the health professional who referred the patient was later asked (at the relevant time) to ascertain whether the patient was still well enough to be contacted.

These patient consent requirements undoubtedly represented an additional time burden to be shouldered by referring staff, and is likely to have been a factor in the failure of some staff to refer at all, or to refer only on occasion. And perhaps they found it difficult to ask patients, or did not wish to threaten the rapport they had established with patients? Or perhaps they did not want to put their patients under any further pressure? It has been noted that where recruiters to studies are diligent in obtaining and checking consent, response rates tend to be low (Wilson-Barnett & Griffiths, 2002). However, for us as for other researchers, “demonstrating a lack of coercion was considered to be a priority over sample size considerations” (Beaver, Luker & Woods, 1999:14).

*The effects of poor patient recruitment.* The limited source of referrals to the study introduced significant sample bias, most notably the under-representation of patients who i) have *no* contact with the specialist palliative care services in the locality, and ii) have conditions such as cancers of the lymphatic system that require patients to have closer than average contact with hospital services (possibly associated with a hospital place of death preference). Given the biased nature of the referred sample, and thus of the achieved sample, we have not been able to use our interview data to infer place of death preferences for the population of terminally ill cancer patients in the MB area. Put another way, our research on patient preferences had to part company with the Townsend et al (1990) study, which was designed to produce generalisations about place of death preferences. The sampling method that we were required to adopt has more in common with purposive than probability sampling (Arber, 2001), and in this way our study of patient and carer preferences and illness experiences has shifted definitively into the realm of qualitative research designed to maximise theoretical understanding. This should not be seen as a project failing, however, but as a necessary re-orientation of an objective:

from one of identifying patient preferences in the MBA *in general*.

to one of understanding the nature and context of preference, together with the match between preferred *versus* actual place of death for *a cohort of patients* resident across the MB area.

In this new methodological scenario, the relatively large number of referrals from seven specialist nurses shown in Table 1 becomes an advantage for at least two reasons: Compared with cancer patients in general, those in contact with specialist palliative care services are likely to have greater opportunity to access services that can facilitate a home death. In this context, the examination of the inability to achieve a home death, if that had been the preference, can bring to light any 'core barriers' to home deaths in the MBA. A relative consistency of service experiences among the patients in our sample (at least as far as contact with specialist palliative care nurses is concerned) provides a helpful backdrop against which variations in preference for place of death, and actual place of death, can be usefully explored.

Despite the limitations of the sampling base, the presentation of the characteristics of our patient sample in the following chapter reveals important clinical and social diversity. This gives the sample some qualities of representativeness. As will become evident in Chapters 7 to 9, important findings of a qualitative nature have certainly been generated in this dimension of the study.

### **The patient and carer interviews**

Our study design involved a series of interviews with patients during what was estimated to be their last three months of life. We aimed to interview the patient's co-resident carer (if there was such a carer. The main carer was approached if there was more than one carer). Carers were twice interviewed for their assessment of the patient's care circumstances: first, whilst the patient was alive and then three months after the patient's death. The interviews were conversational in style, covering a range of pre-defined themes (see below); the interviewer worked to create an informal and relaxed atmosphere. Face-to-face interviews were tape-recorded and fully transcribed. Widely used measurement scales were also administered during interviews, as were project data capture sheets (details below). The three specialist palliative care nurses working with the academic team undertook a total of four patient interviews, and either saw the interview series through to completion or took it part-way in collaboration with the Research Associate. These nurses were given interview training, briefing and support by the Research Associate.

The patient interview series covered the following key areas: quality of life, levels of pain and other symptoms, what the patient felt about current care arrangements, and whether the patient had plans for their future care. In addition we prefaced the interview with a request for a narrative history of the cancer journey thus far. We also tracked care locations/patterns and the reasons for any changes (for example, hospital admission), and determined, through discussion, preferences for place of final care (a) given the existing situation, and (b) if circumstances were

instituted to allow greater choice. Preference for place of death was thus elicited through sensitive questioning on a range of related issues, and could be more or less direct depending on the ease with which the patient could address such matters explicitly. In this way we able to establish preferences as follows:

*Preference for:*

- a home death
- a hospice death
- a home *or* hospice death
- a hospital death
- death to occur elsewhere
- not decided
- no preference ('don't mind')

### **The interview series**

The interview series with patients and carers is outlined in Table 2, with the details described by stage as follows:

#### **1. First patient interview**

Our Research Associate made first contact with patients by telephone. Further information on the project was given and patients were asked if they were willing to be visited for an interview. An appointment was made at their convenience for those who were willing. At the start the first visit, the research was again explained verbally, the Information Sheet provided (Appendix 7), and an opportunity to ask further questions was offered. If the participant was happy to proceed, the Consent Form was signed (Appendix 8). At the first interview the Demographic Data Sheet (Appendix 9) and an Illness Details Form (Appendix 10) were completed. The Present Care interview schedule was then conducted (Appendix 11) and tape-recorded. Subsequently, the Palliative Outcome Scale (POS) (Higginson, 1998), see Appendix 12) was administered, and the patient was asked if they were willing to be contacted again in about a month. If a carer was present they were invited to participate in an interview at the next visit.

**Table 2: The interview series**

<b>Place in Interview series and purpose</b>	<b>Participant</b>	<b>Contact time</b>	<b>Interview type and data collected</b>
1- 4 - patient A, B – carer			
1. Present care	Patient	Initial interview	Present Care interview, POS, illness details, demographic forms
A. Baseline	Carer	4 weeks later	Present and Future Care interview, GHQ, illness details, demographic forms
2. Future care	Patient	4 weeks later	Future Care interview, POS
3. Tracking	Patient	A further 2-4 weeks later	Short tracking interview schedule, POS
4. Tracking	Patient	A further 2-4 weeks later	Short tracking interview schedule, POS
B. Post-bereavement	Carer	12 weeks after death	Bereaved carers interview, GHQ

## **2. Second patient interview**

Telephone contact was again made, and a further interview was arranged, if the participant was willing and able. At this interview the Future Care schedule was used (Appendix 13), and the conversation tape-recorded. The POS was again administered and the participant asked if they were willing to be contacted for a short telephone interview in 2-4 weeks.

## **3. & 4. Tracking interviews with patients**

These were conducted at 2-4 week intervals on two occasions after the face-to face interviews (Appendix 14). Written notes were taken. In addition the POS was administered again.

### **A. First carer interview**

Where there was a resident carer, the individual was approached for interview at the first visit to the house. They were told about the project and asked to take part on the second visit to the patient's home. In practice, however, a resident carer often sat in on the first interview with the patient, and contributed to the discussion. The first carer interview followed a similar pattern to that of the patient, but with a particular focus on the carer perspective. The consent form was signed after discussion. The same Demographic Data Sheet was administered, but the Illness Details Form (Appendix 15) differed slightly. At first interview, the Present Care schedule, adapted for carers, was used (Appendix 11). Instead of the POS, the General Health Questionnaire (GHQ) (Goldberg, 1988) (see Appendix 16) was administered.

## **B. Bereaved carer interview**

The death of participants was notified to the project by referrers. At three months after the death a letter was sent to carers we had already made contact with (see Appendix 17). In most cases, we had already interviewed the carer, but in four cases we had only met the carer at the first interview with the patient and deterioration or death had meant that the second patient interview, and hence the first carer interview, had not been conducted. A refusal form (Appendix 17) and a pre-paid envelope were included with the letter, so that those carers who did not wish to be contacted again could notify us. If after two weeks the carer had not notified us of their refusal, they were telephoned and an appointment made. The Bereaved Carers interview schedule (Appendix 18) was used to guide the conversation (tape-recorded), and the GHQ administered.

*The presence of carers in patient interviews:* It was planned that carer and patient interviews would be conducted separately where possible, but both may have been present at any interview if they so wished. This was for the comfort of participants, as in our previous study we found that patient and carer often wish to be seen together (Morris, 2001). It was both for practical and ethical reasons that we allowed this to happen. With the frailer patients in this project, it was also good to have the carer present to take some of the strain off the patient. We also found that carers performed protective roles (for example, making sure the patient was not overtired, and not in pain), and often a 'clerical' role, as they tended to track and be able to describe the sequence of events (several referred to diaries they had kept). As the patients sometimes found it hard to recall events, due to symptoms or medication, this proved useful in getting a clearer picture of the context in which preferences emerged. Other studies have also reported that carers often prefer to be present in patient interviews in cancer (Beaver, Luker & Woods, 1999).

## **The problem of sample attrition**

The warnings given in the palliative care research literature about the difficulties of undertaking research with dying patients proved to be well-founded. In addition to the referral difficulties described above, we found that some patients became too ill to commence or continue with the series of interviews, or died somewhat earlier than expected (see details in the following chapter). Sample attrition has thus been a significant problem. Of the 41 patients who actually commenced the interview series, only 17 were able to see it through to completion; the others completed part of the series but then deteriorated.

Rinck et al (1997) found that in 4 out of 11 studies reviewed, attrition was a problem. Attrition rates of more than 60% have been described in other studies (Jordhøy et al, 1999). Another

problem (for us, but not, of course for respondents) was that a few patients remained relatively well for unexpectedly lengthy periods of time such that the planned schedule of interviews seemed inappropriate. Both problems (too ill or too well) relate to the great uncertainty involved in assessing illness stages and trajectories. We attempted to manage these problems by being somewhat flexible in the timing of contacts and interviews, that is, shortening or lengthening the time interval between contacts as seemed appropriate. We did, however keep fairly close to the original plan, and most interviews took place at time intervals of around two weeks to a month, with eleven cases having one interval of two months, and one exceptional case having one interval of three months<sup>8</sup>.

It has been noted that terminal patients who take part in research are generally more physically able (Raynes et al, 2000; Lawton, 2001) In our study those who felt too ill usually declined participation, either at the outset, or later in the series. Respondents appeared not to have trouble with this, and did not seem to have a feeling of obligation to carry on when ill. It was the case that some of the participants became tired during the interview, and efforts were made to keep these interviews particularly short. Some interviewees were breathless, and yet they expressed a willingness to talk. Often it was useful if an informal carer was present, as this allowed the participant some breathing space. The shortest interview was conducted with a woman living alone, who was clearly quite unwell. The researcher offered to abandon the arranged interview, but she said she was happy to take part, if it wasn't too long. Despite its shortness, her interview provided useful data on her circumstances, feelings and wishes.

The absence or non-participation of resident informal carers, and the attrition of the carer sample, was also an issue in this study. In 17 cases (41% of patients entering the interview series), the patient lived alone<sup>9</sup>. Some carers were unwilling or unable to participate. Three carers declined to be interviewed following the death. Thus we achieved fewer carer interviews than anticipated (see the following chapter for carer details). However, many elderly people with cancer do live alone and their situation is well represented in the sample.

### **Follow-up patient data**

We needed to have information about the actual place of death of the patients in our cohort. This could be obtained from carers where a post-bereavement interview took place. Our professional colleagues who had served as patient referrers were another valuable source of

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<sup>8</sup> In this case the participant had been referred early in the terminal phase, and in addition was quite disturbed about suggestions that he could become involved with hospice services. The time gaps were allowed in order to avoid distress. It is notable, however, that he became more accepting in later interviews.

<sup>9</sup> The General Household Survey reports that the percentage of households comprising one person living alone was 29% for people aged 65-74 in 2000, rising to 50% for those over 75.

information. In addition we requested information from the two hospices in the MB area so that actual place of death information for individuals could be confirmed and expanded upon. We are very grateful to hospice administrators for completing a Place of Care Form (Appendix 19), which included place and date of death, as well as day care usage and hospice in-patient admissions, for participants known to them.

## Interview data analysis

### **Patient and carer interview data**

All face-to-face interviews were fully transcribed. The patient and carer interviews were entered into the ATLAS.ti analysis programme (Scientific Software Development, 1997) and coded freely for content and themes. Each interview text was also coded for study site, age, gender, respondent (patient and/or carer), and patient tumour type. Using ATLAS.ti, a content analysis of each interview text was undertaken to identify topic categories, with new categories being added as they became apparent. In this way, 64 topic categories were generated, assisting in the manageability of this large data-set. For illustration, categories which featured in the majority of interview texts were (not in any order): preferences, carers, family, lay people other than family, uncertainty, identity, general practitioners, hospitals, hospices, information, nurses, mobility and medication. Other more specific categories, such as body issues, housing, support services, diet, and financial matters, tended to feature in a sizeable minority of cases.

The next stage in the analysis was the identification of analytical themes, although some of the topic themes became analytical themes. This was undertaken initially through the close reading and re-reading of all transcripts by SMM, and of a selection of transcripts by CT, to support the validity of interpretation. This process was then developed through the examination of selected text at the intersection between topic categories and sample characteristics (for example, identity and gender, information needs and informal carers). Sub-group analyses across a range of themes were also undertaken, for example, for: carers' experiences, and gender. Attention was paid to both typical and less typical cases. The interview data analysis thus approximated a grounded theory approach (Bowling 1997) wherein topic categories and analytical themes were derived from, and constructed through, a systematic engagement with the data. We also examined the ways in which theme convergences were presented at interview, particularly in joint patient/carer interviews. In this we used a dialogic analysis, related to both discourse and conversational analysis, but drawing its strength from its focus on relationality between the participants and the context of the speech act (Shotter 1995). In this part of the analysis we paid particular attention to the styles used and the interaction between speakers and addressees (Bakhtin 1986; Holquist 1990).

In addition a half-day workshop was held in March 2002 involving six members of the project team. Two case studies were circulated prior to the meeting, and participants were asked to reflect on their initial reactions, what the important features were, and how the transcripts related to the research questions. As the participants came from academic, practitioner and managerial backgrounds, the session offered the chance to explore different perspectives on the data. The ensuing discussion, which involved a pooling of ideas, reflection on the process of analysing and a consideration of ethical issues, was tape recorded and used as an additional resource in the analysis.

### **Health Professionals interview data**

All health and social care personnel interviews were fully transcribed and analysed manually. Again this was undertaken initially through the close reading and re-reading of all transcripts, followed by the organisation of data into categorical and analytical themes. CT took the lead in the analysis of this data set and SMM examined a selection of transcripts, to support the validity of interpretation.

### **Integration of themes**

Through comparison and integration of the findings generated through the independent analysis of the project's various data-sets, members of the project team (CT, SMM) have sought to identify the overarching findings emerging from this study and to present these using the project's objectives and research questions as the organising framework.

## Chapter 4

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### Sample characteristics

This chapter sets out the key characteristics of our interview samples: professional, patient and carer. It gives details of the referred patient sample and of the patients participating in the interview series. Response rates are considered, as is the attrition involved in the patient and carer interview series. Some findings from the analysis of the patient cohort data are then presented, focusing on place of death preferences and outcomes. The latter provides a useful reference point for later chapters examining the experiential accounts of patients and carers.

#### The interview sample of health professionals

With two exceptions, the professionals who participated in this element of the research were practising in health settings located in MB area<sup>10</sup>. One volunteer worker was also interviewed. In all 19 individuals were approached for interview and 16 agreed to take part. Those who declined to participate were two doctors and one nurse. Interviews were recorded between January 2001 and May 2002. Most interviews were conducted in the participant's workplace, but two took place at the interviewee's home address. As described in the previous chapter, some of the professionals took part in both our project (POD) and Hospice Histories Project (HHP) interviews. The POD interviews lasted between 13 and 54 minutes (average: 28 minutes), the HHP interviews lasted between 28 and 64 minutes (average: 42 minutes). Table 3 sets out the sample characteristics.

#### A note on anonymity

The HHP interview was of its nature in the public domain, and participants understood this. All were provided with, and asked to approve, a transcript of their own interview and a copy of the summary produced by the Research Associate, which were to be posted on the HHP web site along with individuals' name and photograph. A formal consent form was signed and returned to the HHP. For the POD interview, we discussed maintaining anonymity with each participant, and explained that this would not be fully possible, due to the small numbers of palliative specialists in the locality. We offered to return transcripts to interviewees for approval, and several participants took up this offer. In the event, only one participant decided to veto a small part of their interview.

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<sup>10</sup> The exceptions were a service manager who had recently moved to a new job in another area, but who had previously worked for MBHA and a retired nursing team leader who had worked for many years in the area.

**Table 3: The interviewed health professionals sample**

The health professional sample		
<b>Participants' professions:</b>		
<u>Doctors</u>		<b>6</b>
Palliative Consultants	(2)	
Other Consultants	(1)	
Medical Director (hospice)	(2)	
Medical Officer (hospice)	(1)	
<u>Nurses</u>		<b>6</b>
Specialist Nurses	(4)	
District Nurse (special interest)	(1)	
Team Leader (retired)	(1)	
<u>Managers</u>		<b>2</b>
Hospice	(1)	
PCG chief executive	(1)	
<u>Social Workers</u>		<b>1</b>
Specialist social worker	(1)	
<u>Volunteers</u>		<b>1</b>
Lancaster	(1)	
<b>Total:</b>		<b>16</b>
<b>Participation in interviews:</b>		
Care preferences project		15
Hospice History project		9
<b>Total interviews:</b>		<b>24</b>
<b>Gender:</b>		
Male		7
Female		9
<b>Age:</b>		
Average		51
Range		35-64
<b>Location (professional) of interviewees:</b>		
Lancaster		9
Barrow/Ulverston		4
Kendal		2
Other		1

## Patient and carer interviews

### Patients

The recruitment procedures (described in the previous chapter) produced 79 referrals of people identified as having end stage cancer, over a period of eleven months (February 2001-December 2001). Of these 33 (42%) of were male and 46 (58%) were female. The average age of those approached was 66 years<sup>11</sup>. Thirty-four patients resided in the area served by the

<sup>11</sup> Missing data on age in 2 cases.

Lancaster-based Macmillan nurses, 25 in the area served by the Kendal-based Macmillan nurses and 20 in the area served by the Barrow-based Macmillan nurses.

## Referred patients

*Stage one approach to patients:* Of the 79 patients approached by referrers, 10 had told referrers that they did not wish to take part; 6 expressed a willingness to participate but could not be contacted because their health had deteriorated or because they died too quickly; 1 patient became too well to participate<sup>12</sup> - see Table 4.

**Table 4: Referral advice for all cases referred**

Patient to be contacted	62
Do not contact (refused to participate)	10
Do not contact (willing, but too ill/dying)	6
Do not contact (willing, but too well with new treatment)	1
<u>Total</u>	<u>79</u>

This left 62 patients to be contacted by the Research Associate.

## Contacted patients

*Stage two approach to patients:* All of the 62 patients remaining were contacted - see Table 5 for the outcomes. Three patients refused to participate at this stage. A further 18 were willing to be interviewed but quickly became too ill to commence the interview series (in six cases interviews were arranged, but cancelled due to worsening symptoms).

**Table 5: Patients contacted by researcher**

Interviewed	41
Contacted, willing, but too ill to interview	12
Interview arranged but cancelled due to ill health	6
Contacted but refused	3
<u>Total</u>	<u>62</u>

## Response rates: characteristics of patients unwilling to participate:

We can see from Table 4 that the stage one ‘willing to participate’ response rate was 90%, but only 78% could actually be contacted. However, these figures have to be treated with some caution because one or two of our referring professionals may not have notified us of all

patients actually approached. The stage two 'willing to participate' response rate was 95%, but as noted above, the attrition rate was such that only 41 of 59 willing patients (69%) commenced the interview series. The referral forms for those patients who refused to participate either at the stage one (anonymised forms) or stage two approaches provided some useful information (13 cases in total). 'Refusers' consisted of six men and seven women, with an average age of 69 years (range: 51-87). Seven resided in the area served by the Lancaster-based Macmillan nurses, three in the area served by the Kendal-based Macmillan nurses, and three in the area served by the Barrow-based Macmillan nurses. Three of the refusers had a colorectal tumour, two had respiratory tumours, two had gastric and oesophageal cancer, and two had breast cancer. One had a cancer with an unknown primary site, and the remaining three suffered from bladder cancer, myeloma, or ovarian cancer.

On the referral form, reasons for refusal were sometimes suggested by the referrer. In eight cases anxiety or difficulty dealing with the diagnosis in either the patient or carer were cited. In one case the patient lived abroad. In another the patient had just moved into a nursing home and was settling down. No reason was given in the remaining three cases.

### **Interviewed patients**

In total, 41 patients were interviewed at least once. Of these 24 (59%) were female and 17 (41%) were male. Their average age was 67 years (range 41-88). Seventeen patients resided in the area served by the Lancaster-based Macmillan nurses, 12 in the area served by the Kendal-based Macmillan nurses, and 12 in the area served by the Barrow-based Macmillan nurses. There was no resident carer in 17 cases. A variety of tumour types were represented, with larger proportions for the more common cancers. Details are given in Table 6. All patients and carers were from a White ethnic group (reflecting the overwhelmingly White composition of the population in the MB area), with many having been born and raised in this locality.

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<sup>12</sup> He was treated with thalidomide, which caused a good remission.

**Table 6: The patient interview sample**

<b>The Patient sample</b>		
<b>Gender:</b>	Male	17
	Female	24
<b>Age:</b>	Mean	67
	Range	41-88
<b>Tumour type:</b>	Lung	9
	Colorectal	8
	Breast	6
	Oesophagus/gastric	6
	Ovarian/endometrial	4
	Prostate	2
	Other	6
<b>Lives with carer:</b>	Yes	24
	No (lived alone)	17
<b>Location:</b>	Lancaster	17
	Barrow	12
	Kendal	12
<b>Total:</b>		<b>41</b>

**Place of death of this patient cohort**

The data we collected from the local hospices on participants, along with data from the carer interviews, provided information on date and place of death, and on hospice usage. These are presented in Tables 7 and 8.

**Table 7: Place of death**

	Total: 41 <i>% given for those who have died</i>
Died at home	8 (23.5%)
Died in hospice	17 (50%)
<u>Died in hospital</u>	7 (20.5%)
Died in nursing home	1 (3%)
Place of death uncertain, but died either at home or in hospice*	1 (3%)
Still alive at the end of the study	7

\* We contacted the health professionals involved in this case but they were unable to confirm whether the death had occurred at home or in hospice, but they were certain that it had occurred in one of these two settings.

**Table 8: Hospice usage**

	Of 41 cases (not all of whom have died):
Died in hospice	17
Attended Day Care at hospice	17
Was an in-patient at hospice	24
Attended Day Care at hospice and was an in-patient at hospice	20
Range of number of hospice in-patient episodes	1-12
No. of patients with no direct contact with hospice	10

## Carers

Carers were recruited into the study via our contact with patients, and were not approached by health personnel in the first instance. It was felt important that the patient should identify their main carer during the first interview. If the carer was co-resident s/he was usually asked for a (later) interview at the time of the first patient visit. In practice, the carer was sometimes present during the first interview with the patient (10 cases, see the discussion in the previous chapter on this). This was especially true where there an older couple were involved. Twenty-five resident carers were identified, and 18 agreed to take part<sup>13</sup> (a response rate of 72%; all 7 'refusers' were male). Of those that refused, five just said they were not willing, one was very frail, and one gave full time work as a reason.

We only approached bereaved carers where contact had already been made while the patient was alive. A letter was sent offering a chance to refuse, before telephone contact was made. Three bereaved carers returned the slip stating that they did not want to be contacted, but nine agreed to be interviewed.

## Interviewed carers

Eighteen carers participated in at least one interview. Almost equal numbers of female (n=13) and male (n=12) carers were identified, but all the refusers were male, which meant that the final sample had a higher proportion of women carers (72%). The carers' average age was lower than that of patients at 61 years (range: 33-82). The majority of the sample (n=14) were in a spousal relationship to the patient, and sixteen had been living with the patient prior to the diagnosis. One patient had moved in order to live with his sister after diagnosis, and one carer was prepared to move in with the patient if necessary, but at the time of interview lived in her own house. Nine carers resided in the area served by the Lancaster-based Macmillan nurses, six

<sup>13</sup> In fact, one carer was not co-resident but was the patient's daughter who lived close by. She was included in the carer sample because she spent a great deal of time with the patient (who lived alone) and was present during the first visit to the patient's home.

in the area served by the Kendal-based Macmillan nurses, and three in the area served by the Barrow-based Macmillan nurses. See Table 9.

**Table 9: The interviewed carer sample**

<b>The Carer sample</b>		
<b>Gender:</b>	Male	5
	Female	13
<b>Age:</b>	Mean	61
	Range	33-82
<b>Relationship to patient:</b>	Wife	10
	Husband	4
	Sister	2
	Daughter	1
	Son	1
<b>Lived with patient prior to cancer diagnosis:</b>	Yes	16
	No	2
<b>Location:</b>	Lancaster	9
	Barrow	3
	Kendal	6
<b>Total:</b>		18

**Completed interviews in the series: with patients and carers**

The interviews took place between February 2001 and June 2002. All interviews, bar two (which took place in St. John's Hospice), were conducted in the patients' homes. In total, 87 face-to-face interviews and 38 telephone interviews with patients and carers were conducted. See Table 10.

**Table 10: total interviews**

Total no. face-to face interviews with patients	65
Total no. face-to face interviews with carers	22
Overall total no. face-to-face interviews	<b>87</b>
Total no. telephone tracking interviews	38

There was a high rate of attrition, with only 17 patients completing the whole interview series (41%). Once the initial interview had taken place, however, none dropped out due to refusal. All those that failed to complete the series did so because of worsening symptoms or death. In all, twenty-three face-to-face interviews with carers took place, 14 while the patient was still alive and nine after the patient had died. In four cases the first interview with the carer had not taken place, although they had been asked and were willing. This was usually due to the patient's worsening condition. In these cases the carer was approached for bereavement interview. See Table 11.

**Table 11: Completed interviews with patients and carers**

First interview with patient completed	41
Second interview with patient completed	24
First tracking interview completed	21
Second tracking interview completed	17
Patient died or too ill before completing series	24
Completed series with patient	17
First interview with carer completed	14
Bereaved carer interview completed	9

The interviews lasted between 11 and 74 minutes. The average time for the recorded interview was 37-39 minutes for first patient and carer interview and second patient interview, but the bereaved carer interviews tended to be longer, averaging 47 minutes. See Table 12.

**Table 12: Length of interview recordings with patients and carers (in minutes)**

Type of interview	Average time (minutes)	Range (minutes)
First patient	39	11-67
Second Patient	37	14-71
First carer	37	10-67
Bereaved carer	[47]	[27-74]

### Patient cohort characteristics

Table 13 gives a profile of every patient entering the interview series; patients are grouped by area of residence: the Barrow/Ulverston, Kendal and Lancaster areas. Housing tenure and occupation (prior to retirement if applicable) are useful indicators of individuals' socio-economic status. This Table serves as a useful reference point when examining the chapters presenting extracts from the interviews (the patient identification number (ID) allows these individual profiles to be linked to individuals' narrative accounts).

**Table 13: Characteristics of all cancer patients in the interview series: clinical, social, place of death preference and outcome**

ID <sup>1</sup>	Sex	Age	Tumour Type	Lives with	Location	Tenure <sup>2</sup>	Occupation (prior to retirement if marked ®)	Contact with a Hospice <sup>3</sup>	Expressed Preference For Place Of Death	Place Of Death
B1	Female	50	Lung	Alone	Hamlet	Owner	Teacher	Yes	Home/Hospice	Hospice (U)
B10	Female	63	Unknown	Husband	Village	Owner	Accounts clerk ®	Yes	Home/Hospice	Hospice (U)
B11	Male	72	Bowel	Wife	Village	Owner	Pathologist ®		Home	Home
B12	Female	82	Bowel	Alone	Town	Owner		Yes	Home/Hospice	Unclear: home or hospice <sup>4</sup>
B2	Male	65	Lymphoma	Alone	Hamlet	Owner	Vicar	Yes	Not decided	Hospital
B3	Female	79	Breast	Retirement home	Small town	Rent – p	Nurse ®	Yes	Not decided	Alive (Oct. 2002)
B4	Female	73	Ovary	Alone	Hamlet	Owner	Domestic ®		Home/Hospice	Home
B5	Female	76	Colorectal	Alone	Town	Owner	Microfilm clerk ®	Yes	Home/Hospice	Hospice (U)
B6	Female	61	Breast	Husband	Small town	Rent – p	Care assistant		Hospice	Alive (Oct. 2002)
B7	Male	57	Lung	Female partner	Town	Rent – c	Technical clerk	Yes	Not decided	Hospice (U)
B8	Male	63	Prostate	Wife	Town	Owner	Manager ®	Yes	Home	Hospital
B9	Female	85	Oesophagus	Alone (recently moved into nursing home)	Hamlet	Rent – p	Nurse ®		Nursing Home	Hospital
K1	Male	67	Colorectal	Wife, father	Small town	Owner	Manager ®	Yes	Home *	Home
K10	Female	77	Breast	Alone	Town	Owner	Nurse ®		Not decided	Alive (Oct. 2002)
K11	Male	79	Gastric	Wife	Town	Owner	Civil servant ®		Not decided	Hospice
K12	Female	65	Ovarian	Husband	Village	Owner	Teacher ®		Home	Home
K2	Male	64	Prostate	Wife	Small town	Owner	Teacher ®	Yes	Not decided	Nursing Home
K3	Female	67	Ovary	Husband	Hamlet	Owner	Farmer ®	Yes	Hospice	Hospice (L)
K4	Male	50	Lung	Alone	Hamlet	Rent - p	Professional	Yes	Home	Hospice (U)
K5	Female	67	Colorectal	Husband	Small town	Owner	Family business ®	Yes	Hospice	Hospice (L)
K6	Female	75	Lung	Son	Town	Rent – c	Domestic ®	Yes	Hospice	Alive (Oct. 2002)

<b>K7</b>	Female	72	Lung	Son	Town	Owner	Domestic ®		Hospice *	Alive (Oct. 2002)
<b>K8</b>	Female	44	Breast	Alone	Town	Owner	Accountant	Yes	Hospice/home	Hospice (L)
<b>K9</b>	Female	84	Lung	Alone	Small town	Owner	®		Hospice	Alive (Oct. 2002)
<b>L1</b>	Male	69	Oesophagus	Wife	Town	Rent – p	Engineer ®	Yes	Home	Hospital
<b>L10</b>	Male	56	Renal	Wife	City	Owner	Lecturer ®		No Preference	Hospital
<b>L11</b>	Female	48	Breast	Husband, daughter, grandchild	City	Rent – c	Domestic	Yes	No Preference	Alive (Oct. 2002)
<b>L12</b>	Female	70	Colorectal	Husband	City	Rent – c	Domestic ®	Yes	Home	Home
<b>L13</b>	Male	77	Lung	Alone	City	Rent – c	Bus driver ®	Yes	Home	Home
<b>L14</b>	Male	72	Gastric	Wife	Town	Owner	Civil engineer ®	Yes	Home	Home
<b>L15</b>	Male	63	Bladder	Sister	City	Rent – c	Labourer	Yes	Hospice	Hospice (L)
<b>L16</b>	Female	70	Lung	Alone	City	Rent – c	Domestic ®	Yes	Not decided	Hospice (L)
<b>L17</b>	Female	81	Stomach	Alone	City	Rent – c	Domestic ®	Yes	No Preference	Hospital
<b>L2</b>	Male	41	Thyroid	Wife	Town	Owner	Electrical inspector	Yes	Home/Hospice	Hospice (L)
<b>L3</b>	Female	43	Breast	Husband, son	Village	Owner	Care assistant	Yes	Hospice	Hospice (L)
<b>L4</b>	Male	57	Pancreas	Alone (staying with Sister, brother-in- law)	Hamlet	Owner	Manager	Yes	Home/Hospice	Hospice (L)
<b>L5</b>	Female	76	Bowel	Husband	Village	Owner	Opera singer ®		Not decided	Hospital
<b>L6</b>	Female	72	Oesophagus	Alone	City	Rent – c	Publican ®	Yes	Not decided	Home
<b>L7</b>	Female	60	Endometrium	Alone	Town	Owner	®	Yes	Home	Hospice (L)
<b>L8</b>	Male	79	Colorectal	Wife	City	Owner	Fireman ®	Yes	Not decided	Hospice (L)
<b>L9</b>	Male	88	Lung	Alone	City	Rent – c	Joiner ®	Yes	Home/Hospice	Hospice (L)

Key:

1. B= lives in the area served by the Barrow based Macmillan nurses; K= lives in the area served by the Kendal based Macmillan nurses; L= lives in the area served by the Lancaster based Macmillan nurses
  2. Tenure: Housing tenure. Owner = owner occupier; Rent-p = privately rented accommodation; Rent-c = council rented accommodation
  3. Contact with a Hospice: either as an in-patient and/or as a Day Care patient
  4. In this case, the patient's GP and SPCN did not know whether the patient died at home or in hospice – but the place of death was definitely one or the other.
- \* In these two cases it is the patients overriding preference that is recorded here (c.f. Table 20)

## Carer characteristics

Table 14 gives a profile of every carer interviewed. Carers carry the patients' ID numbers (for linkage) and are grouped by area of residence: the Barrow/Ulverston, Kendal and Lancaster areas.

**Table 14: Characteristics of all carers in the interview series**

ID (patient)	Carer's sex	Relation -ship to patient	Age	Patient's tumour	Carer's occupation (prior to retirement if marked ® )	Carer's own health problems
B11	Female	Wife	70	Bowel	Auxilliary nurse ®	Heart failure
B2	Female	Daughter	33	Lymphoma	Nurse P.T.	No
B8	Female	Wife	60	Prostate	Personal Assistant ®	Spinal operation
K1	Female	Wife	63	Colorectal	Teacher	No
K11	Female	Wife	76	Gastric	Civil servant ®	Arthritis
K2	Female	Wife		Prostate	Housewife	No
K3	Male	Husband	67	Ovary	Farmer ®	Parkinson's
K5	Male	Husband	67	Colorectal	Tourism and transport	Has developed cancer
K6	Male	Son	38	Lung	Builder (u/e)	Testicular cancer
L1	Female	Wife	77	Oesophagus	Office cleaning ®	Deafness
L10	Female	Wife	52	Renal	Music teacher	No
L11	Male	Husband	49	Breast	Quality control-factory	No - but recent incapacity: depression
L14	Female	Wife	70	Gastric	Hospital admissions officer ®	Stomach problems
L2	Female	Wife	40	Thyroid	Cleaner (p/t)	No
L4	Female	Sister	58	Pancreas	Small business ®	No
L5	Male	Husband	75	Bowel	Manager ®	Heart disease
L8	Female	Wife	82	Colorectal	Office work ®	No
L15	Female	Sister	66	Bladder	Waitress ®	Heart disease

## Patient cohort: place of death patterns and preferences

Although the numbers of patients in our interview cohort are small and the sample biased in favour of patients with some contact with specialist palliative care services (see the previous chapter), it is of interest to look for patterns in the data. In so doing, it should be noted that patients in contact with specialist palliative care services have a greater chance than other cancer patients of accessing services that can facilitate a home death. Tables 15 to 18 show place of death preferences (for patients who have died) by actual place of death, first for the sample as a whole, then (despite the very small numbers) for sub-samples in the three areas of residence in this study (Barrow/Ulverston area, Kendal/South Lakes area, Lancaster/Morecambe area). What emerges in these tables is that:

- Of those who had died by the end of the study (n=34), half died in hospice (50%, n=17), a quarter died at home (24.5%, n=8), a fifth died in hospital (20.5%, n=7) (in addition, one died in a nursing home, and one died either at home or in hospice). In chapter 6 we report on the analysis of 6,900 cancer deaths in the MB area (1993-2000); this produced a baseline place of death pattern that contrasts with our sample findings: 33% of MB deaths occurred in hospice, 22% at home, and 35% in hospital. Clearly, a higher proportion of patients in the sample died in hospice and far fewer died in hospital than would have been predicted; but similar percentages are found for home deaths (24.5% and 22%). This contrast highlights the biases in our sample, as discussed in Chapter 3.
- 60% (n=6) of deceased patients whose sole preference was to die at home actually died at home.
- 100% (n=4) of deceased patients whose sole preference was to die in hospice actually died in hospice.
- 100% (n=9) of deceased patients whose preference was to die *either* at home *or* in hospice actually died at home or in hospice; 7 of these 9 died in hospice.
- No deceased patients had a preference to die in hospital, though 7 did die there.
- Of deceased patients whose sole preference was to die at home, 50% (n=2) in the Barrow/Ulverston area died at home; 66% (n=2) in the Kendal/South Lakes area died at home; 60% (n=3) in the Lancaster/Morecambe area died at home.
- Of those patients who expressed a preference for place of death (n=28), 36% (n=10) preferred a home death; 29% (n=8) preferred a hospice death, 32% (n=9) preferred a home *or* hospice death; 3% (n=1) preferred a nursing home death. Another way of putting this is that a home death would be a *preferred or acceptable* option for 68% (n=19) of patients while a hospice death would be a *preferred or acceptable* option for 61% (n=17) of patients. It is interesting to compare our preference pattern with that of other studies (see Chapter 2). The Townsend et al (1990) study, which we drew upon in the design of this project (see Chapter 3), found that of the 59 patients (from a sample of 84) with terminal cancer who stated a preference for place of death, 34 (58%) chose home, 12 (20%) hospital and 12 (20%) hospice (1 for 'other'). In a larger study (Dunlop 1989) of 160 patients referred to a hospital support team, of the 90 who could express a preference the majority chose home (48, 53%), with 26 (29%) preferring hospice, 13 (14%) hospital and 3 (3%) a nursing home.

Table 19 shows the place of death of patients by their living circumstances – whether they lived alone or with others. It reveals that:

- 21% (n=3) of deceased patients who lived alone died at home compared with 28% (n=5) of patients who lived with others. Thus living alone did not automatically result in death in an institutional setting.

Table 20 enables us to look at the degree to which patients changed their preference for place of death over time, or to be more precise, during the course of the interview series (in the presentation of results above and elsewhere, the place of death preference is recorded as the one first expressed). For those cases where the interview series was completed (n=17), it shows that:

- Four (23%) changed or altered their preference. One changed from ‘home if possible’ to ‘hospice’, one changed from ‘hospice if I’m bad’ to ‘home’, one expanded his preference from ‘hospice’ to ‘hospice or local hospital’, one slightly altered his preference from ‘home or hospice’ to ‘hospice or home’ (that is, hospice became the favoured of the two options).

**Table 15: The preferred and actual place of death of patients in the MB area**

Preference for place of death	Actual place of death – MB area							
	Home	Hospice	Hospital	Other	Alive (Oct. 2002)	Total (Preference)		Preference met (of those who died)
	<i>n</i>	<i>n</i>	<i>n</i>	<i>n</i>	<i>n</i>	<i>n</i>	%	%
<b>Home</b>	6	2	2			10	24%	60%
<b>Hospice</b>		4			4	8	20%	100%
<b>Home or Hospice</b>	1	7		1*		9	22%	100%
<b>Hospital</b>							0%	
<b>Other</b>			1			1	3%	0%
<b>Not decided</b>	1	4	2	1	2	10	24%	
<b>No Preference</b>			2		1	3	7%	
<b>Total (Place died)</b>	8 (24.5%)	17 (50%)	7 (20.5%)	2 (6%)	7	41 (100%)		

\* This person’s place of death is not certain, but was either home or hospice.

**Table 16: The preferred and actual place of death of patients in the Barrow/Ulverston area**

Preference for place of death	Actual place of death – Barrow/Ulverston area						
	Home	Hospice	Hospital	Other	Alive (July 2002)	Total (Preference)	Preference met (of those who died)
	<i>n</i>	<i>n</i>	<i>n</i>	<i>n</i>	<i>n</i>	<i>n</i>	%
<b>Home</b>	1		1			2	50%
<b>Hospice</b>					1	1	-
<b>Home or Hospice</b>	1	3		1*		5	100%
<b>Hospital</b>							
<b>Other</b>			1			1	0%
<b>Not decided</b>		1	1		1	3	
<b>No Preference</b>							
<b>Total (Place died)</b>	2	4	3		3	12	

\* This person’s place of death is not certain, but was either home or hospice.

**Table 17: The preferred and actual place of death of patients in the Kendal/South Lakes area**

Preference for place of death	Actual place of death – Kendal area						
	Home	Hospice	Hospital	Other	Alive (July 2002)	Total (Preference)	Preference met (of those who died) %
	<i>n</i>	<i>n</i>	<i>n</i>	<i>n</i>	<i>n</i>	<i>n</i>	
<b>Home</b>	2	1				3	66%
<b>Hospice</b>		2			3	5	100%
<b>Home or Hospice</b>		1				1	100%
<b>Hospital</b>							
<b>Other</b>							
<b>Not decided</b>		1		1	1	3	
<b>No Preference</b>							
<b>Total (Place died)</b>	2	5		1	4	12	

**Table 18: The preferred and actual place of death in the Lancaster/Morecambe area**

Preference for place of death	Actual place of death – Lancaster area						
	Home	Hospice	Hospital	Other	Alive (July 2002)	Total (Preference)	Preference met (of those who died) %
	<i>n</i>	<i>n</i>	<i>n</i>	<i>n</i>	<i>n</i>	<i>n</i>	
<b>Home</b>	3	1	1			5	60%
<b>Hospice</b>		2				2	100%
<b>Home or Hospice</b>		3				3	100%
<b>Hospital</b>							
<b>Other</b>							
<b>Not decided</b>	1	2	1			4	
<b>No Preference</b>			2		1	3	
<b>Total (Place died)</b>	4	8	4		1	17	

**Table 19: Actual place of death of patient by whether patient lives alone**

Living circumstances	Actual place of death – MB area							
	Home	Hospice	Hospital	Other	Alive (July 2002)	Home deaths of whole sample %	Home deaths of those who have died %	Total
	<i>N</i>	<i>n</i>	<i>N</i>	<i>n</i>	<i>n</i>	%	%	
<b>Lives alone</b>	3	8	3	1*	2	18%	21%	17
<b>Lives with others</b>	5	8	4	1	6**	21%	28%	24
<b>Total</b>	8	16	7	2	8	20%	25%	41

\* This person's place of death is not certain, but was either home or hospice.

\*\*one woman lives in a retirement home

**Table 20: Patient change in place of death preference over the course of the interview series**

ID <sup>1</sup>	Sex	Lives with	Place of death preference at <u>start</u> of interview series	Place of death preference at <u>end</u> of interview series	Contact with a Hospice <sup>2</sup>	Place Of Death
B1	Female	Alone	Home if possible	Hospice	Yes	Hospice (U)
B10	Female	Husband	Home or hospice	Not Available	Yes	Hospice (U)
B11	Male	Wife	Home	Not Available		Home
B12	Female	Alone	Home or hospice	Home or hospice	Yes	Uncertain – home or hospice*
B2	Male	Alone	Not decided	Not decided	Yes	Hospital
B3	Female	Retirement home	Not decided	Not decided	Yes	Alive (Oct. 2002)
B4	Female	Alone	Home or hospice	Not Available		Home
B5	Female	Alone	Home or hospice	Not Available	Yes	Hospice (U)
B6	Female	Husband	Hospice	Hospice		Alive (Oct. 2002)
B7	Male	Female partner	Not decided	Not decided	Yes	Hospice (U)
B8	Male	Wife	Home	Not Available	Yes	Hospital
B9	Female	Alone (recently moved into nursing home)	Nursing home	Not Available		Hospital
K1	Male	Wife, father	Hospice if bad	Home	Yes	Home
K10	Female	Alone	Not decided	Not decided		Alive (Oct. 2002)
K11	Male	Wife	Not decided	Not decided		Hospice
K12	Female	Husband	Home	Not Available		Home
K2	Male	Wife	Not decided	Not Available	Yes	Nursing Home
K3	Female	Husband	Hospice	Not Available	Yes	Hospice (L)
K4	Male	Alone	Home	Home	Yes	Hospice (U)
K5	Female	Husband	Hospice	Hospice	Yes	Hospice (L)
K6	Female	Son	Not decided	Hospice	Yes	Alive (Oct. 2002)
K7	Female	Son	Hospice	Hospice or local hospital		Alive (Oct. 2002)
K8	Female	Alone	Home or hospice	Not available	Yes	Hospice (L)
K9	Female	Alone	Hospice	Hospice		Alive (Oct. 2002)
L1	Male	Wife	Home	Home	Yes	Hospital
L10	Male	Wife	No preference	Not Available		Hospital
L11	Female	Husband, daughter, grandchild	Not decided	Not decided	Yes	Alive (Oct. 2002)
L12	Female	Husband	Home	Home	Yes	Home
L13	Male	Alone	Home	Not Available	Yes	Home
L14	Male	Wife	Home	Home	Yes	Home
L15	Male	Sister	Hospice	Not Available	Yes	Hospice (L)
L16	Female	Alone	Not decided	Not decided	Yes	Hospice (L)
L17	Female	Alone	No preference	No preference	Yes	Hospital
L2	Male	Wife	Home or hospice	Not Available	Yes	Hospice (L)
L3	Female	Husband, son	Hospice	Not Available	Yes	Hospice (L)
L4	Male	Alone (staying with sister, brother-in-law)	Home or hospice	Home or hospice	Yes	Hospice (L)
L5	Female	Husband	Not decided	Not decided		Hospital
L6	Female	Alone	Not decided	Not Available	Yes	Home
L7	Female	Alone	Home	Home	Yes	Hospice (L)
L8	Male	Wife	Not decided	Not Available	Yes	Hospice (L)
L9	Male	Alone	Home or Hospice	Hospice or Home	Yes	Hospice (L)

Key: <sup>1</sup>B= lives in the area served by the Barrow based Macmillan nurses; K= lives in the area served by the Kendal based Macmillan nurses; L= lives in the area served by the Lancaster based Macmillan nurses

<sup>2</sup>Contact with a Hospice: either as an in-patient and/or as a Day Care patient

\* This person's place of death is not certain, but was either home or hospice.

## Chapter 5

### Place of cancer deaths in the Morecambe Bay area: a geo-epidemiological analysis

#### Introduction

One of this project's objectives was to attempt to answer the questions 'Where do cancer patients die in the MBA?' and 'Why do they die in these locations?' through the exploration of geographical variations in the place of death of all cancer patients in the area. What patterns in place of death could be discerned? And what geographically informed factors - for example, distance from service centres - could predict place of death?

In this chapter we present findings on the place-to-place variation in where cancer deaths occur using two scales of analysis; first, among small areas (electoral wards) and, second, among individuals. We use a range of possible predictors, both socio-demographic and geographical. The methods employed were outlined in Chapter 3, but are repeated here for ease of interpretation<sup>14</sup>.

#### Material and methods

The area covered by the former Morecambe Bay Health Authority has a population of approximately 320,000 persons. There are two main centres of population; Lancaster-Morecambe and Barrow. The area also includes the semi-rural district of South Lakeland, the main focus of which is the market town of Kendal. There are district General Hospitals in Lancaster and Barrow and a smaller hospital in Kendal. There are two hospices in the study area, one just north of Lancaster with 21 beds, the other in Ulverston (near Barrow) with 8 beds.

Anonymised patient data were provided by MBHA in 2000, and comprised the Death Extract File (1993-1997) and the Public Health Mortality File (1998-2000), as supplied by the Office of National Statistics (ONS). Data fields included: age at death; sex; year of death; postcode of home address; electoral ward of residence; place of death (home, hospital, hospice, nursing/retirement home, or elsewhere); and cancer site (tumour type). We removed from the file those deaths that occurred outside the study area. This yielded 6900 individuals, all with home addresses within 89 electoral wards of Morecambe Bay.

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<sup>14</sup> This chapter is based on a paper written for publication, and adopts a style of presentation that contrasts with the other chapters in this Report. The paper will appear in *Public Health Medicine* in 2003.

We added to the file the Carstairs deprivation index (Morris and Carstairs 1991) for each electoral ward, based on 1991 Census data. Using a postcode look-up table, relating postcode to Ordnance Survey grid reference, and digital road network data (from Bartholomews Ltd) we calculated travel distances by road from postcode of home address to the nearest hospital and hospice. We also constructed a notional hospital 'catchment area', based on travel distance to the nearest hospital; this served to distinguish between wards in the three main geographical areas: Lancaster/Morecambe; Barrow; and South Lakeland.

For the ward-level analysis we fit binomial regression models, using the GLIM (generalised linear modelling) package, modelling the observed proportion of deaths in each setting and using the total number of deaths as the binomial denominator (the sample size). We look first at the effect of deprivation but then control for possible proximity effects by including travel distance from ward centroid to nearest hospital and nearest hospice as predictor variables. We also see if the general relationship holds across all areas; does catchment area have any effect? We take the Lancaster/Morecambe area as the reference 'catchment'.

In the individual-level analysis we use binary logistic regression models, where we consider a death to be: at home (or elsewhere); in hospital (or elsewhere); and so on. These models are estimated using the SPSS package. Backward elimination with a 5 per cent significance level is used in both analyses to determine the best model. In the binomial regression models, goodness of fit is measured by 'scaled deviance'; for a well-fitting model the scaled deviance should not be much larger than the residual degrees of freedom. For the binary logistic regression models we express results in terms of odds ratios and 95 per cent confidence intervals. A variable is taken to be a good predictor if the confidence interval does not include unity. Lancaster-Morecambe is again taken as the reference area. Breast cancer is used as the reference category for tumour type, and male for gender. In the absence of any information on socio-economic status for individuals we have attached the ward-level Carstairs index to each patient; while crude, this provides one means of describing the areas within which patients live.

## Results

Of the 6900 deaths, 35 per cent occurred in hospital, 33 per cent in a hospice, and 22 per cent at home. Just over half of all deaths were due to cancers of either the digestive (29 per cent) or respiratory systems (24 per cent), with smaller proportions due to cancers of the breast, genitourinary, or lymphatic systems.

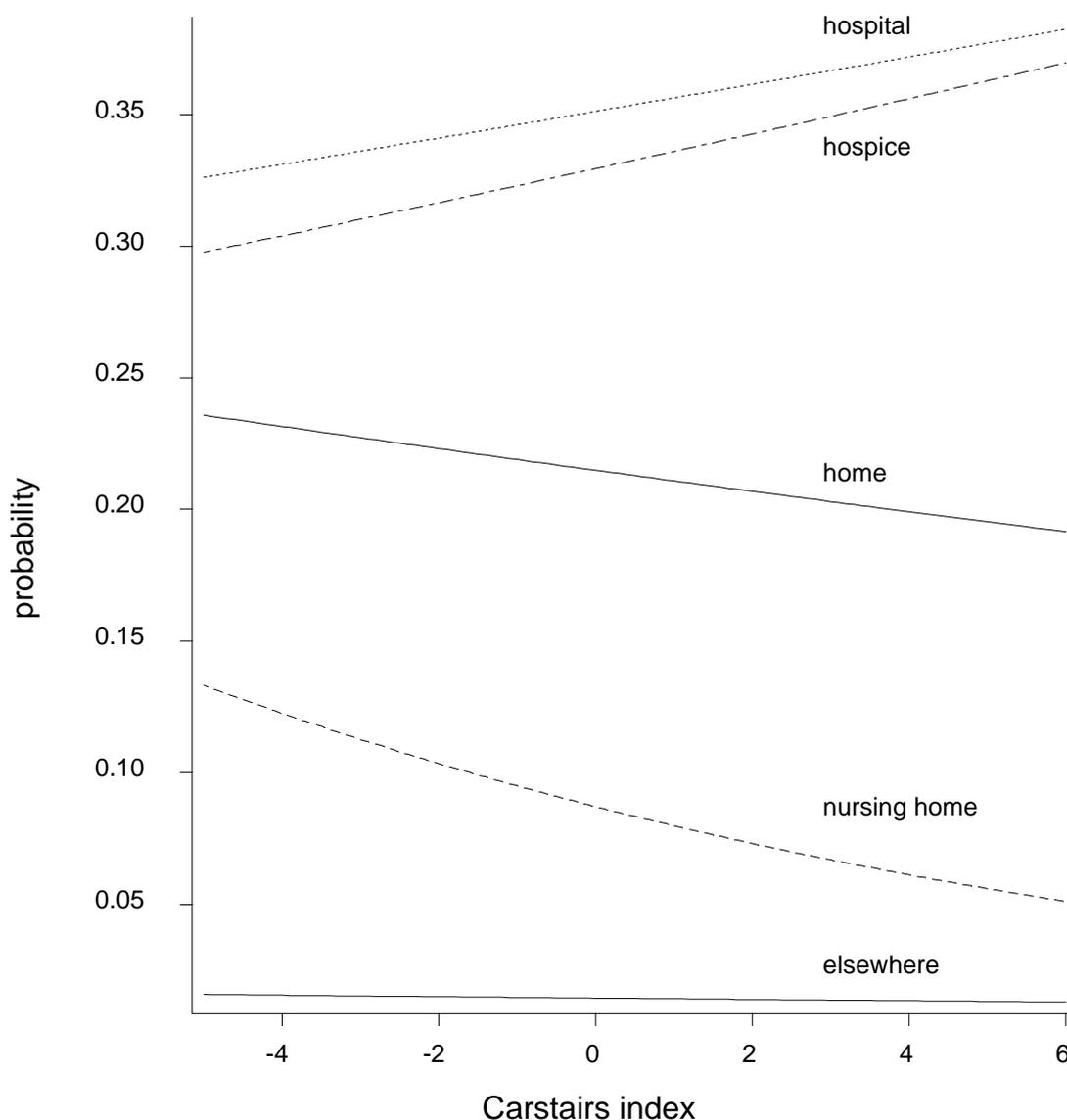
### Ward-level analysis

Results (Figure 1) indicate that the probability of dying in hospital or in a hospice increases with area deprivation, while the converse is so for dying at home or in a nursing or retirement home.

### Death at home

The only variable that predicts successfully the probability of dying at home is the catchment area. Small areas in South Lakeland (O.R. 1.337, C.I. 1.540-1.548)<sup>15</sup> and in the Barrow area (O.R. 1.321, C.I. 1.157-1.510) are significantly more likely to have cancer patients dying at home than those in Lancaster-Morecambe. The model fit (scaled deviance 147.2, 86 df) is not particularly good, however.

**Figure 1: Fitted probabilities against deprivation (Carstairs index)**



<sup>15</sup> O.R. = Odds Ratio; C.I. = Confidence Interval

### Death in hospital

These results (Table 21) indicate that there are independent effects, on the probability of dying in hospital, of both deprivation and proximity to place of death. Deprived wards are significantly more likely to have cancer patients dying in hospital. Small areas near a hospital are more likely to have patients die in hospital, while those living near a hospice are significantly less likely to die in hospital. The probability of dying in hospital is elevated if the patient was living in Barrow or South Lakeland. This model fits the data reasonably well (scaled deviance 103.6, 83 df).

**Table 21: Ward-level analysis**

#### a) Deaths in hospital

Parameter	O.R.	C.I.
Carstairs index	1.038	1.015-1.061
Distance to nearest hospital (kms)	0.982	0.973-0.992
Distance to nearest hospice (kms)	1.014	1.003-1.024
Barrow catchment	1.809	1.580-2.071
South Lakeland catchment	1.751	1.344-2.281

#### b) Deaths in nursing or retirement homes

Parameter	O.R.	C.I.
Carstairs index	0.934	0.899-0.970
Distance to nearest hospice (kms)	0.974	0.959-0.990
Distance to nearest hospital (kms)	1.029	1.012-1.045
Barrow catchment	0.879	0.706-1.095
South Lakeland catchment	1.357	0.921-2.000

### Death in hospice

Small areas in both the Barrow and South Lakeland 'catchments' are significantly less likely than in Lancaster-Morecambe to have cancer patients dying in hospice (O.R. 0.492, C.I. 0.429-0.564, and O.R. 0.518, C.I. 0.393-0.680, respectively). In addition, there are proximity effects, with wards relatively close to a hospice more likely to have patients dying in a hospice (O.R. 0.986, C.I. 0.976-0.996). This model fits the data well (scaled deviance 89.4, 85 df).

### Death in nursing or retirement home

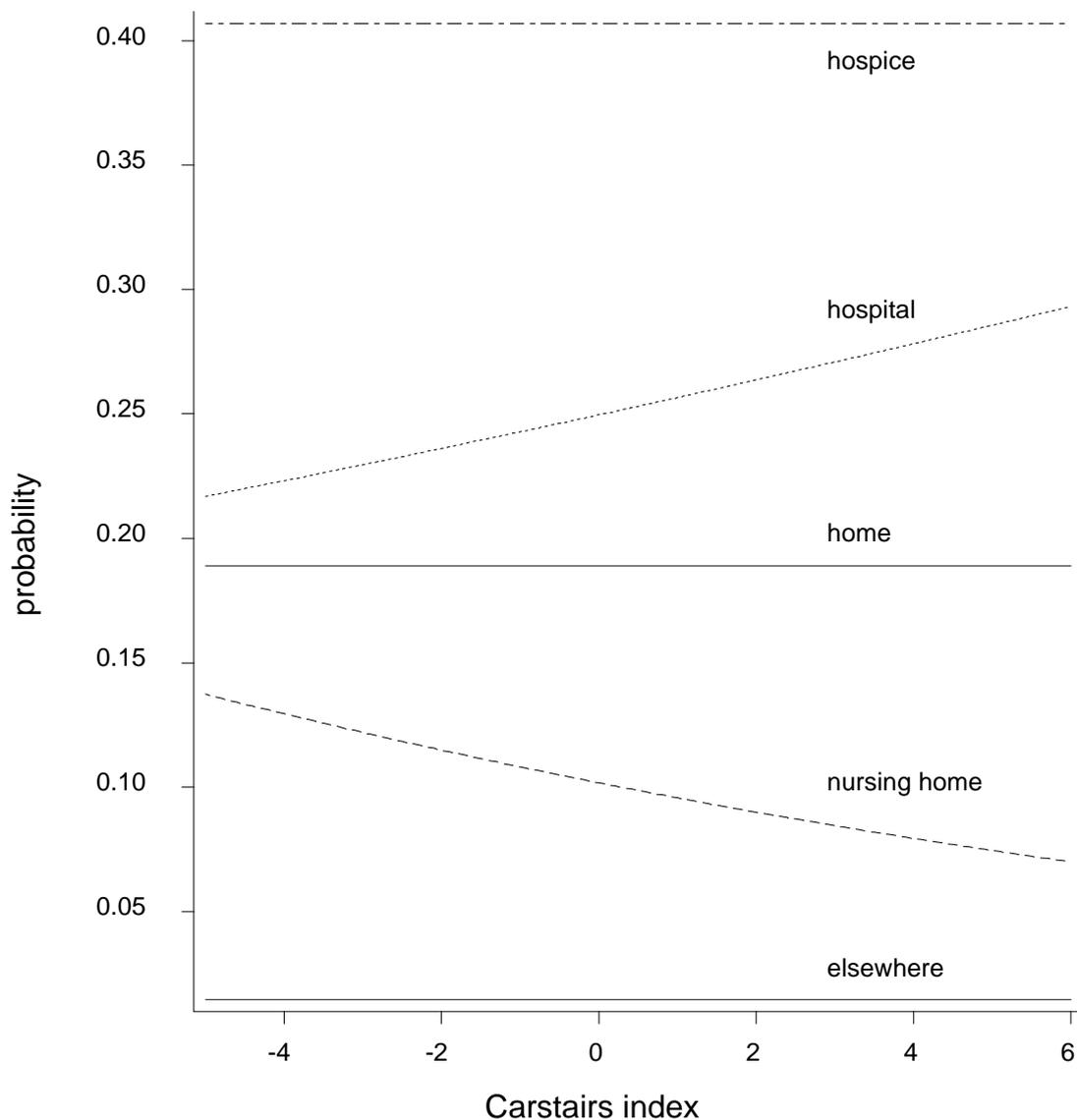
Ward-level deprivation is a significant determinant of whether patients from those wards die in a nursing or retirement home, with less deprived wards more likely to have patients dying there (Table 21). Electoral wards that are more remote from a hospital are significantly more likely to

have patients dying in a nursing or residential home; the converse is true of distance from a hospice. However, the model does not fit the data well (scaled deviance 285.6, 83 df).

Figure 2 summarises the effect of deprivation on place of death once other variables are controlled for, taking a hypothetical ward located about 15 kilometres from Lancaster. This shows that deprivation has no effect on the probability of dying either in a hospice or at home. As ward-level deprivation increases, and *controlling for other variables*, the probability increases that a deprived ward will generate more patients dying in hospital. Equally, a more affluent ward is more likely to generate more patients dying in a nursing or retirement home.

We conducted separate analyses on three subsets of cancers (respiratory, digestive and breast). The results are broadly consistent with those for all sites as a whole, though some variables (such as deprivation) have explanatory power for some tumour types and not others.

**Figure 2: Fitted probabilities against deprivation (Carstairs index) for a ward**



## Individual level analysis

### Death at home

The logistic regression model suggests that cancer patients are more likely to die at home if: they live in relatively affluent wards; they are male; they are relatively young; they have a cancer of the respiratory system; and live in Barrow or South Lakeland (Table 22a). They are much less likely to die at home if they have cancer of the lymphatic system (O.R. 0.592, C.I. 0.410-0.855). The probability of dying at home is higher in the earlier part of the study period.

**Table 22: Individual-level analysis**

#### a) Deaths at home

Parameter	O.R.	C.I.
Carstairs index	0.976	0.953-0.999
Age	0.979	0.974-0.983
Female	0.812	0.717-0.919
Lymphatic system	0.592	0.410-0.855
Respiratory system	1.338	1.034-1.731
Barrow catchment	1.264	1.105-1.445
South Lakeland catchment	1.334	1.139-1.562
Year of registration	0.973	0.948-0.998

#### b) Deaths in hospital

Parameter	O.R.	C.I.
Carstairs index	1.040	1.017-1.064
Age	1.015	1.010-1.019
Female	0.876	0.786-0.976
Lymphatic system	2.928	2.216-3.870
Barrow catchment	1.835	1.595-2.111
South Lakeland catchment	1.677	1.266-2.223
Distance from hospital (kms)	0.981	0.971-0.991
Distance from hospice (kms)	1.016	1.004-1.027
Year of registration	1.027	1.004-1.050

### c) Deaths in hospice

Parameter	O.R.	C.I.
Age	0.975	0.971-0.980
Lymphatic system	0.477	0.353-0.645
Barrow catchment	0.489	0.424-0.563
South Lakeland catchment	0.640	0.480-0.854
Distance from hospice (kms)	0.977	0.966-0.988

### d) Deaths in nursing home

Parameter	O.R.	C.I.
Carstairs score	0.959	0.921-0.997
Age	1.115	1.103-1.127
Female	1.391	1.150-1.683
Digestive system	0.575	0.411-0.805
Lymphatic system	0.468	0.283-0.772
Respiratory system	0.590	0.408-0.854
South Lakeland catchment	0.647	0.504-0.831
Distance from hospital (kms)	1.039	1.022-1.055

### Death in hospital

Cancer patients are more likely to die in hospital if: they live in more deprived electoral wards; they are male; if they are older people; and if they have cancer of the lymphatic system (Table 22b). The probability of dying in hospital has increased slightly during the study period. Those in Barrow are 84 per cent more likely to die in hospital, while those in South Lakeland are 68 per cent more likely to do so than those living in Lancaster. Patients living close to a hospital are more likely to die there. Those living further away from a hospice are more likely to die in hospital.

### Death in hospice

The probability of dying in a hospice increases if cancer patients are relatively young and live close to a hospice. Patients living outside the Lancaster area are between 36 and 51 per cent less likely to die in a hospice than those living within the Lancaster 'catchment', or if they have cancer of the lymphatic system (Table 22c).

### Death in nursing home

The probability of cancer patients dying in a nursing home increases if: they are female; they are older; and if they do not live near a hospital. Patients are less likely to die in a nursing or retirement home if they live in a deprived area, live in South Lakeland, and if they have cancer of the digestive, lymphatic and respiratory systems (Table 22d).

## Discussion

Earlier work (Higginson et al 1999) has shown that, for all electoral wards in England, there is an inverse association between the proportion of deaths at home and social deprivation. Our research in a small part of the country confirms this, but indicates that when we adjust for other influences this relationship disappears. Only the inverse relationship between the proportion of deaths in nursing homes and deprivation, and the positive association between the proportion of deaths in hospital and deprivation remain when we adjust for other factors. Small areas that are deprived are more likely to have higher proportions of deaths in hospital. This modifies the findings of others who have not adjusted for other variables (in particular, local variations in the supply of hospice services) when looking at home deaths and deprivation. Those living in more deprived areas may have fewer resources with which to gain access to nursing homes and may therefore be more likely to die in a hospital. These are our conclusions from analysing data aggregated to small areas.

We have only a limited set of data at the individual level to help predict place of death. Other studies (Sims et al 1997) have demonstrated that cancer patients in relatively unskilled occupational groups were more likely to die in hospital, and less likely to die in hospice, than those in higher status occupations. As Higginson and her colleagues (Higginson et al 1999) found, the relative paucity of occupational data in the death files renders difficult the assessment of the impact of social class on place of death. As in their study we simply used area deprivation as a surrogate. Interestingly, this variable is retained in the model, suggesting that 'area characteristics' (to the extent these may be captured by a deprivation score) may play some role in predicting place of death at the individual level.

We have found, in common with other studies, that there are associations between gender and age and place of death. Men are more likely to die at home but gender has no effect on the likelihood of death in hospice. Women are more likely to die in nursing homes. Younger patients are more likely to die at home or in a hospice, while older cancer patients are more likely to die in hospital. If it is assumed that most people would prefer to die at home, there are clearly inequalities according to age and gender in place of death.

Tumour type is a determinant of place of death, particularly for lymphatic cancer (and to a lesser extent, cancers of the respiratory and digestive systems). Those with lymphomas are much more likely to die in hospital (supporting Higginson's (1998) work and numerous studies reviewed elsewhere (Grande et al (1998), reflecting their longer stay for treatment and the closer association they perhaps have with hospital settings and staff. Those with respiratory cancers

are more likely to die at home (a finding again shared with Higginson and colleagues (Higginson et al 1998) and less likely to die in a nursing home. Like Higginson et al (1999) we find some evidence that the probability of death at home has declined during the study period.

As Higginson points out (Higginson et al 1999), we need data on supply-side variables to explain adequately variation in the proportion of home deaths; areas with high proportions may simply reflect an absence of specialist inpatient palliative care provision. We have taken into account the supply side by measuring proximity to hospitals and hospices. At the individual level these are significant influences; proximity to a hospice increases the probability that a cancer patient will die there while the same is true for hospitals.

Our results at aggregate and individual scales are broadly consistent. We have established that there is, in the Morecambe Bay area, distinctive geographical variation in the probability of cancer death in specific settings. Those in Barrow and South Lakeland are more likely to die at home or in hospital than those in Lancaster, while those in Lancaster are more likely to die in a hospice than are those elsewhere. Both gender and age are determinants of place of death. Male cancer patients are more likely than women to die at home or in hospital, while women are more likely than males to die in nursing homes. Younger patients tend to die at home, and older ones in hospital or nursing homes. These findings reflect patterns of caring and partnerships through the life-course. Many of these findings are consistent with those summarised elsewhere (Grande et al 1998).

Our results confirm the findings of earlier research into the determinants of home death among cancer patients, though we have extended previous analyses to examine other possible places of death. Most importantly, we have added geographical influences into the picture, since we need to account for proximity to alternative places of death and the extent to which such alternatives are distributed differentially.

## **Summary: key findings**

The geo-epidemiological analysis of 6,900 cancer deaths (1993-2000) in the MB area found that:

- 35% of deaths occurred in hospital, 33% in hospice, and 22% at home.
- Deprived electoral wards are significantly more likely to have cancer patients dying in hospital.
- Ward-level deprivation is a significant determinant of whether patients die in a nursing or retirement home, with less deprived wards more likely to have patients dying there.

- Ward-level deprivation has no effect on the probability of dying either in a hospice or at home.
- The probability of dying in hospital is elevated if the patient was living in Barrow or South Lakeland.
- There are proximity effects, with wards relatively close to a hospice *more* likely to have patients dying in a hospice. The same is true for hospital deaths.
- Cancer patients are *more* likely to die at home if: they are male; they are relatively young; they have cancer of the respiratory system; and live in Barrow or South Lakeland.
- Cancer patients are *more* likely to die in hospital if: they live in more deprived wards; they are male; they are older people; they have cancer of the lymphatic system.
- Cancer patients are *more* likely to die in a hospice if they are relatively young and live close to a hospice.
- Cancer patients are *less* likely to die at home if they have cancer of the lymphatic system.
- Patients living outside the Lancaster area are between 36% and 51% *less* likely to die in a hospice than those living within the Lancaster area. Those in Barrow are 84% *more* likely to die in hospital, while those in South Lakeland are 68% *more* likely to do so than those living in Lancaster.
- The probability of dying at home is higher in the earlier part of the study period, suggesting a trend away from home deaths.

## Chapter 6

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### **Professionals' perspectives on palliative care and place of cancer deaths in the Morecambe Bay area**

#### Introduction

To build up an understanding of patterns of place of death in the MB area, and to solicit informed views about current and future palliative care service provision, we interviewed 16 people closely involved with specialist palliative care provision: 12 health professionals, one social care professional, two service managers and one voluntary hospice worker (see Chapter 4 for sample detail)

In nine cases, two linked interviews were conducted with our respondents. One interview, the 'project' or POD interview, concentrated on the respondent's current role in, knowledge of, and perspective on palliative care services and place of death patterns in their locality. This type of interview set the pattern for other respondents who were interviewed only once. The second interview was recorded for the Hospice History Project and focused on the personal histories of our respondents in the palliative care arena (see Chapter 3 for detail).

In the project interview, informants were asked to:

- describe their role *vis a vis* palliative care service provision;
- describe current services and, if possible, give an account of their development;
- reflect upon patterns of place of cancer deaths;
- reflect upon patient and carer preferences concerning their receipt of palliative care and place of death;
- reflect upon their own ideals for palliative care services.

The bulk of the interviews took place in 2001, giving a snap-shot of services at that time. Of course, health services are a 'moving picture', and some changes in service configuration will have occurred since the time of interview.

This is a lengthy chapter that presents data, respectively, for groups of professionals or individual service personnel, as follows:

1. Palliative Care Consultants
2. A Hospice General Manager
3. A Hospice Medical Director
4. A GP/Hospice Medical Officer

5. Specialist Palliative Care Nurses (SPCNs)
6. A Senior District Nurse
7. A Social Worker
8. Other Interviews

In each of these sections, findings are presented for respondents’:

- descriptions of their roles and services;
- views on patterns of, and explanations for, place of cancer deaths;
- observations regarding patient and carer preferences for place of death;
- ‘ideal’ models of palliative care service provision.

## 1. Palliative Care Consultants

The two palliative care consultants interviewed had rather similar views about the ideal pattern of palliative care service provision. Interestingly, their former careers in medicine had little in common. Each had arrived in palliative medicine by very different career routes – one via hospital anaesthetics and the other through general practice and hospice medical directorship. Located at opposite ends of the MB area, each was working with contrasting service configurations.

### **Barrow and Ulverston area**

In the Barrow and Ulverston area, the consultant was based at the general hospital but practised palliative medicine in a number of settings: mainly hospital and hospice but sometimes in the community/home. He also held sessions in Grange and Kendal. Patient referrals came via a number of routes: out-patient referrals via GPs and specialist palliative care nurses (SPCN), in-patient referrals via hospital consultants. Patients were predominantly cancer cases but those with other conditions were seen on occasion. It was noted that medical colleagues varied in their referral habits, and this influenced the tumour types presented to the palliative care team. This consultant described the focus of his role as symptom control although he became involved in most aspects of the ‘all-embracing’ palliative care approach.

In the interview, the relatively recent development of specialist palliative care services in the area is reflected in the following chronology and features:

- the establishment of the St Mary’s Hospice in 1989; this currently has eight beds, a relatively small number by hospice standards. Our respondent had served as St Mary’s first Medical Director;

- there is an established community based Macmillan nursing service in the area, funded by the hospice, and respected and utilised by local GPs;
- his appointment as Consultant in Palliative Care in 1996;
- the hospital oncology unit provides day-care chemotherapy and has no in-patient beds (at the time of interview);
- a hospital specialist palliative care nurse has been in post since 1998.
- a hospital lung cancer nurse has become involved in the palliative care team in recent years;

At the time of interview, the immediate plans for the development of specialist palliative care services in the area included the following:

- the building of a new oncology unit at the hospital, to include a number of palliative care beds. These beds would complement those in the hospice, boosting the number of beds available in the locality;
- the development of a truly multi-disciplinary team beyond the current doctor-nurse expertise, to involve physiotherapy, occupational therapy and social work. Ideally, the team would work across hospital-hospice-community boundaries irrespective of individuals' employing organisations.

Longer-term plans for the development of these services were associated with the provision of greater support to patients who wished to stay, and die, at home. This was *not* seen as a substitute for palliative care provision in the hospital or hospice settings, rather, services in all settings needed to be sustained. It was emphasised that specialist palliative care provision in community settings should operate in complementary collaboration with existing primary care services (GP, district nurse) and community based Macmillan nursing services.

### **Lancaster and Morecambe area**

In the Lancaster and Morecambe area, the consultant in palliative care, appointed to a new post in 1996, was based at Lancaster's St John's Hospice. This consultant outlined the core elements of her role as, first, establishing that a patient is actually dying and not in need of further medical treatment for their condition, and second, the provision of symptom control for dying patients - for the benefit of both patients and their close relatives. Other key aspects of her role were outlined, especially communicating with other members of the care team, and interacting with and informing relatives. The great majority of patients who were seen had cancer.

Our respondent described developments in her role over recent years, focusing especially on the broadening out of the settings in which she practised – from exclusively hospice in-patient based to a mix of hospice in-patient and out-patient (day-care, clinic) and hospital in-patient and out-patient (clinic, day-care). However, this consultant rarely saw patients at home. As the following interview extract indicates, this broadening of care settings reflected the relatively rapid extension of specialist palliative care provision from purely hospice in-patient care, together with the development of more active patient management:

Consultant in palliative care (2): St John’s Hospice has moved into being a specialist palliative care centre, which means you can’t just [have medical cover] Monday to Friday. I guess we are a bit more [selective] about the patients we take in – we’re no longer just a good nursing home, which is what a lot of hospices were, and St John’s was a bit of that a few years ago. We are now saying - from the time patients come in - where are they going? What are they doing? What are our aims? Is it the patient we need to sort out? Is it the family? Is it financial? Lots of things you can do, really. So we’re more structured, we have a discharge rate, patients are moving between different parts of the service. So they may need an in-patient bed, they may need to go home, be supported in the community, they may need day care, they may get dashed into hospital – where they can now get palliative care because we’ve got a [specialist] nurse there. So it’s extending palliative care to where the patient happens to be.

This respondent’s perspective on the priorities for the further development of specialist palliative care services focused on the following:

- Extending palliative care support so that all cancers are covered and patients with non-malignant conditions have access to such provision;
- Strengthening and extending the specialist multi-disciplinary palliative care team in and across all settings.
- Finding ways to see patients in their home settings at an early stage in their move from active treatment into palliation. This would greatly assist in patient management:

Palliative care consultant (2): Because seeing them in their own homes gives you all the background, and you feel the atmosphere, and you see the dog and the cleanliness or not, and the stairs or not – and all of that immediately helps you plan your next few weeks without you sitting down and writing anything [as in a clinic visit]. You just know instinctively what your problems are going to be. So community visits are enormously valuable...

... we know that most of the last year is spent at home and palliative care is much more than the last few days, so we *should* be in the community.

While such an outreach service, and the building up of a domiciliary service, was desired, there was a deep appreciation of the necessity to work in collaboration with existing community based and primary care professionals. There should be no suggestion of usurping the place of other service providers or replacing their expertise:

Palliative care consultant (2): you shouldn't take over from the primary care team; you should assist them, be a support, a resource. They are the people who should be in charge of the patient – ninety per cent of the patient's last year is spent at home, that's what we always say – and we are a resource for the GPs to dip in and out of as they want, so we shouldn't take over.

There was also a need to acknowledge and work with the sensitivities of those people who had devoted much of their time and energy to building and running a hospice, an organisation whose original philosophy was to 'invite people in' rather than to seek them out at home. That is, their vision of the hospice was as a place where people could go to peacefully end their days, for extended periods if necessary.

### **Reflections on place of death patterns and patient and carer preferences for place of death**

The Barrow-based consultant saw patterns of place of cancer deaths in his area as a reflection of the availability of specialist palliative care beds and the recent history of service developments. His ideal was to offer a service that enabled people to die in their preferred location, and this may mean supporting them at home. However, the development of any 'hospice at home' type of service should not be at the expense of other forms of provision: 'I don't want to lose the beds I've got at the hospice or this new oncology unit so there would have to be additional funding and I'm not sure where that would come from-'. From his perspective, patients did not always want to die at home – whether this was explicitly expressed or not:

Palliative care consultant (1): A lot of people say I don't want to die at home because I'm worried about how my family will cope, about how they will see it, they [may] have young kids and don't want them to remember that I died at home -. A lot of people will request to come into the hospice, but some people just can't face it and therefore would

prefer to die in the hospital because they're not willing to face up to the fact that they're dying...

Interviewer: and the hospice has those connotations?

Palliative care consultant: it has had that connotation, obviously we try to broach that and talk about it so people are prepared- [but we have to accept their wishes] probably deep down they know what's happening, but they may find it easier to come and die in the hospital.

In this specialist's experience, patients who expressed a wish to die at home in the earlier stages of their illness sometimes changed their minds as the illness progressed. He commented that the high proportions of people expressing a wish to die at home found in research studies could reflect the tendency for researchers to pose their questions early in the illness trajectory. He also observed that social class probably had an impact on place of death preferences and patterns. Those from lower class backgrounds in the Barrow locality often had longstanding family support networks in the area, a support system that often rallied to the care of the dying cancer patient at home; in contrast, professional people who had moved into the south Lakes were often without wider family networks in close proximity.

The consultant in the Lancaster/Morecambe area also saw the local patterns in place of cancer deaths as a reflection of the availability of specialist palliative care beds and the development of services in recent years. This locality had had an unusually high number of hospice beds, although fewer beds were now open than in previous years. Given the long-standing availability of hospice beds and the acceptance of the hospice service among local health professionals, she noted that 'I think you have to be really strong-minded, in this area, to die at home'. As discussed above, this consultant would like to be able to offer specialist palliative care support to enable people to be cared for at home, and if they so wish, to die at home; '... the question is really whether we can give people better choice...'.

She observed that one, more recent, 'draw' factor influencing the high proportion of hospice deaths was the effect of inviting patients into the hospice for out-patient care. Patients often had a pre-existing fear of the hospice, but their fear was usually dispelled quickly once they had crossed the threshold; they discovered that the hospice was a 'wonderful place' and frequently opted to end their days there. This, she suggested, supported the need for the greater provision of specialist care in home settings. This consultant's ideal configuration of specialist palliative care provision would involve a service with a range of options – in-patient, day-care, hospital and community services. Ideally, a GP referral would follow consultation with patients and carers about their care preferences *early* in the palliative phase: '... it's structured [care], and patients flow through the service and get what they want when they want it'. What was to be

avoided was what sometimes happened at present: a patient unknown to the palliative care team is suddenly admitted to the hospice or hospital at a late stage in their illness, and in considerable distress.

Palliative care consultant (2): [At present, the service is] all a bit ragged, and until it gets more streamlined and we know [patients] in the community, and we're putting masses of support into the community – and we're sending out our occupational therapist, our physiotherapist and our social worker – then they're going to keep coming in [to the hospice or hospital].

## 2. A Hospice General Manager

The General Manager of St John's Hospice in Lancaster was interviewed about his role and perspectives on palliative care and place of death. His description of the Hospice service covered much of the same ground as reported above, though his focus was on the need to modernise the management arrangements. He confirmed the organisation's intention to 'spread out into the community more', including the provision of support for people to die at home. This was something he supported. However, a theme in this interview was the challenge of working with the micro-politics of the organisation: the hospice was funded and built to provide beds for 28 people. Thus the reduction in active bed numbers to 17 or 18 (maximum 22) in recent years, together with the intention to extend the service out into the community, was seen by some supporters to run counter to the hospice's founding philosophy, to their sense of what the hospice is there for. This means that there is some resistance, in influential quarters, to change, with implications for charitable fundraising.

Manager: I suppose looking from outside the hospice movement, you tend to see hospices as wonderful, great, caring buildings and organisations. But of course, once you get underneath, so many people have got so many different motives for being involved. And those motives are very, very strong... I'm not saying it's a problem. It just surprised me a little bit sometimes.

... We shouldn't stop doing good things because we're going to end up with a space. But we are controlled by people who don't like spaces.

This respondent thought that the hospice could, and should, make its services available to people with non-malignant conditions, but again, there were vested interests to consider. On the

one hand this might keep beds open and occupied, but on the other hand fundraising might be less successful for conditions other than cancer:

Manager: I guess to a certain extent both the hospice and CancerCare feed off the fact that people are afraid of cancer. People are so afraid of it, they'll give more to people that might help them if they had it... And on the whole everyone's got a relative that's had it, it's very close to people...

In this respondent's view, place of death patterns were associated with: the nature and quality of the primary care team's support for patients at home; the support offered by family or other carers; severe symptom management needs – these usually required hospice admission because such specialist medical care is not offered to patients in their home settings. The ideal configuration of services would involve:

Manager: A rainbow of services from home to hospice, on demand, fully supported, fully funded.

### 3. A Hospice Medical Director

The Medical Director (MD) of St Mary's hospice in the Barrow-Ulverston area was among our interviewees. With a background in general practice, she had worked at the hospice as a medical officer for five years before taking over as the hospice MD in 1999. A number of features of the hospice service were noted, including the following:

- Medical care at the hospice is provided by 2 GPs and the MD, with the consultant in palliative care visiting twice a week.
- Doctors support the specialist nursing staff, giving medical input, information and advice when problems arise. They get involved principally with patients having difficulties with pain and symptom control or with difficult family circumstances.
- The hospice has a day-care service.
- The hospice has a policy of making maximum use of its eight beds. This involves encouraging shorter in-patient stays and patient discharge: 50-60% of patients return home - those not in what this specialist refers to as the 'terminal phase'.
- The past two years have seen a marked increase in admission, bed occupancy, and patient throughput rates.
- Most patients come from Barrow – the area's population centre, one that contains the most socially disadvantaged communities in the South Lakes region.

- A high proportion of the hospice's funding (85%) comes from charitable sources. This is a finite and not entirely reliable source – especially if charitable donors are called upon to support other causes.

In connection with the last point, the MD was concerned about the potentially negative impact on hospice funding of the proposed development of a specialist palliative care unit at the local hospital (see the Barrow-based consultant's account above). This development required a considerable fundraising effort in the locality.

The palliative care philosophy of the hospice was described as follows:

MD: We provide high quality patient-centred palliative care. I think those are the principles, which means – and the patient-centred part is really important to me – that we don't over-medicalise, and that we try and empower and enable the patients in decision-making – that includes the patient's family as well – when we can.

'... we try to work very much at the pace of families, and the pace of the patient, and to work with them'.

One issue touched upon was the need of non-cancer patients for specialist palliative care services:

MD: palliative care has got to somehow spread its wings to non-cancer illnesses, but I don't really see at the moment how that will work in this area.

### **Reflections on place of death patterns, and patient and carer preferences for place of death**

The St Mary's Hospice MD made a number of observations indicating the service-driven character of place of death patterns: the availability and nature of services played a key role in determining where people die.

For example, she was forthright in her assertions that the hospice, and the hospice movement in general, excluded certain groups of cancer patients within the population. This was not of deliberate intent but the unfortunate effect of the rather 'white middle-class' hospice ethos, together with limitations in funding and thus bed number.

MD: We tend to see people that haven't got as much social support, and people that have major difficulties with symptom control, and we also see people who may appear to have a lot of social support but whose carers are absolutely exhausted or, for whatever reason, unable to continue. It worries me that people that are not particularly articulate, and who are perhaps not empowered to seek help, may not easily access the hospice system.

While the policy is to make maximum use of hospice beds, it was not uncommon for beds to be occupied for lengthy periods, until death, because there were no other options for patients:

MD: ...there is a facility to move people on to a nursing home, except that it's so difficult to get a vacancy, and people who are in here, in this safe place, are a low priority with Social Services. The other thing that is becoming more of a factor is that, of course, the care here is totally free, and nursing home care usually isn't – or residential with nursing care isn't.... So, residential or nursing home care – there really isn't any other option, unless we put in a huge package of care at home. Again, Social Service's budget is stretched and we have to bargain for that and resort to emotional blackmail at times.

... we are getting increasing numbers of very complex problems. It then becomes impossible to move people on elsewhere – particularly younger disabled adults, under retirement age. There are not really adequate facilities at all in this area, and that's a huge criticism.

The growing complexity of cases was an interesting theme in this interview, reflecting general changes in the management of cancer patients in the palliative care phase:

MD: Yes, complexity of cases, cancer patients are being salvaged in a way, so that they are living a great deal longer – long enough to get horrendous complications. The most significant, from our point of view, are bony secondaries in the spine, affecting mobility, so that you tend to end up with a patient who is probably stabilised, but who then requires considerable nursing input, and they are not usually managed at home. And then there's a huge problem about placement, and of course, by then, they've been here for a few weeks, the situation here is luxurious compared to many local nursing homes, and then we have a great deal of problems. [For example], we have one person who, being under retirement age, we cannot move from here, his nursing needs are so great and his needs for equipment and three people handling him, mean that we cannot place the person anywhere else, so the bed's blocked indefinitely.

With regard to the management of the patient through the entire palliative care phase – at home and in hospice or hospital, the MD believed that there had been marked improvements in the last two-three years, reflected in the growing rarity of the emergency admission:

MD: ...we used to get a lot of admissions of people who came in *in extremis* and who died within 24 hours. That happens extremely rarely now. I think that is partly because of better care and also because more people are on-board with the principles of palliative care, there's better community nursing, and more acknowledgement of the final phase and more planning.

Related to this more streamlined and co-ordinated management of the patient was:

- A growth in understanding of, and skill in, palliative care among some GPs and community bases nurses.
- The existence of a Macmillan 'whole care' team 'who try to predict and pre-empt crises, and who work closely with the community nursing team'.
- Increased working with the GPs' out-of-hours co-operative, to improve out-of-hours care.

With regard to deaths at home, this respondent was keen to see greater opportunities for patients who wished to die at home to be able to do so.

MD: I don't see hospices as necessarily somewhere that is ideal to come in to and die.... So, if good terminal care can be easily achieved in the home, if there's adequate support, I would not see it as ideal to take people out of their own surroundings and into a hospice to die. I really think that we [the hospice] should be used to give people the skills and abilities to cope, if they can, at home. If that's appropriate...

However, given the current configuration of community based services – both in health and social care - there were limitations on the proportion of home-deaths that could be supported.

The MD noted that, in general, the majority of people say they would prefer to die at home. However, she also knew that some people change their minds. One key influence is the effect of introducing patients and families to the hospice environment. People who had a pre-existing antipathy to the hospice because of its cultural association with death were quickly won over to it once they had witnessed it at close hand and experienced its supportive services:

MD: ...the interesting thing is, within 24 hours people's concepts of the hospice have changed, 100% usually. A person that comes in terrified is, within 24-48 hours, so

relieved to be within the safety net. That is sometimes a problem, because we can be too safe and comforting and then they don't want to leave'.

Thus patients often change their preference about where they want to end their days, opting for the hospice, although in practice a hospice death may not occur due to the service limitations and the prioritisation of clinical need discussed above. A related issue is the desire of some patients to relieve their families of the burden of dealing with the dying process. The hospice offers the prospect of such relief.

In this respondent's view, to improve place of death options within the area would require local service 'gaps' to be filled, in particular:

- the lack of a 7-day/24-hour, nursing service in the community;
- the lack of nursing home places.

A 'hospice nursing home', or related forms of 'intermediate care', were seen as potential ways of providing services for those not in need of specialist hospice care, but who are 'too heavy for the community to cope with at home' (MD). Here, a service offered by nurses trained in palliative care would be the priority:

MD: ... more of a generalist [hospice] service with nurses with palliative care skills and training. It wouldn't need the sort of expertise required here, and wouldn't need as much medical cover. Perhaps GPs could look after their own patients. Some people are talking about re-opening cottage hospitals, that's another sort of option... But I'm realistic about the economics of these things.

The MD noted that this was not the direction that services were taking in the area.

Eliciting patients' preferences for place of death was not something that hospice staff, or service providers in general, undertook to do because of the cultural sensitivities surrounding discussions about death and dying:

I think that one of the big problems is that there is difficulty and a reluctance in getting that dialogue established with patients, about where they want to die. We are still in a society that skates all around it, and we'll find all sorts of clever ways of avoiding the issue. If people aren't prepared to talk about [things ahead] – what sort of funeral they want, which can be fairly detached and seen as a long time ahead, they're even less likely to talk about the emotional issues of how or where they want to die. I suppose we don't seek to ask that of people, we tend to pick up clues, but if someone who was in

the hospice said, 'I really want to die at home', we would raise heaven and earth to get them there if it was at all possible.

#### 4. A GP/Hospice Medical Officer

One of the GPs who served as a part-time Medical Officer at St Mary's hospice was interviewed. He outlined the stance that he and his primary care partner take towards the terminally ill patients on their list:

GP: ...we'll hopefully jack up the care we'll provide to them and perhaps be a little more proactive, more phoning up or even visiting unannounced or without being called just to see how they're getting on... We'll also rely heavily on input that we get in our weekly meeting from the district nurses who'd probably be involved more, and the social workers who come to the meeting as well...

Supporting patients might involve giving them his home phone number for out-of-hours contact if that was necessary.

This doctor undertook sessions at the hospice as well as regularly calling at the hospice to see how particular patients were progressing. He stressed the importance of 'being there' for patients, of countering any fears the patient may have of being abandoned by their GP, of ensuring continuity of care once patients had entered the terminally ill phase. Emphasis was also given to supporting carers - giving them assurance and attempting to get as much help for them as possible, for example in the form of night sitting and Marie Curie nursing. Carers were supported irrespective of which General Practice they were registered with. It was noted that there were insufficient Marie Curie type services in the locality.

One theme in this interview was the nature of General Practice, and this doctor's belief that involvement in end of life care was an essential aspect of being a GP:

GP: ... I think that's a really important part of what General Practice is, actually caring for people for a long time. We have the privilege of perhaps caring from cradle to grave if we're in post long enough. You do build up a relationship with a family or with a patient over a number of years and hopefully within that there's quite a lot of trust, and I was going to say love, but there is a bond there...

In this context, he saw it as regrettable that some GPs viewed the development of palliative medicine as a reason for disengaging with patients in the palliative care stage, handing care over to a specialist:

GP:... so palliative medicine has in a way taken something away from us and quite a lot of GPs, I think, are frightened of it. They feel ‘Oh no’ they can’t do that.

In this respondent’s view, GPs should undertake palliative care but should not be embarrassed to seek extra guidance, support, and help from a consultant in palliative medicine where necessary.

### **Reflections on place of death patterns, and patient and carer preferences for place of death**

This GP noted that a lot of patients would prefer to die at home but that the meeting of this preference was frequently not possible. He identified a number of factors determining place of death, as follows:

- Difficulties can arise when out-of-hours services become involved:  
GP: ... unless there’s been communication with the on-call service to prime them ready for any disaster that may happen then they may well take the only course of action open to them which is actually to admit the patient to hospital, not knowing the background...

Better communication and preparation between and within services might avoid such outcomes.

- The attitude of the relatives: they may get alarmed if symptoms worsen and they find they cannot cope. Support for relatives can often alleviate their worry.
- The carer may be old and infirm, or the patient may live alone.
- The lack of a community based specialist palliative care team in the area to support the patient at home means that home-care may not be an option. However, there is a new night-time district nurse service in the locality that is of great value in supporting patients at home: ‘... if you’re going to have somebody at home you need to be able to have expert help throughout the night’.
- Night-sitting services, such as Marie Curie, are insufficient in the area.
- The nature of the patient’s symptoms and his/her need for symptom control may mean that home-care is not an option under present arrangements.
- If a hospice bed is not available, there is an option of using one of a number of GP beds available at Ulverston hospital.

- Social services are sometimes slow in reacting to client's needs; this may mean that home-based care is not possible.

A number of potential improvements in services were suggested. These included:

- Making available higher grade Social Service home care workers – who had authority, for example, to administer doses of medication carefully specified and prepared by doctors.
- Patients having case-notes at home, contributed to by all involved in care provision, so that another doctor unfamiliar with the patient's circumstances could refer to them.
- Improved use and storage of palliative care drugs by GPs and out-of-hours staff.
- Improved financing for the local hospice so that it is not dependent on the vagaries of charitable funds.
- Greater equity in the funding of palliative care across the MB area.
- One problem GPs face is that there is often a delay in getting diagnostic information about their patients forwarded from hospital consultants. The speedy receipt of such information would assist the GP in supporting patients with cancer, and GPs can then play an important role in co-ordinating patient care.

## 5. Specialist Palliative Care Nurses (SPCNs)

Four specialist palliative care nurses (SPCNs) practising in the community were interviewed in this study. Three of these were members of the project research team. Each nurse took part in both the hospice history interview and the project interview. One was based at, and employed by, the hospice in Ulverston/Barrow; one was employed by the district's Primary Care Trust, was based in Kendal and served the large south Lakes area; two were employed by the Primary Care Trust and based at the hospice in Lancaster. With community service remits, each co-ordinated closely with health and social care professionals across a range of service settings.

### Roles

The specialist palliative care roles of these community nurses were common in some details but variable in others. To a large extent, the variations reflected the histories and particularities of service configurations in their localities. One of the Lancaster based nurses had a more tightly defined remit to work with primary health care teams. Common features in their roles were as follows:

- these nurses were not primary care givers, but had a consultative role – acting as assessors, advisors and co-ordinators of service inputs (medical, nursing, teaching, social) required by patients and families;

- all stressed that their role was to support the ‘hands-on’ formal care givers, particularly district nurses and GPs, and was certainly *not* to undermine the skills, or substitute for the input, of these professionals in the primary health care services;
- all emphasised their role as *specialists* who should concern themselves mainly with patients who were facing particular difficulties and had complex needs, although they also represented a more general consultative resource;
- all underlined the importance of good team working – both in their immediate nursing teams and in the wider multi-disciplinary team involved in the patient’s care. Team building was an important aspect of the role;
- three nurses talked about their responsibility to assist in the palliative care education of other health professionals, building up others’ knowledge and skill;
- all worked almost exclusively with cancer patients although they felt that their services were needed by patients with other terminal conditions.

The following interview extracts add definition to these features:

SPCN(1): ...we’re not the primary carers, and I think it’s very important that we don’t de-skill district nurses and GPs who have a good grasp of the palliative care approach. I really do think that’s very important: that they are the primary carers... I’m very fortunate, I work with a good set of district nurses who are keen to learn palliative care and they are keen to work as a team. I think palliative care teamwork is essential: nobody has all the answers and it really does have to be a team approach.

SPCN(4): ... the ideal is that the patients that we see are the ones that have complex needs. For some patients who have a non-troublesome form of cancer - in the sense that they’re not running into difficult symptom control problems, that they have a good home situation, that they have good family support, that they have a good relationship with their GP and district nurse – then those patients should be very ably managed by their primary health teams without ever needing the support of the hospice inpatient unit or the community palliative care team.

While these nurses were clear on where they set the boundaries of their own roles, they noted that the laying down of and maintenance of these boundaries was something that had had to be worked upon, and that their role was not always well understood by other health professionals. The latter could lead to the receipt of inappropriate referrals, to the absence of appropriate referrals, and to the receipt of late referrals in circumstances when earlier contact with a patient would have been beneficial. All of the nurses noted that the late referral of some patients to their care was a problem that needed to be tackled. Our interviewees noted their responsibility to

educate other health professionals both about their own roles and about the principles and practices of palliative care more generally.

### **Recent service developments**

These nurses had been in their present community posts for between 18 months and 6 years, but all had had much longer careers in palliative care-related posts in a range of settings (hospice, acute hospital, community), two within and two outside the MB area. They had a close knowledge of changes in specialist palliative care provision, both locally and nationally. They all portrayed specialist palliative medical and nursing care as a rapidly changing and developing field, and emphasised its move towards more active patient management, especially in pain and symptom control. The drive to make services more efficient and effective was noted, especially the diversification of hospice services, including the development of out-patient care, higher patient throughput and discharge, and the specialisation and standardisation of nursing roles. There was a very different 'feel' to nursing care in the new world of specialist palliative service provision, and in their view this had brought with it both gains - improved patient symptom management, greater service efficiency, professionalisation and specialisation of the nursing role - *and* some losses. For one respondent, losses included less participation in interaction with patients and families because of greater involvement in meetings and policy making:

SPCN(3):... the multidisciplinary team is growing and growing and growing, and I think its becoming a bit unwieldy really. We've got *so many* people who are involved in every aspect of the work that I find myself sitting on committees and thinking, 'Why am I here?', ... and 'I don't want to be here'. *I know* we should be taking part in policy making but it gets very tedious... We've had to have standard ways of working and I don't think things can be that inflexible: I think its horses for courses, and what an elderly man in a council estate in Lancaster needs, compared to somebody who lives in a big detached house in Grasmere needs – we can't have just one uniform blanket approach. Every patient is an individual and all this jargon – care pathways – and protocols we're having to draw up, I can see the value of it in some cases but, when you go across somebody's doorstep and you're a guest in their home, you've really got to go with what they want.

Loss of time to spend with patients was also seen by another nurse as an unfortunate, if necessary, consequence of changes in palliative nursing. Before working in the community, she had nursed in-patients at the Ulverston hospice, since its earliest days, and had seen many changes:

SPCN(2): ... there is a more professional and medical idea behind things now. It was very much terminal care in the early days, and I got a lot of satisfaction out of feeling you'd done something well and made somebody comfortable, and been there for them in whatever way they wanted you to be there. I sometimes feel now that nurses get more stressed out on the ward because there's so much going on: it's almost like being on an acute ward sometimes because there's interventions, there are drips up and there are people with epidurals in and having blood transfusions, and Aredia transfusions, these sorts of things.... But perhaps we're a victim of our own success – we've moved along so much and we know how to do things so much *better*. You've got to give people these things whereas we didn't, it just wasn't there twelve years ago.

... I [used to] spend a lot of time with patients, especially on nights. I can remember all kinds of illuminating conversations and things happening – different situations, or deaths, and relatives. I just felt you had more time and you got closer to them on a personal level...

This nurse also commented, with regret, on the loss of the hospice's ability to offer much respite care, something that had been important in earlier years. Respite care is fundamentally about offering emotional and spiritual support to the carer, but this now tended to take second place to the need to control the patient's symptoms and manage their other physical problems.

The loss of a certain quality in palliative care nursing was noted by another respondent who has nursed in a hospice in another part of the country during the early years of the hospice movement:

SPCN(4): I think there's going to be, well I hope anyway, that there is going to be some kind or rediscovery of what hospice was originally all about, because it seems to me that there is a danger of us moving further towards a medical model in the hospice movement and losing some of the creative influences that I think were there at the beginning in terms of the hospice being a place of sanctuary for people...

...[A couple of things a nurse told me have stuck in my mind from my early hospice days]. One was to do with the relationship between Macmillan nurses and patients and it was very much to remember that you're there on the sidelines, you're not actually a member of the families, you're there just on the sidelines and that's the little bit of influence that you might have. And the other was around the difference between doctors and nurses and it was to do with doctors having knowledge and nurses having wisdom, and between the two of you, you can offer something that's really quite special, but if only one of those predominates over the other then you get stuck. And I think we're in

danger in some ways of getting stuck, because I don't see a great deal coming from nursing at the moment.

### **Reflections on place of death patterns and patient and carer preferences for place of death**

As front line professionals dealing with cancer deaths our respondents had many rich insights concerning what influenced the place of death and the factors shaping patient and carer preferences. All of the nurses said that many patients and carers start out with a preference for the death to occur at home, but that this preference frequently changes as the illness worsens, when crises occur, or when patients become familiar with a hospice. There are a host of factors that come into play, the most important of which will be considered in turn although in real situations these combine in complex ways.

### **Service 'supply side' factors**

As was the case for the palliative care consultants discussed above, the Specialist Palliative Care nurses linked patterns of place of cancer deaths in the MB area to the availability of in-patient beds (hospice and hospital) and the absence of any service analogous to 'hospice at home' in the district. The services required to support patients and carers at home - such as 24-hour district nursing and GP cover, Marie Curie night sitting services, and social service cover - were patchy across the MB area.

### **Palliative care beds**

The relatively high number of hospice beds in Lancaster was seen to account for the higher proportion of hospice deaths in the Lancaster area as compared with the Kendal/South Lakes and Ulverston/Barrow localities. One nurse explained that the stature of the hospice had also given rise to a 'hospice culture' in the Lancaster area:

SPCN(1): ... we've got a 20-bedded hospice [in Lancaster] which I think is double the national average of hospice beds. I think a culture develops within the healthcare professions that you access those beds because they are there. Yes? They are there, so you can get people in, so it actually becomes the normal way of life. The culture changes. Because the hospice isn't feared – St John's is seen as a very good place - I think that cultures and attitudes change. So [professionals tend not to think:] 'We need to keep this patient at home'. It's seen as a centre of excellence, so perhaps hospital staff see it as a place where people who are dying should go.

Despite the high number of hospice beds in Lancaster it was noted that patients were occasionally admitted to hospital, and died there, because a hospice bed was not available. The

hospice had a policy of a maximum of three admissions a day (so as not to compromise the quality of patient care) although four might occur in exceptional circumstances. A hospital death might also follow a hospital admission at the weekend when a difficulty had developed at home and home-support services were not available, or after an admission for a particular type of investigation.

In the Ulverston/Barrow area, the lesser availability of hospice beds meant that a hospital admission and death was a more regular occurrence. The SPCN in this area explained that patients and their relatives understood that this was sometimes the only option:

SPCN(2): If [the patient] had to die in hospital the relatives are often very grateful for what we've done in the past and they realise there's nothing we can do about that - we can't throw somebody out of bed [in the hospice]. Its all down to money and funding, we just can't open 11 beds because there's no money there, we can't afford to pay for it...

### **Home deaths – a lack of service support**

The nurses discussed the ways in which a lack of palliative care services in the community – 24-hour district nursing services, an out-of-hours on-call specialist palliative care service, all-week Marie Curie night sitting services, social service support - often meant that 'crisis' situations arose for patients and carers that could not be coped with alone. This might lead to a hospice or hospital admission, followed by a death in these settings:

SPCN(2, Ulverston/Barrow)...you can't always get Marie Curie nurses – I've had lots of problems. District nurses are great and a lot of them have done palliative care courses and are really interested, and they're good, but its just one aspect of their whole role and you can't expect them to devote everything to [palliative cancer care]: they've got patients with chronic liver disease, kidney disease, asthma, bronchitis, the lot... They're already running around like headless chickens half the time.

SPCN(1, South Lakes)We only have the Marie Curie Service two nights per week, there is no 24-hour district nursing service, so that impinges on the carer. Sometimes the carer gets scared, they don't know how the illness is going to unfold, so the carer might become anxious. I feel that the patient can sense that anxiety sometimes and the patient themselves will say, 'I think it's time I went to the hospice now'.

SPCN(3, covering areas of Lancaster). ... there isn't 24-hour nursing care, and that may have a bearing, especially if people live alone. The night-times can be difficult and you can't get Marie Curie every night....When people die in their home, when it's been

well-managed and well-supported, it's wonderful. And the same with the hospice: when they die well there it's wonderful.

SPCN(4, covering an area in Lancaster/Morecambe). My experience is that, generally, when people say they want to die at home, they change their minds because something is happening that is making them frightened: either they've got symptoms that are running out of control, or they're getting panicky, or there are organisational problems with not being able to get the kind of support that people might need....

[I try to foresee and avoid the development of crisis situations:] where somebody's vomiting and in pain in the evening, and you've got an on-call doctor who doesn't have a syringe driver around, doesn't have any of the drugs that they need. That will precipitate an admission to hospital – and sometimes that means going in an ambulance into the [hospital] to go through casualty.

This nurse (SPCN4) also reflected on the different levels of commitment that GPs had to supporting a home death – there was considerable variation. It was noted that in his patch, the district nursing service was well organised and offered 24-hour care, making 'a huge difference'. There was also a 'Rapid Response Nursing Service', 'So there is, I think, a good nursing service'. However:

SPCN(4): I do wonder whether there could be more of a medical speciality from the hospice reaching out into the community. That doesn't happen to any great degree. We meet with the medical staff from the hospice on a weekly basis to talk through our patients, and there is an outpatient clinic, but there isn't any sense of medical management of patients in the community, and maybe that's something that could be expanded, such as more domiciliary visits.

The Lancaster based palliative care consultant made a similar point, (see above).

### **The location of specialist symptom control**

In the absence of a comprehensive community based specialist palliative care service, attention was drawn to the fact that patients sometimes had to travel from home to access specialist pain/symptom control services and other specialist facilities. This drew patients towards institutional settings, and deaths thus tended to follow in such settings, acting as another 'supply-side factor' shaping patterns in place of death. This was compounded by specialist nurses' dependence on GPs to prescribe treatments, together with the time taken to bring about changes in medication:

SPCN(2)...even getting changes in medication can be extremely difficult because then I have to go back to the GP. I have to say 'Mr X's pain is not properly controlled, and he's got abdominal colic, or he's got lots of secretions, do you think he could have some Hyocine, or can we increase his syringe driver, MST, or can we commence a syringe driver...?', or something like that. I have to put my case to a GP who may or may not agree with me. Often they see it as a threat, though I work with a lot of GPs who are brilliant - if you ask for something they say 'Right, fine, no problem, will write the prescription, get it, the district nurse or you start the syringe driver'. But some GPs will not, so patients can miss out in as much as a doctor may not do what you suggest, or he may have his own ideas which you may think are contrary to best practice or the current protocol. And I had a patient who lived so far out in the country that the post van brought changes in the prescription – it took two days! It's slow. It just doesn't work if you need to react to a situation very quickly. It might take you a day, whereas if you were in the hospice you would get it done straight away, you're improving that person's symptom control and care straight away. If you have difficult symptoms the patient is better off in the hospice.

### **Patient and carer experiences – 'demand side' factors**

A range of factors linked to carers, patients, and their social circumstances, led to a need or 'demand' for certain types of service response. These factors became associated with both patient and carer preferences for, and with actual patterns of, place of death.

### **Carers dealing with fears and crisis**

In the discussion of supply side factors above, reference has already been made to the occurrence of difficulties, sometimes amounting to 'crises', in home care situations. The nurses had observed many scenarios in which a carer reached a point when they felt they could no longer cope alone with a patient's illness - for example, with the patient's pain or other symptoms, or the patients' emotional state. Carers themselves could become exhausted through lack of sleep, or may no longer be able to manage the emotional strain of seeing a loved one slipping away. Thus, for a number of reasons, carers often needed to call upon some form of professional assistance, though they might leave this to the last 'crisis' moments, only giving up their struggle to manage alone when all resources were used up. If the assistance was not forthcoming, or did not allow for the full support of the patient *and carer* at home, patient care would usually be relocated to a hospice or hospital. In such situations, many carers had to give up on their hope that the patient could die at home.

SPCN(1): I think people say that they would like to die at home, but within that there are so many variables and factors that come into play, so I think that each area is

unique, each death is unique, with a unique set of circumstances. If they have a carer its things like, how old is the carer? How fit is the carer? And what impinges on the carer is the amount of support that can be given. If they are up at night and not sleeping because they're worried or because the patient is poorly and needs to be cared for through the night, the carer generally isn't able to carry on coping because they get worn out. We only have the Marie Curie Service two nights per week, there is no 24-hour district nursing service, so that impinges on the carer. Sometimes the carer gets scared, they don't know how the illness is going to unfold, so the carer might become anxious. I feel that the patient can sense that anxiety sometimes and the patient themselves will say, 'I think it's time I went to the hospice now'. . . . . I think it's through the night that the carers get worn out, if they're not sleeping, and people's minds tick over and worry sets in. I think that's the hardest part, when there aren't people around and there are very few people to call on.

SPCN(2): [Carers] are sometimes frightened, very, very frightened of being alone. You get 'What happens if he's in pain and I can't... , what do I do?', this is especially if [the patient has] been in hospital or hospice and come home. For carers it's very difficult sometimes. People can feel so guilty because [the patient] had to go into the hospital or hospice, because they just couldn't physically and emotionally cope.

SPCN(1): Sometimes the carers can't cope and it wouldn't matter how much input you gave – they *feel* that the hospice would actually give better care than they can give.

### **Patients' and carers attitudes and feelings**

The attitudes of patients and family members were seen by the nurses to be of relevance to place of death matters. Some patients and carers had strong, clear and consistent intentions and feelings about care arrangements, and these had to be acknowledged:

SPCN(4): Some people will make it very clear from early on that 'I don't want to die at home', that 'I want to come into the hospice', and therefore I have a commitment to that patient to enable that to happen. There are other patients who at the beginning will say very clearly that where they want to be is at home, and my responsibility there is to enable that to happen.

SPCN(4): I guess the first factor is the family: the family and home situation. If there is a willingness within the family for the patient to die at home, then I believe there is no reason why somebody, regardless of what is happening to them, can't be managed at home. Since I've been here I've looked after patients who've had the most horrendous symptoms – fitting from brain tumour for example - but where there's been such a

desire by the family to manage this at home they have managed it. The [support] services were there [for them]. It wasn't smooth, it wasn't easy, but none the less it was managed.

SPCN(3): ... one of the patients I've been to see this morning came into the hospice over the last week because of an emergency. She was forced to come in and from the minute she was in she was agitated to get home. She's at home now, she is *so* much more relaxed, she knows what's happening, she's happy to be at home and she's not going to go anywhere, no matter what happens now. And her daughters and sons and husband are there, wanting to look after her.

The nurses reported that other patients and carers were less certain about their wishes, or adjusted their views as time moved on. Despite expressing the wish to die at home earlier in the illness, as their condition worsened patients often changed their minds about where they wanted to be cared for and to die. This might be because they did not feel completely secure with their care in the home environment, or because they feared a loss of dignity in receiving intimate bodily care from a relative. Alternatively, it might be because they did not want to burden their loved one with the care load:

SPCN(2): Well I suppose we'd all like to die at home, in our own beds, wouldn't we?, surrounded by our friends and family, like some Victorian deathbed scene [laughs].

People say they want to die at home until they start to realise what the disease is doing to them. And I think that's when their ideas change. Or the relatives didn't realise what it was going to be like.

SPCN(3): ... what [patients] say right at the beginning can be very different towards the end: they get frightened, and they often want their intimate nursing procedures to be done by fairly anonymous professional nurses rather than their grand-daughter or whoever... A lot of it is about not becoming a burden on families, and about dignity. They can be reasonably anonymous in professional carers' hands... I know a lot say 'I want to die in a hospice, I don't want my wife to...', or 'If I become incontinent I don't want...', you know, that sort of thing.

One nurse reflected on the difficulty patients' have in recognising what is happening to them or the stage that they have reached:

SPCN(3): People may like to hold the hospice in reserve, but its very difficult for them when they're in that situation to be able to judge when that reserve is necessary. It's

difficult for them to know what stage they're at, even though they know they are dying... Like the man I saw this morning. He's obviously deteriorated, he's off his legs. But to him that wasn't a consideration - he was still going to struggle to the toilet, he wasn't going to let anyone take him, he was still going to drag himself upstairs - even though he was off his legs. But there was no way he could do that, if he attempted it he was going to fall... I've often thought this of a lot of cancer patients: they can't possibly see themselves as the rest of us see them.

Another noted that, in her view, some carers lacked necessary caring qualities:

SPCN(2): [Some carers..] they're not, it sounds awful to say 'trained' as if you can train somebody to be compassionate or care, but they don't always know the right cues to pick up on or give out, or to explore things deeper and find out what's bothering people.

A minority of patients presented nurses with what they perceived to be a problem: the denial of their impending death, or their refusal to accept it:

Interviewer: What about people who don't accept that they're dying, there must be a few of those? What happens to them?

Nurse: There aren't that many of them really. You get a few people in denial, or you get some people who are confused. We get people in the hospice who are in denial, who won't discuss it. Or you get people who just refuse to acknowledge it - there is a subtle difference between that and denial - who refuse to face it, bury their head in the sand and won't talk about it; I can't recall where their [place of death] preferences lie particularly. (SPCN3)

#### *Patient's knowledge and feelings about hospice as a place of death option*

Nurses quite often encountered resistance to a hospice among patients. This was attributed to patients' lack of familiarity with hospices and the range of services they offered. Patients often held the preconceived notion that hospices were types of hospital (with all the restrictions and features of hospital regimes) where you go to die. The hospice was often an object of fear.

SPCN(2): It's surprising how many people resist the idea of coming to a hospice, and then when they do come in they want to come back, because they realise it's not like [a hospital]... It's 'I don't want to go into hospital', which is often why the day care is very good because it introduces people to the service and they aren't scared'.

(Ulverston/Barrow)

SPCN(3): A big thing about coming into the hospice to die is familiarity with it. I think getting people to hospice day care can have a *huge* impact on them. The biggest stumbling block is accepting admission to day care because hospice day care has such awful connotations. But once they step over the doorstep and they're in that environment they're usually quite happy, and they're quite happy to be admitted. If they've never had any contact with the hospice they have their own images of it and don't want it. (Lancaster)

SPCN(1): Once they actually develop a rapport with the hospice staff and feel safe and comfortable in there, that's ultimately where they would like to go.

### **The suitability of the home environment**

Our respondents noted that the home environment – for example, the location, lay-out and size of rooms, the range of care work facilities on hand, and the level of cleanliness - often presented practical difficulties in sustaining care at home.

SPCN(3):... a lot of the time it's about the practicalities of dying at home when you've got an upstairs bathroom and the bed's downstairs, or vice versa. It's about trying to get lifting equipment into homes where there's no room to swing a cat.

### **The social circumstances of patients and carers**

A range of factors associated with the patients' and carers' social circumstances were identified by the nurses as relevant to place of death. These included:

- social class
- age and gender
- whether patients lived alone or with others
- household composition – who lived in the household and their relationship to one another
- nature of the wider social network in which patients and carers were embedded, especially the geographical proximity of relatives
- carers' employment status and childcare responsibilities
- geographical distance between the patients' and/or carers' home and hospices and other services.

One nurse commented in some detail on some of these factors:

SPCN(1): I can see that somewhere like Barrow, which has a lot of social deprivation, it also has extended families and good community support, so perhaps that enables people of a lower social class to remain at home...(MN1)

SPCN(1)...families with young children - they obviously need very different support than someone who's elderly.

SPCN(1): People living on their own – its very difficult to keep people at home because there just isn't the support for them.

SPCN(1): I think the Lake District has a unique set of its own differences, maybe sometimes they're problems, because although people stay within the local community, within the wider community you have a very diverse set of people. You have people who, generally speaking, have owned their own businesses, been quite wealthy, perhaps used to the private sector, and then retired into the Lake District. Obviously housing is quite expensive, some of it is very beautiful, and they perhaps don't expect to become ill. And that's a real problem - or it can be - because they move here to what they feel is going to be an idyllic retirement, and then they may develop a cancer and they've actually severed their ties from their families or their friends that they used to live nearby. And they've moved to the Lake District and they find themselves actually really quite isolated. And that can be a problem for them, that can be quite difficult for them.

It's almost the opposite situation for the farming community - obviously at the moment we're hit by foot and mouth which is a big worry for them - but generally speaking the farming community are a very close-knit community and support each other very well, within their own communities. So you've got lots of these very different types of communities within the Lake District. And then you also have some semi-retired people who've come to open up a B & B for a few years, so again, that's a different type of community. And also you have a transient community with the hotel workers, who generally speaking don't come on to our caseloads. And we have people coming on holiday so quite often we might get asked if they could access us if they need to because they've come on their holidays for a week or so. So it's a very different type of community to perhaps another rural area because of the tourist industry and because people want to come and retire here as well. And even within the Lake District and its surrounding areas you will find different pockets of people again. Whereas, say, Grange-Over-Sands has a really elderly population of perhaps people who have been for their holidays for years and years from Lancashire and Yorkshire and they then want to come and retire here - but they're a different type of person to the person who comes and is quite wealthy and has owned their own businesses that come to retire into the Lake District National Park. And they all present different attitudes and cultures and problems to sort out really. So it's quite diverse - although it's quite white and middle-class - they are very different people with different needs.

SPCN(1): Within our area people are a long way from the hospice and that impinges on their visiting. We have got quite an elderly population in parts, and a lot of the women don't drive, so for them to actually be able to get to the hospice [is difficult] because transport isn't that good and it's at least 25 miles away.

Other nurses also talked about the fact that home deaths were not usually an option for people living alone. However, one nurse spoke of the difficulties faced by such patients if they were not a priority for a scarce hospice bed because they did not have complex symptom control needs:

SPCN(3): I can think of people on their own, frightened. They've got Social Services coming in three times a day to make sure they've had their lunch or to give them a wash, and you try to do everything that you can because you're terrified that you're going to arrive one day and they're going to be this crumpled heap at the bottom of the stairs or something. Often there's nowhere for them to go.... You are leaving them on their own with no-one, perhaps you've got them a call-bell or something, but they need looking after and their medicine sorting out. But there's nowhere for this any more. I suppose they might go into residential homes, nursing homes, but that isn't always satisfactory.

The difficulties posed for carers if they had other demands on their time might rule out the option of a home death:

SPCN(2): If the carer has to work full-time or they're a single parent – that's among the reasons they just can't look after somebody at home.

### **Ideal models of care**

As we have seen from the discussion above, the nurses are aware that patients and carers vary in their preferences for place of death, and that these preferences often change as the illness progresses. They wished to facilitate and support patients and carers in their choices but were acutely aware of the barriers imposed by current service limitations (the limited number of hospice beds, especially in Ulverston/Barrow, and the absence of 24-hour specialist palliative care services in the community). The development of comprehensive community based palliative care services, perhaps in the shape of a hospice-at-home service, was seen by all to be important, though not at the expense of other services (a view shared with the consultants). But such a development was not seen as a short-term possibility given the current configuration of services and funding constraints:

SPCN(2): ‘... hospice-at-home is a long, long way off I should imagine. I wouldn’t mind piloting something like that....

It [needs] an awful lot of thought and development – where’s the finance? Where’s [the demand] coming from – is it generated from the bottom? But in an ideal world to have some kind of specialist input out in the community 24 hours a day, teams quickly accessible, and medication. I mean Macmillan nurses might have a kit they can keep in people’s homes so that if there is a bleed, or something terrible happens, they can give the appropriate drug quickly, rather than [having to call a doctor]. We haven’t had that here but I don’t see why if they can do it in big centres, it’s only resistance from medics I think.

Focusing on what might be more realistic in the short term, this nurse suggested that in her area (Ulverston/Barrow) an immediate priority was for more hospice beds:

SPCN(2): ... we need more beds, not a huge amount more because I think [we are now] much more efficient and manage the people we bring in better having a small number of beds, but we could do with some more to deal with the difficult problems, to offer more respite, and deal with people who cannot go home again – because that’s what we feel so bad about [sending them out].

In contrast, a Lancaster based nurse emphasised the importance of primary health care services:

SPCN(4): I would be putting resources into primary health care teams. They’re the service that I think needs the greatest support: the district nurses are all absolutely run off their feet and there’s virtually no opportunity for education for them. I think that we as Macmillan nurses for the population we cover, if the primary health care teams were better resourced, we wouldn’t need any more nurses. I think we could manage very well the population that we cover. But where the gap in resources lies is in the community.

Overall, the nurses’ descriptions of ideal specialist palliative care arrangements focused less on the *location* of services (home, hospice or hospital) than on the ingredients of an effective service. ‘Good deaths’ could occur in a number of settings. What was important was that there was effective team working between professionals in the provision of the best possible support to patients and carers. If the death is to occur at home then the quality of inter-professional understanding and co-operation in the management of the dying process is key, something that has to be newly established around every case:

SPCN(3): ...the times I've had good deaths at home there's been a *good* GP, an attentive, knowledgeable GP with an experienced team of district nurses who have worked well in a team, and who I've worked well with, and you've had the addition of good support from people like OTs and anybody else that needs to be involved. If it's all slotted in well it can be brilliant. We've all been talking, we've all been in contact every day – not perhaps meeting, but we've all been around and we've had good working relationships and good relationships with families.

Two nurses suggested that in an ideal world palliative care services would also be available to people with non-malignant diseases. This meant training up other health professionals in palliative care skills:

SPCN(1): ... my particular interest is the patients with non-malignant disease, because that is my nursing background. I feel quite strongly that they should have access to good standards of palliative care. I don't know logistically whether that could be done by the Macmillan nurse, or whether what we ought to be doing is disseminating the practices of the palliative care approach so that those patients have equal access to high standards of palliative care. That's a challenge for the future.

SPCN(2): [Palliative care] should be for everybody, everybody should have that kind of access... So instead of the hospice being like a building [that people come in to] we should be going *out* more. That's what we do with the community nurses, with the district nurses, and I assume the hospital Macmillan nurses do too – raising awareness and knowledge of people on the wards so that everybody should be at an adequate level to give people that care. I think that's where the challenge lies – going out more now and taking the message out and teaching people, not making [palliative care] one little place where everyone's a super intelligent nurse with all these qualifications, and specialist this and specialist that. We should be going out and helping other [health care professionals], not de-skilling but passing on skills. Whether that will happen or not I don't know, but there's a need for it.

6. A Senior District Nurse in a primary care led palliative care service: the Kendal model
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## The nature of the service

Within the MB area there is a Kendal-based General Practice that has pioneered its own model of specialist community based palliative care, a service led by a team of district nurses (DNs) working with GPs. This rather unique DN/GP service was the result of both the vision and efforts of the senior District Nurse interviewed for this study. The service had a twelve-year history and, according to our respondent, had involved periods of sharp disagreement with district community health service planners and agencies and with some hospital-based cancer specialists (consultants). These disagreements arose when these authorities and practitioners had other perspectives on what DN services should look like, and on the role of primary care in cancer services more generally.

Our respondent described her long struggle, with the full support of Practice GPs, develop the service and to vigorously defend it when necessary, a service which has the following features:

- All newly diagnosed cancer patients that are referred to the DN team receive a home visit and assessment of need (patient, carers and family need). A pattern of DN visits is then established, as appropriate. Thus supportive care is offered from very early on in the cancer journey, with hands-on nursing care available when required – especially when a patient moves into a terminal phase. There may be some withdrawal from regular visits in periods when the patient is managing the illness well.
- Both nursing care needs - especially symptom control, and spiritual needs, are attended to. Spiritual care is deemed to be important and is written into the nursing plan. The importance of *listening* to patients was stressed,
- Palliative care is offered not only to cancer patients, but also to those with other terminal conditions. 'DN: we would see palliative care as much wider than just cancer'.
- DNs tend not to have a lesser role in the early care of breast cancer patients because of an 'excellent Macmillan breast care nurse' in the locality.
- A greater proportion of cancer patients die at home now than was the case in the early days of this DN service, reflecting the development of DN skills in supporting patients at home.
- At the time of interview, the DN team numbered ten nurses, some with qualifications in palliative care, (6 GPs; 14,500 patients).
- Good relationships with local Macmillan nurses and the Lancaster hospice were reported. In a reversal of the established arrangements, our respondent viewed the DN/GP team to be the rightful specialist palliative care service providers in the community. They could draw upon the resource represented by Macmillan nurses and other specialists, as appropriate.
- The DNs work closely with Social Service 'Home Care' services, co-ordinating their respective inputs into patient care.
- This DN service does *not* operate a 24-hour service.

The following extracts give a flavour of this DN's service perspective and motivations. In the first extract, she gives an account of events that prompted her to develop the early-in-cancer-contact district nursing model; building a trusting relationship with a patient soon after a cancer diagnosis was key:

DN: [Some twelve years ago we got a call to visit a patient – a lady with a sore back]... When I went round this lady was actually in the terminal stage of cancer, and I was absolutely horrified that I didn't know about it. We got moving very, very quickly. The lady only lived maybe two or three weeks after that, but I found myself wishing that it hadn't been a hassle like this at the end... I thought that if we'd known about it we could have done lots of symptom control, we could have made her life much easier. Then after that we has several instances where the Macmillan nurses were involved – and I have no problem with Macmillan nurses at all – but they had been involved with patients and handed the patients to us, handed the care over to us when it was time for hands-on care. Well, by that time the patients themselves had got used to the Macmillan nurses – they knew them, they trusted them, they had confidence in them – but we were [then seen] like amateurs, we were strangers to them. And so by the time our hands-on care was needed they sometimes actually ended up in hospital and died there, or occasionally in the hospice, but usually the hospital right at the last minute. That happened several times. And I really believed it was because the families didn't trust us. They really regarded us as amateurs, it was the Macmillan nurses who were the experts – and, of course, they are specialist nurses, and I have no problem with that. But it did occur to me at the time that if we'd known about the patient earlier we could have built up a relationship so that when the hands-on care was actually necessary then we would already be friends. And not only that, I believe that patients were suffering from symptoms that really they need not - if we could sort it out a bit earlier. [I experimented first with my own district nursing practice] which gave me the evidence that I needed - that, in fact, *where* I was involved quite early on, and *where* I'd made pretty regular visits, symptoms were sorted out, and when it came to hands-on care the patients already trusted me. [This was then spread to the DN team approach]. I really felt that I was right about this... The GPs here were wonderful and they really supported what I was doing and they found the benefit of it.

DN: ....now the team itself is passionately keen on it, because they've seen the real benefit – patients where we've gone in, a routine visit, maybe a monthly visit, weekly, whatever, and we've seen something that the patient's struggling with, and because

we're there they've told us about it, we've got it sorted out, and they've got on with life. So my belief is that we've actually *saved* the NHS thousands of pounds. I really believe that, but it's difficult, of course, to prove.

DN: Our aim is to achieve a peaceful death, that the patient should achieve a peaceful death and that the carers feel supported...

... we're already into symptom control, and we'd be looking at the spiritual care. We'd be looking after the carers too, we'd be a sounding board for them. We'd certainly be there for the patients, looking at their anxiety. Quite personally, I make relaxation tapes for patients; I personalise those, including the readings patients want. You know, they sometimes love poetry, or they'll describe a place to me that I then put on tape and they imagine they're there. I do quite a lot of those. We're looking at alternative methods of pain control or methods that go alongside the medication. So we're looking at anxiety, and the actual nursing care needed. Of course, there's bowel care, constipation can be a problem with the medication, taking care of pressure areas – the usual general nursing care. But we certainly look after the carers as well – husbands, wives, and children.

DN: ...Certainly we do a lot more of the symptom control now, the pain control and nausea, so our knowledge of medication has improved dramatically....

... symptom control is now seen as very much a part of nursing care which we should be giving.

### **Reflections on place of death patterns and patient and carer preferences for place of death**

In this DN's view, patients and carers tended to prefer a home-based death. But this was not true of all:

DN: Most of them prefer to die at home. There are some who really don't want to, and that's fine, and some where relatives don't want them to, but that happens less these days.

She was certain that the proportion of home deaths had risen markedly since the DN service in palliative care had developed:

DN: [Patients die at home] much more now, since we've started the service and got much more developed, far more patients die at home... the majority of our patients do actually die at home.

Other factors influencing the location of cancer deaths were very similar to those identified by the interviewees already discussed. Particular attention was drawn to the following:

### **Home deaths – a lack of service support.**

The limited availability of the Marie Curie night-sitting service was highlighted:

DN: Where [a home death] falls down is usually because we haven't been able to get a Marie Curie nurse during the night. We don't have a night nursing service in Kendal. So where it has fallen down – and we've had a couple recently that have been quite sad, one got to the hospice hours before they died, that was really sad, very frustrating...  
...We can't always get Marie Curie nurses when we want them.

DN: ...more Marie Curie care during the day would [also] be lovely, somebody who'd be there for two or three hours so the relatives can just go off anywhere... I mean the relatives often really need to get out.

*Carers dealing with fears and crisis, and patients' and carers attitudes and feelings.*

DN: the carers, the family, really need to be confident, and I think, hopefully, our team does give them that confidence. They carry a far larger burden than we do. But we need to teach them, to help them, to show them what to do and to give them the confidence to know that they can actually do it. But also to make sure that proper support services are put in, such as Marie Curie, so that they can have a good sleep every so often.

### **Ideal models of care**

This Practice's current service model was close to our respondent's ideal for specialist palliative care provision:

Interviewer: What do you think would be the ideal configuration of services for dying cancer patients?

DN: A good district nursing team with the specialist Macmillan team there as a resource. Of course, not just the district nursing team, a good GP team – that works well together, the team effort between doctor and nurse that we're very fortunate to have here....

...where a patient is under the care of a hospital-based palliative care team the care can be really fragmented. Whereas if they're under the care of the GPs here it's much more together somehow. If we could use the [other] palliative care teams as specialist teams

for when we're not getting it right, that would be ideal, but I think sometimes they tend to take everybody, and that really fragments the care...., it's disjointed, very disjointed.

DN: I see this as a model for practice. I really believe that what we're doing here should be emulated by every district nursing practice: this should be the way ahead, this should be the way to go. It's cost-effective, it really is, and it enables patients to live a much better quality of life – we're in there, we give them the confidence to do that, and they get out and live. We've seen that time and time again....

...to have a specialist cancer centre doing all the care doesn't seem terribly helpful to me. I think it should be within the primary care teams, using palliative care specialists as advisors rather than them doing it or trying to do it all themselves, because they *can't* do it all themselves.

In her opinion, the type of palliative care services available to cancer patients should also be accessible by patients with other conditions: 'It seems a shame that you can give more help to one group of patients than another'.

## 7. A Social Worker practising with terminally ill patients and families

We interviewed a social worker who, although hospital based (Lancaster), had a community service remit and was employed by Social Services to work with patients who were diagnosed as terminally ill and their carers. Her caseload included non-cancer patients, but the interview focussed on her work in the cancer field. She covered a large geographical area in North Lancashire (north of Preston), up to the Cumbria border.

Although this respondent described her work as in some ways quite isolated, she also stressed the importance of multidisciplinary team working with colleagues in health care. In particular, this involved close working partnerships with hospital and hospice (community) Macmillan nurses: 'My closest relationship is with the hospital Macmillan nurse. We work very closely and liaise most days'. Referrals are made from a range of sources, including: hospital Macmillan and breast care nurses, the (NHS) Rapid Response service, hospice, other social workers. As a specialist social worker, she tends to concentrate on cases involving some complexity and difficulty, with a case-load of around 25-30 clients:

SW: If it's a straightforward package of care it doesn't need my skills because any social worker can go in, do an assessment and put a package of care in. But if its complex, if the family dynamics are difficult, if the patient themselves is not accepting

of the situation for whatever reason – unrealistic, or just don't want to be there and angry – then it's seen that I'd be the best person to be involved.

She described her work with clients as combining the following: setting up a package of care, sorting out welfare benefits (beyond those dealt with by Macmillan nurses), monitoring, and the provision of emotional support. The importance of establishing trust was emphasised.

SW: From the basic package of care and assessment, if that's needed, and monitoring. It could be as simple as that. But within the monitoring there's a lot of emotional support, because I'll be doing home visits and just checking everything is running smoothly. And that's about trust, building up a trust. Financial advice – that's a biggie. My remit is wider than say the hospital social workers who won't touch the benefits side. Whereas I will look at that and advise, I do a lot of work on benefits.

Patients were often first contacted during their stay in the hospital Macmillan unit: 'So while they're in hospital I meet them and do the care package, then I follow them through [in the community]'. Both patients and their carers were the practice focus:

SW: With some families a lot of [my work] is support for carers. I find, with people who are not living alone, a lot of my time is taken up with carers, giving support to carers and making sure that they're not getting run down. Because they're the important ones that need to be emotionally strong and stable in their own health. Because they're the ones carrying the burden. And that is really difficult – day-in, day-out. ... Although my service user may be the patient, the one with cancer, I can't separate [patient and carer]. Because the one can't function without the other. The reliance is often total, and so you just can't separate them.

This respondent described a division of labour with Macmillan nurses such that she dealt with social care and the latter engaged with health care needs, but there was inevitably some role-overlap, and 'sometimes I can be more involved in a case than a Macmillan nurse'. If the patient dies at home, her involvement was usually on-going until the death was imminent, though she generally withdrew when nursing care took over in the last two or more weeks:

SW: ... right at the end, there's less of my involvement [and social care is superseded by health care] – the final fortnight, or whatever, district nurses will take over and do the hands on care. And they tend to pick up on what social carers have been doing.

## **Reflections on place of death patterns and patient and carer preferences for place of death**

In reporting this social worker's reflections on place of death patterns it is helpful to make use of some of the 'factor' headings already featured. There is considerable overlap in the types of factors identified, although the service 'supply side' factors highlighted pay greater attention to meeting social care needs.

### **Service 'supply side' factors**

#### **Social Service restrictions**

In our respondent's view, patients who lived alone were often very frightened to be alone as death approached, and where a carer was present they were not always able to cope, especially if elderly and frail.

SW: ..your instinct tells you really that the person would be better off in a nursing home with qualified nurses around them, because on a day to day basis [things] need monitoring.

However, the policies and practices of Social Services, her employer, frequently failed to meet the needs of the clients she dealt with:

SW: I just get so frustrated by the structures and process of Social Services, and the restrictions....The policies sometimes do not fit in with palliative care.

In her perspective, a key issue is the tension between the Social Service imperative, encouraged by central government, 'to stop older people going into care' on the one hand, and the needs that she observes among some older people who are dying precisely for a type of institutional care, whether in the shape of residential care that is accredited to provide nursing/palliative care, or hospice care. Such institutional care is frequently not an option under present service arrangements and policies. This meant that 'people actually don't get any choice in where they do die'.

Dealing with such tensions meant that working across a Social Service and NHS divide was often problematic:

SW:... ideally I think I'd be better employed by Health, being part of the multi-disciplinary team, totally, than being as I am. I have more in common with Health than I

do with the rest of the social workers – job-wise anyway, though I have to use the same systems as everybody else.

Other service supply issues are as follows:

### **Lack of a comprehensive home care support service**

SW: There is a real gap in good standard home care for people who want to stay at home... because district nurses' resources are stretched enough. [It would be good to have] a dedicated palliative care team – like a hospice at home team, that could go in and do the hands on care at the crisis point. That would plug a big gap.

### **Lack of residential care home places**

One of the factors shaping current place of death patterns, in this respondent's view, was a shortage of care home beds, both for basic residential care and for nursing care in the palliative care phase.

SW: I also think that for those who can't stay at the hospice for any prolonged length of time, to have a nursing home [would be desirable], because I think there is a shortage of nursing home places.

### **Patient and carer experiences – 'demand side' factors**

Other factors identified as relevant to place of death are as follows:

#### **Patients' and carers attitudes and feelings**

SW: if we're looking at people who have family support, we're looking at things such as their own values and beliefs. And looking at how they've coped in the past. If they're copers, people who are copers in life, I think they are more likely to be able to cope with the situation at home.... It may be that the carers are not copers, and although somebody may want to go home to die they know that they can't put that burden on the family.

#### **The suitability of the home environment**

SW: [For some people, being at home is] just not practical – because you couldn't have a bed downstairs. The sheer practicalities of the living accommodation could prevent somebody who actually may want to die at home from doing so.

## 8. Other interviews

Three other interviews were conducted, one with a former employee of MBHA who had undertaken development work in palliative care services in the locality (now a PCT Chief Executive), one with a Consultant Urologist, and one with a Hospice volunteer worker. These respondents confirmed many of the observations about services reported above. To avoid repetition, only additional points will be noted in this section.

### **The benefits of the hospice to patients and carers**

The volunteer worker at St John's Hospice described features of the hospice that made it so appealing to patients and relatives, once they had overcome any anxieties that they had held about coming to a hospice for the first time. These features included its peaceful environment, the friendship offered, and the love that emanated from volunteers and staff:

Volunteer: It's such a very, very peaceful place to be.

[...] ... once they've been into the hospice, most people are very willing to come back in, because they know they get the care and the love really. There's a lot of love there, a lot of love there.

Speaking of the day-care service, this volunteer noted the benefits for both patients and carers:

Volunteer: Well, it's a place where a patient comes in for a day, giving the carer a break, which is very important for the carer. They come in and they sit and chat, and they have a lovely lunch, if they're able to eat, I mean we care for a special diet. And they just give a nominal fee for their lunch, and especially for a patient who lives alone, it may be the best meal that they have in a day, so that's very important for them. You get people who will tell you the first visit, they're very frightened, because they're very apprehensive with what they're going to face when they come into the hospice. And yet by the end of the day they're so bright, they've really enjoyed it. We try to get them laughing, I think that's very important, and they go away having had a lovely day, hopefully, I mean they say that to you – as they leave the hospice, they've really enjoyed it and they're looking forward to the next time.

Patients sometimes confided in a volunteer about personal matters or about pain; this could help the patient relieve worries or tension:

Volunteer: ... sometimes [patients talk about] personal things, things that they can't speak to their families about, they don't want to upset their family. But they know that you're like in-between the family and the staff at the hospice. Very often they're very willing, they want to talk – they get your attention and they obviously want to talk...[...] If they've got pain, for instance – people don't like to appear to be moaning about pain, but the staff need to know about that, don't they? Because often they can help them with the pain

If the matter raised was 'medical' then this volunteer would ask the patient if she could pass the information on to staff, because in her view they should know because they may be able to tackle the problem.

### **Factors that are associated with place of death:**

Former MBHA professional: It's probably about knowledge of the services that are available. I suspect that knowledge comes from family and friends, but I think the role of the health professional is crucial. I suspect people get on a conveyor belt of expectation that it would be difficult for them to get off of, even if they'd got a preference elsewhere.

Former MBHA professional: ... if people need a 24-hour care package, the reality is that it wouldn't be available under the NHS or from Social Services.

Former MBHA professional: I think one of the issues is to look at the capacity in primary care... [...] I think that there's probably been a de-skilling over time in palliative care. [Among one or two GPs in Lancaster] there was some anger that the development of services at St John's had effectively de-skilled some of the GPs, and actually although there are continuous moans about GP workload, palliative care is one of the most satisfying areas of general practice. But a patient's path would sometimes go from the district nurse into the hospice, with the GP only signing the form, or agreeing to it, and feeling marginalised from the overall care of the patient. I suspect that that's probably true generally, that we've changed the model of care, so the GPs are less at the centre of it.

## Summary: key findings

The interview data presented above contains a wealth of insights concerning the nature of palliative care services in localities within the MB area, and offers a rich understanding of the factors that shape place of cancer death preferences and outcomes. Attention is drawn to a number of service ‘supply side’ and user ‘demand side’ factors that determine or are associated with i) actual place of death, and ii) preference for place of death. Key findings are as follows:

- All of the professionals interviewed saw *actual* place of death patterns as determined, in large measure, by the pattern of service provision in the MB area. That is, service supply side factors were a key influence on place of death outcomes.
- Specialist service provision was reported as variable across the MB area. While there were many common service ingredients across the Bay, there were also marked variations by locality; for example, in the number of palliative care beds and hospice capacity; the range of specialist staff involved in services; service funding levels; the availability of: Marie Curie night-sitting services, 24-hour district nursing, out-of-hours palliative care expertise. These variations were partly bound up with the historical development of specialist palliative care services in particular localities – services that were initially on the fringes of NHS provision, and remain subject to the vagaries and uncertainties of charitable funding. Some professionals had a sense of inequity in the distribution of resources across the Bay, with the Barrow end of the patch being the ‘poor relation’.
- All respondents wished to see greater opportunity for home deaths if that was the patient and carer preference. However, none could see how significant progress could be made on this front without increased resources for specialist and non-specialist palliative care. All commented that the current configuration of health and social services in their localities meant that real limits were placed on the number of home deaths that could be supported. The further development of specialist community based palliative care services was seen by all to be important, though *not* at the expense of other services. Other limitations on achieving change were noted by some, in particular the ‘political’ resistance, in some quarters, to reducing the number of hospice beds in Lancaster.
- The specialist palliative care nurses (SPCNs), in particular, discussed the ways in which a lack of necessary palliative care services in the community – 24-hour district nursing services, an out-of-hours on-call specialist palliative care service, all-week Marie Curie night sitting services, more comprehensive social service support - often meant that ‘crisis’ situations arose for patients and carers that could not be coped with at home. This might lead to a hospice or hospital admission, followed by a death in these settings:
- SPCNs and other front-line professionals reported having observed many scenarios in which a carer reached a point when s/he felt they could no longer cope at home with a

patient's illness - for example, with the patient's pain or other symptoms, or with the patient's emotional state. Carers could become exhausted through lack of sleep, or may no longer be able to manage the emotional strain of seeing a loved-one slipping away. Thus, for a number of reasons, carers often needed to call upon more comprehensive professional assistance, though they might leave this to the last 'crisis' moments, only giving up their struggle to shoulder the main care burden at home when all extant resources were used up. If the assistance was not forthcoming, or did not allow for the full support of the patient *and carer* at home, patient care would usually be relocated to a hospice or hospital. In such situations, many patients and carers had to give up on any desire for the death to occur at home. This could leave the carer with post-bereavement regret or guilt.

- All specialist palliative care professionals had a deep understanding of the need to work in close partnership with members of the primary health care team – especially with GPs and district nurses. Most noted that there was considerable variation in the willingness of GPs to involve themselves in palliative care provision, and reported much variability in the level of skill possessed by GPs in this regard. The same could be said of district nurses, although there were many complimentary accounts of the palliative care work undertaken by district nurses.
- One General Practice in Kendal had a unique primary care/district nurse led approach to palliative care, resulting in a relatively high proportion of deaths occurring at home.
- Two respondents spoke of the need for increased nursing home provision in the MB area, especially provision for intermediate or non-specialist palliative care.
- All respondents noted that patients and carers often start out on the palliative care journey with a preference for a home death, but frequently alter their preference as illness and personal circumstances change.
- All respondents were aware that current Service Frameworks play an important role in moulding patient and carer preference for place of death. That is, preferences tend to be shaped in the light of the limited options that are known to be available.
- Most respondents noted that patient and carer preference for place of death could not always be met given the current service configuration. This was especially the case where the preference was for a home death, but it was also sometimes the case where the preference was for a hospice death due to the non-availability of a hospice bed.
- Overall, the professionals' descriptions of ideal specialist palliative care arrangements placed greater emphasis on the ingredients of an effective service than on the *location* of services (home, hospice or hospital). That is, 'good deaths' could occur in a number of settings. What was thought to be important was the availability of a full range of services and place of death options. Effective team-working among professionals in the provision of the best possible support to patients and carers was thought to be essential. If the death is to occur at home then the quality of inter-professional understanding and co-operation in the

management of the dying process is identified as key, and is something that has to be newly established around every case. In this context, the attitude and capacity of the primary health care team is deemed critical.

- *Non-malignant conditions:* Most of the professionals interviewed noted that they dealt overwhelmingly with cancer patients (the specialist medical professionals interviewed occasionally dealt with patients with other conditions). All thought that palliative care services should be available to patients with non-malignant conditions, but noted that this could not be achieved within the constraints of existing services and resources. One respondent doubted, with regret, the fund-raising appeal of provision for conditions other than cancer.

## Chapter 7

### Body matters

#### Introduction

Our analysis of the patient and carer interview data drew attention to the role played by a range of factors associated with their concerns about the state and management of the patient's diseased body, together with the emotional sequelae this concern engenders. These factors were important in shaping place of death preferences, or the absence of a preference, on the part of both patients and carers. Patients and carers also had concerns about the carer's body – whether it could cope with the physical stress of caring, especially if the carer had a chronic condition of their own. This is dealt with in chapter 8. Here, the focus is on the patient's bodily state.

#### Patients' perspectives

##### **How will I know that I am close to death? What do the symptoms signify?**

Contemplating the dying process is difficult when one is functioning relatively well, or perceives one's functioning as manageable, even if this is with the aid of medications and equipment. Many in our sample expressed this difficulty. It was presented as hard to imagine what would happen as death approached, and a matter of great uncertainty. Planning was therefore seen as dependent on the 'how it goes'. This inability to fully imagine the dying process, or to anticipate the bodily changes that would occur, meant that place of death preferences might not be formulated at all, or were recognised to be uncertain or contingent. Changes in the body, and the meaning and significance of these changes, were matters were of central concern here.

Female patient: I don't know what I'll need in the future, do I, because I don't know how it's going to progress. Slow – fast – suddenly? I don't know. I'll just deal with it when it comes I suppose, that's me, though I do like to know or have an idea so I can be half prepared. K5, Age 67, lives with husband, bowel.

The desire to be prepared can be compromised by a lack of knowledge or information about bodily deterioration. The following patients are keen to know more about what will happen, yet they both indicate that these questions are socially difficult, and refer to it being 'morbid' to ask questions about the dying process, despite the fact that it is their own bodies and future they are talking about.

Female patient: It might sound morbid, but I'd like to know what's going to happen, what moves on and how you're going to end up, if anybody could tell me. And I mean they must have come across it some time, either at the hospice or at the hospital, mustn't they? I mean, I'm not the only one in the world that has got it, or had it. But it's knowing who to talk to, the right people, and nobody's sort of offered 'Oh, go and see so and so', or offered the advice you want. If they put you in touch with somebody you'd feel better, but there isn't. B6, Age 62, lives with husband, breast.

Male patient: I asked the, I don't know how to put it, morbid question: how would I know that I was not going to have long to live? Because the doctor has said, 'Oh, you've got two months and that's it'. There must be an easier way to know that when you're going. Would it be the pain factor, that would get more and more and more and more and more, where I just couldn't really control it? [Then] I'd be on greater doses of morphine, and I'll be spending more time in either here or [the hospital], and you'd get to the point where you're spending the time in [the hospice] for greater lengths. And you'd notice that your morphine's going up from say, I don't know, a hundred milligrams every four hours, to say six hundred milligrams every four hours. Then you know you're going on your slow boat to China, and then you'd know that is one way. You would know. Because it does get, it is, painful- when it decides to kick in it's the most excruciating pain I've ever had in my life and it is for everyone who's got it. L2, Age 41, lives with wife, thyroid.

Some felt their questions about what will happen to their bodies, and about the dying process, had been answered, and this was reassuring:

Female patient: I know that I'm not going to be here all that much longer, but it's just, you know, you get worried about how it's going to be.

Interviewer: And you've asked them and they've said that you - .

Patient: Yes, and they just say, 'Well, you're - you'll just get tireder and tireder, and sit in the chair more and more.' And being a person that always likes to get out every day - I used to go bowling, I organised the bowling, I organised everything - now it's all gone. B12, age 82, lives alone, bowel.

People often constructed speculative signposts, centred on bodily matters such as weight loss, incontinence and pain, as well as needs for particular services, to guide them on their journey. They evaluated their own signs and sought information, often expressing surprise that health professionals did not seem to put as much importance on small signs of change as they did. Maintaining hope of a reasonable period of good quality of life was a task that many set

themselves. Bodily signs like loss of weight, and contradictory information about symptoms, were opposed to hope and a positive attitude by this couple:

Male patient: I've been losing weight again. When this [illness] first started I was ten and half stone, and now I'm just eight. There's one person saying to me: 'You will put on weight, but it will be very slowly'. And there's another person saying to me: 'There's no way you'll put on weight, you might lose more'. Now that worries me.

Female carer: I think that's quite the wrong thing to have said, to be honest, I think if you – that knocks any sort of hope of putting weight – he's very conscious of weight, of his weight.

Patient: Well I am. I'm worried in that I think, if I lose a lot of weight other organs are going to start getting damaged and what not. [...] But that's what I worry inwardly about. But they [health professionals] don't seem to worry about it at all, do they? L14, Age 72, lives with wife, gastric.

Along with weight loss, pain was frequently used as a 'marker'

Male patient: And I'm a bit worried because it looks to me, with this pain I've got here, that this therapy might be dying off. It were grand at first, but it looks as though it might be just finished its purpose. And it's terrible this pain, it is. L9, age 88, lives alone, lung.

Promises of pain relief were both reassuring and used as information on 'how it would go':

Female patient: They say 'we'll keep you pain free', so I mean the pain must be going to come worse as you go along. So I think that's about all they can say. B6, age 62, lives with husband, breast.

However, there were a few who did not relate pain to deterioration and who expressed a strong focus on the present:

Male patient: It gets rid of the pain for you. Because one of the doctors, the pain doctor, said: 'What doses do you take?' And I said: 'Oh, about that much' [indicating with fingers]. He meant, how many spoons? – well I just, I used to keep it in my pocket and just drink it out the bottle [amusement]. I take that instead of the tablets because it seems to work quicker. But I think you've got to look it on the positive side and the negative side...

If it turns negative, what will I do? I mean, you're just in the lap of the gods then really, you can't say. One thing you can do is rely on just pure medicine, or pure medical treatment then, you know. But otherwise, I always try to look on the positive side, and it seems to be working, and with my family around me it seems to be working. B7, age 57, lives with partner, lung.

More general attitudes to death play an important part here. Some related dying to their past experience, particularly to the witnessing of others' deaths from cancer or to their own previous episodes of serious illness, and sometimes it was related to the future (in the form of an afterlife). These patients tended to be quite matter of fact about dying, and not to be particularly concerned about place of death. Like others, they did not know how dying would be, but they felt that death was a process they could go through relatively smoothly:

Male Patient [a Vicar]: I mean life does seem unfair at times, and I'm not complaining. Why should I? And who said life was fair anyway?, some of us have, I think I've had, a fairly good life. I've enjoyed most of it. One's not going to be here forever anyway, and ought to have the wit to recognise to this, one hopes – and I hope there's – I believe there's something better eventually beyond, so the whole process of dying isn't – isn't too painful or difficult, the actual moment of it, you know – I mean, I will see. B2, age 65, lives alone, leukaemia.

Female Patient: [the consultant] just said, 'Now I can't give you a time E.,' he said, 'how long it will be.' So, I said, 'Well that's something, that's a quiz, isn't it.' And he said, 'Yes.' 'Well,' I said, 'Never mind about it, whatever happens, happens, and I've had a good life. I've got to 81. I said, 'there's many a little kiddie that hasn't had a life, and they're just dying of [cancer], what the hell have I got to grumble about?' He said, 'That's a nice way of looking at it.' So, he said, 'There is a tumour there and I've been told you I daren't touch it. Now that will grow, and when it gets to the end, that will be your lot.' 'So nicely put,' I said to him. [Laughter] And he just looked and me and laughed. I said, 'It's only way you could put it. Well that's all right then. I'll wait and see what happened now – eh?' He said, 'Right, now you're all right? Do you want anybody to come and talk to you?' I said, 'No thank you. You've talked to me and told me what I want to know. I've got it there and I know what I am going to do.' He said, 'What are you going to do?' I said, 'Be happy..., I'll be happy when I die I hope. I hope I'm giggling from here to kingdom come.' So I think this is why I keep giggling, you know. I am happy, it's not a put on. L17, age 81, lives alone, stomach.

Male patient: I've been through the business of not knowing what's going to happen to me before. In 1977 [my heart nearly failed] and since then things are-, it's not something that concerns me particularly. Well, it's nice to live for another year. L10, age 56, lives with wife, kidney.

The three quotations above are interesting because they illustrate the important bearing that biography has on managing illness and dying. The first was a vicar, whose wife had died of cancer a few years ago, and the other two of them had nearly died earlier in their lives. None of these people were concerned about where they died, although one of them said she would not like to die in the street (she actually died in the hospital). The man with long standing heart failure had a history of hospital care; thus he was happy to go to a hospital in his current circumstances, and did in fact die there unexpectedly. The vicar died in the hospital shortly after an emergency admission, having collapsed after a holiday.

### **The role of symptom management in determining preferences for and actual place of death**

The need to cope with the 'abject body' (Kristeva, 1982), which threatens to run out of control, is a matter which concerned several of our respondents, and had a direct effect on their expectations and preferences for place of care. Anxieties about the particular degenerative processes of advanced cancer, which often leave the body 'unbounded', were frequently expressed (Lawton, 2000). Some did not want to impose 'unpleasant' symptoms on loved ones, or felt that it was inappropriate for a relative to have to deal with such symptoms. The nature of the familial relationship seemed to have a bearing on preference for place of care in the event of physical dependency and the need for intimate nursing. Put generally, spouses were seen as appropriate carers, but other familial relationships were less favoured by many. Sometimes feelings of embarrassment were mentioned by respondents in relation to same sex relationships (such as mother/daughter), but was much more frequently invoked where the relationship was not spousal and the patient and carer were of opposite sexes.

Male patient: I had said that when I got close to dying that I wanted to go into the hospice and die, because I didn't wish to burden my family with the unpleasantnesses, whatever they might be. And I still hold to that, but whereas before I was quite certain that I would do it, I would now only do it if the unpleasantnesses were there. So, I have altered my tack on that. K1, age 67, lives with wife and father-in-law, rectal.

Male patient: You never know I might just go to sleep one night and not wake up, and if that's it then all well and good. But I won't like to start being incontinent and stuff like that, put that on them [family], which I wouldn't expect.

Interviewer: Even if they had nurses to come in and help?

Daughter: The Curie nurses, or something like that, will help out in that sort of situation apparently. The nurse did talk me all through it and there really is no reason for it to come to that.

Patient: I know that, but-

Daughter: It's just my dad's dignity that he is worried about. I don't think you need dignity in this sort of situation. L4, age 57, has moved to live with sister and her husband, daughter visits weekly from London, pancreas.

Generally home has been discussed as a 'private' space and institutions as more 'public' (Cornwell 1984). But in these instances distinctions between private and public spaces were blurred by emotional and social considerations. In situations of dependency 'home' does not always offer the privacy, which is desired. Hospices offer a site where the drawing of boundaries around bodies happens at a literal, physical level. In hospice, it is possible to maintain a separation between the hygienic life world and the disintegration of the flesh (Lawton 2000), and where containment of death imposes order and meaning and diminishes the threat to the remaining social body (Mellor & Shilling 1993). Lawton (2000) argues that hospice is a 'no place' where death is overt, but 'dirty' processes of dying are veiled, glossed over, as symptoms requiring control, thus reinforcing contemporary western cultural values of individualism and self-containment. Many of our sample seemed to subscribe to these prevailing values. However, the stating a preference for removing the unbounded body from habitual social settings was highly contingent, depending to a large extent on judgements of the appropriateness of the social relationship with the carer.

Troublesome symptoms did precipitate the relocation of patients in several cases, as this carer recounts:

Female carer: He was increasingly bothered by swollen legs from the treatment that was containing the tumour. And his failing heart couldn't cope with removing the excess fluid, so he had very swollen legs and they were beginning to get ulcerated. And it was pain in his legs that made him say 'I need to go into hospital', a week or a bit less than a week before he died. So he took himself in because he was worried about his legs mainly, and the pain in them. L10, age 56, lives with his wife, kidney.

There were cases where events quickly overtook plans laid so that place of death preferences could not be met. Several bereaved carers recounted situations where sudden, and often frightening, deterioration meant admission. For example, this patient's sudden cognitive change meant he was admitted to hospital, where he died:

Female Carer: He trundled out the shower and he sat on the bed and I helped him to get dry. And then he said to me, 'Will you get me some of that Oromorph, my leg is really, really sore.' So I said, 'Right.' So I got him the Oromorph, went back, he took it and he said, 'I'm going to stay, lie on the bed for a few minutes till it-,'. I said, 'Well, are you all right?' He said, 'I'm fine.' I said, 'Well I'll tell you what, I'll go and get a shower,' - it's en-suite you see, so I was there. I was only in the shower three or four minutes, and when I came out he was sitting in the middle of the bed punching the air and he couldn't speak. And he was making horrible noises. And I couldn't, I couldn't put his arms down, he was so strong he was throwing himself all over and I thought, oh my, so I ran next door and they both came. B8, wife, age 63.

Another man died suddenly in the hospice, where he had gone several times to have his pain relief adjusted:

Female carer: The only thing that we did discuss was when we thought it would be gradual, we would know that it was coming, we didn't realise it would happen the way it did. We thought it would be a gradual thing, and I was just going to ply him with drink and drugs, and just carry on sedating him and just pumping him full of stuff. L2, wife, age 40.

One patient, a man who lived on his own, had plans to take his own life when death grew close – as the following extract reveals. However, others identified his mental deterioration, and he died in the hospice:

Male Patient: It will not get intolerably worse, because I won't let it, and that's all I'm going to say.

Interviewer: Yeah, OK.

Male Patient: I'm sure you understand what I'm saying, but I'm not saying it. K4, age 50, lung

In one case, a patient insisted on staying at home despite his collapse on the floor and the inability of his wife to lift him, but a chance intervention by a caller to the house some time later meant that the death actually occurred in hospital:

Female carer: [My husband fell onto the floor and] I said to him, let me phone for some help. 'No, no [he said]. So I stayed up all night with him. [...] He fell on the Saturday, he fell about midnight on Saturday, well, he lay there all day Sunday. I managed to move him so I could get to the bathroom, and I was up with him the rest of Saturday

night, I was up with him all Sunday night. Then, as I say, this insurance agent came on the Monday.

Interviewer: So you felt you couldn't phone the ambulance because he didn't want you to, but it was fortunate someone else came along and sort of said, right, well, this is it, this is what we're doing.

Carer: I never said anything [to my husband] till after [the caller] had phoned – I said, 'Look, he's phoned.' I said, 'The ambulance is coming for you, I can't move you, you can't move yourself, so the ambulance is going to move you – oh, my.'

Interviewer: So he was quite with it when he was lying on the floor?

Carer: Yes, oh yes

Interviewer: But when he was in the hospital he didn't know you?

Carer: Well, he'd gone down, you see. L1, wife, age 77

Mental deterioration was particularly dreaded by some participants, and represented a situation of loss of control:

Female patient: I said, 'Well I'm not giving up.' I said, 'I feel I've a lot of living to do yet,' because I've always said I want to live to be a hundred, and when I had my 75th birthday, the minister's husband said to me, 'I think you'll make it, you know, M'. I said, 'Well I hope so, as long as I keep all right up here.' I said, 'I don't mind how decrepit I get in my body, I can get a chair to get about in, but if I start going up here, I shall shoot myself'. B3, age 79, lives in a residential home, breast

Female Patient: They can give me pain –enough pain killers to keep me out of pain, and as long as I can keep my wits about me. B12, age 82, lives alone, bowel

The ultimate loss of control is, however, death, and some patients imagined the effect of witnessing death on those around them. This could influence their perspective on where it was best to die:

Male patient: I wouldn't like to put that on my sister. I wouldn't want her to come in one morning and see me [lying] there, you know what I mean? L4 age 57, has moved to live with sister and her husband, daughter visits weekly from London, pancreas.

Female patient: Well, you see, I can go to my daughter's, and I can stay at my daughter's, but I don't feel that my daughter would be able to cope with me actually dying at her house. She's not said it. But I get this feeling that it would put more strain on her. My daughter-in-law could cope better. But I don't think my daughter could

cope if I died in her house. So I've told them that I want to go, either here [at home], with them supporting me, or into the hospice or the hospital. B12, age 82, lives alone, bowel

## Carers' perspectives

### Carers and the failing patient body

Carers' voices were heard to a limited extent in the previous section, but here they move more centre stage. The carer's relationship to the patient's deteriorating body is clearly different from that of the patient, but some similar themes emerged. While patients tended to talk about managing their altered state, carers were directly confronted with the sight of the failing body. This could have an important bearing on the carer's sense that help was required, and may shape their place of care preference, though carers might lack knowledge and information about what kind of support might be available.

In interview, carers often expressed their distress about the altered body, in contrast to patients who acknowledged such distress less readily. Carers' desires to hide their sadness at these changes from the patient are apparent in the following extracts.

Female carer: You've only got to look at the man to know he's dying, and I see him on a daily basis getting thinner and thinner. [...] I mean he was asleep yesterday and he was as yellow as that biro, just completely jaundiced skin, like parchment. You look at him and you think it's just like a corpse laid there. It's a bit like when your children are asleep as babies, you sort of check them out to see if they're still breathing. L4, sister, age 58, pancreas, CA1

Female carer: I could tell he was tired, he'd be nodding in the chair, and dropping cigarettes on the floor and stuff, and I'd really try and get him to go to bed, just for an hour for a lie down, and he'd be fighting it constantly, and that used to upset me. Then as soon as I'd managed to get him up to bed, on the rare occasion he would go, I just used to sit here crying, you know, because he always seemed to be fighting it constantly, and I could tell he needed his rest, but he just wouldn't go. L2 wife, age 40, thyroid, CA(B)

Female Carer: He'd never bother about taking his clothes off, and actually, you know, it got to the point where I didn't like that, which is horrible because he'd lost so much- I mean he looked so dreadful, if you actually saw him – skin and bone, nothing to him.

And then you're trying to hide that from him, that you actually think he looks so awful. I mean he'd started actually saying -I think it was in June when he went to this Oxford reunion - he was bothered about his clothes not fitting him, and he wanted to wear his old Oxford blazer and, and he'd got it out and wanted me to try it with him and see whether I needed to adjust it for him. And he said, 'I do look funny these days,' and I thought it was the first time he'd actually acknowledged that - he'd looked in a mirror. I mean I don't think he was ever a vain person. I don't think he spent much time looking in mirrors, but presumably then he had actually looked in a mirror and thought, 'I just look so different', body image had changed so much really. B2 daughter, age 33, leukaemia CA (B)

As noted in the previous section, some patients expressed the dread of loss of their mental capacity, but a few carers experienced the consequences of a patient's actual cognitive deterioration. This was particularly frightening for carers, since it entailed a loss of the 'person' prior to death:

Female Carer: He can't sequence what he's to do, and he's physically very weak and he forgets the routine. He's lost his concentration and his memory and his confidence. So in the mornings, I found that time very hard. If I'm being honest, I've panicked a bit because I thought I don't know how to deal with this mental thing, I was a bit frightened by it because it wasn't him. He looked different he sounded different and he behaved differently, and yet he was desperately in need of help and ill and didn't want anybody else to help him. K1, wife, age 63, colorectal, CA1

Carers in this situation required a lot of support. In some cases support was forthcoming, but in others the need was not well responded to by health professionals. The patient's wife in the previous extract expressed her appreciation of the Marie Curie nurses at this time, but a compounding difficulty was that he was wary of people in uniform having had the experience of waking up in the hospice when he had not wanted to go there:

Female carer: I was glad that the Marie Curie nurse came, but she was wearing a uniform and J wouldn't let her do anything. He was worried that having a nurse meant he was near the end. They seem to feel is that he hasn't come to terms with dying, really, that whilst he was in charge of his intellect he could push the dying bit to the end of his thoughts; but waking up in the hospice with people very physically and volubly dying around him, and not knowing why he was there and feeling so out of it, has made him think this is what's going to happen to me, that he's panicked a bit about his mental capacity and about dying. And I didn't feel that I had enough skills to cope with that, so

I was glad that the Marie Curie nurse was there, that there was a professional around, but all he would let her do was sit with him while he had his breakfast whilst I got dressed and washed, and nothing else. K1, wife, age 63, colorectal, CA1

Another carer witnessed her husband's distressed and distressing behaviour but found the ambulance service unhelpful in a crisis situation; this episode led to her husband's admittance to and death in hospital:

Female carer: [My husband, B] was still roaring, it was like animal noises, and he was still punching out and flaying with his arms, so [the ambulance crew called to the scene at home] decided to bring a chair to put him in. Well, he fought and he fought. They asked me, going down this path - obviously they don't know that I have a poor balance and don't walk very well, I'm fine in the house but get me on concrete and I've had it - they're asking me to keep him in the chair. Well he was punching – not punching out at me, but, we got in the ambulance. The ambulance sat outside for 10 minutes and they said to me, 'Is he diabetic?' I said, 'No, he's been diagnosed with diabetes but only in the last five or six weeks.' It might, I presume, have been something to do with the medication, I don't know. But, 'Well, we'd best do a test.' So they do that. 'It's normal.' And B. is still thrashing about in this ambulance and they ask me, would I keep him down while they tried to get a line in. Well, you know, I'm thinking, 'This is not right, because he's fighting me as well.' They knocked me over backwards, and I said, 'There'll be two of us needing admitting if we don't move soon.' And eventually we got to the hospital, that was fine, I mean obviously things weren't right with B. They gave him something to sedate him but every 10 minutes, then he was back again fighting, with his arms and what have you. B8, wife, age 60, prostate, CA(B)

This carer went on to describe his last days in hospital and her feelings of distress, her sense of letting her husband down, and of being let down by the hospital. She notes that he may have experienced a more 'peaceful' death had he been in the hospice, but acknowledges that his condition prohibited his transfer to the hospice:

Female Carer: They put him in one of the side wards behind the nursing station, they have a couple presumably for people who are-, they can keep an eye on them. And I have got to say for two and a half days he was like that [fighting, as above] and in pain, and that distressed me very, very much. They just did not seem to be able to do anything for him and that was distressing. And when I saw [the doctor] I said, 'You've got to do something, it's awful.' And he said, 'Well, the amount of medication I've given him, if it was me I would be out for a week, but he seems to be fighting it.' And

he was coming out every 20, and you couldn't touch his legs, he would not have you touch his legs. And all the time he couldn't speak, and he, it was awful because he was throwing himself over the bed and, and putting his arm round my, like this, and looking at me as if to say, 'please do something.' And I was so disappointed in them and the nursing staff. I know they can't work miracles... of course he had to be catheterised and every half-hour we were wrestling to keep him in the bed. And if we went to ask for help – 'Oh we'll be there in a minute, we'll be there in a minute'. It's not good enough when it's one of yours. ... The hospice, yes, they were brilliant, absolutely wonderful but they decided at [the hospital] that B was too ill to be moved to the hospice. With hindsight, yes, I know he probably was, but I feel if he'd been there he would have been far more peaceful, far more peaceful. And when you get nursing staff coming in, you send for them, 'Can you help us?' and they come in and they pat him on the head and they say, 'Oh come on, you're not helping yourself.' I said, 'I don't believe you said that.' So eventually on the Friday evening [the doctor] said he was going to put a line in here so that they could get drugs in that were faster acting. So he settled for about two hours. Then it started again. So I said to [my son], 'Go and get somebody, he'll need some more.' Well [the consultant] hadn't authorised anybody to use the drugs so that was an hour's wait before they found a doctor. We are physically fighting because he was a big man was B. And I thought, 'It's not right.' [When I'd asked months before] 'What is going to happen when we get to the final stages? What am I faced with? Is this going to affect his internal organs, is he going to be vomiting? Just tell me what to expect so that I am prepared for it'. [I'd been told] 'Oh absolutely not, no, he'll just get weaker and he'll just sleep,' and that's it. B8, wife, age 60, prostate, CA(B).

In addition, the horror of the death lingers in her mind as a lasting vision of her husband:

Female carer: So when I'm faced with this horrendous two and a half days, that was the most distressing thing for me, and unfortunately even though it's nearly four months on, if I close my eyes and think of B., that's where I see him. I can't get that out of my mind yet. I wish I could. But it seems to have blanked everything else off. All the lovely times that we had. All the laughs and the, and I can't bring it back, because when I think about it I just see how helpless I was when he probably needed me most and I couldn't do anything. That was my most distressing time. B8, wife, age 60, prostate, CA(B).

Pain in their patients was a major concern for carers, both before and at the point of death. Carers were often vigilant about overseeing pain medication, and several held and dispensed such medication to the patient. This is illustrated in the following interview exchange:

Female Carer: Do you want a top up, M?

Male patient: No I'm fine, - oh a drop of Morphine?

Carer: Because you haven't had any.

Interviewer: Do you have some more at lunch time?

Patient: I normally, because I've been sat here since ten o'clock, I get up say every half hour and have a little walk around, but sometimes. [...] The doctor told me to take this as a top up during the day.

Carer: His tablets are slow release.

Patient: Basically what this is for is so pain doesn't come at all.

Carer: You don't have to have pain, M. Get it down your gullet.

Interviewer: So does it work?

Carer: I don't know, I don't have any pain, but I think it does, M., doesn't it?

Patient: It does, the only problem I've ever had basically that bothered me was me bum being sore,

Carer: But you weren't on morphine then.

Patient: But I wasn't on morphine. L4 Age 57, has moved to live with sister and her husband, daughter visits weekly from London, pancreas. PT2

Several carers expressed relief that pain had not surfaced:

Female Carer: I think I'm fairly clear in my mind that although it's very panicky not to be able to breathe freely, it doesn't hurt. So I don't think he had a painful death. L10, wife, age 52, renal, CA(B)

In another case there had been a pain crisis in the hospice. This had finally been resolved, and allowed a more comfortable death for both the patient and the carers. The carer emphasises how the pain must have been very bad, because her brother had never been one to complain and she valorises his determination:

Female carer: Saturday and Sunday he just seemed to be getting worse, but on the Monday when we went - my daughter was there before I got there - she come running out - I said, 'What's the matter, S?' And she said, 'Oh I'm not going back to see him now, he's the only one in there that's crying with pain'. I said, 'Well, I think they're trying to get it right, S.' 'I don't want to see him like that', she says, 'He's just crying

with pain', and the idea of the hospice is pain relief - palliative care. [...] But anyway, they were very, very good, the staff were absolutely brilliant, couldn't fault them, none of them. I went to see him on the Friday night and I didn't leave till after 9.00pm, and he kept opening his eyes and shutting them, and I thought, 'Oh, he's not going to be here this weekend'. [...] [on Saturday] we went over and it were very peaceful, he'd gone...., but he'd gone pain-free, he wouldn't have felt the pain. As a patient, T. wouldn't [want to show distress], and he'd try and do things which was an impossibility, he couldn't do them, he couldn't, but he would have a bash. L15, sister, age 66, bladder, CA(B)

However, in some cases (as in B8 above) dying was accompanied by pain and distressing symptoms which were not well controlled. The following narrative tells of one such situation. It conveys the sense of panic that can be experienced by a carer in a home setting:

Female carer: And so of course that night was a pretty dreadful night because he was needing much more sedation. He was becoming agitated. We didn't know he also needed something for his lungs, he was beginning to fill up with fluid. The Marie Curie nurse sent for the doctor but of course it was an off duty – on-call doctor. That doctor said to her, 'I am responsible for 6000 patients, can you come to [the hospital] and pick up some drugs?' I think it was more than 6 [drugs], forgotten the number now, but basically he said, 'Look, you know, I'm on call and can you come out for it?' And she said, 'No, firstly I'm not leaving my patient, he's desperately ill. Secondly I'm not coming over for some monitored drugs without you having seen the patient.' So he did come and out and he said, 'I'm afraid because of the Shipman new regulations, I'm unable to give him more than the equivalent of two teaspoons of Oromorph', which I could have given him.

Interviewer: Did you have the drug, did you have the Oromorph to give him?

Carer: We had Oromorph, yes.

Interviewer: But you were hoping he was going to give him something else?

Carer: But, the Marie Curie nurse said he needed an injection or he needed basically the line in, you know, with an ongoing infusion of Hyoscine, for the fluid and also for the distress. But he said that's all he could do, he couldn't do any more. So he gave him the diamorph injection which he said was only the equivalent of two teaspoons of Oromorph and went away. And he just went on through the night getting more and more distressed. So much so that at about 5 o'clock in the morning my daughter was horrified and said, 'This is just dreadful, I want you to ring that doctor again, something else has got to be done.' And [the doctor] came again and he said, 'I'll give him some Hyoscine in an injection, I'll give him another injection of-,,' what he'd given him. But

it wasn't anything like enough. And of course by which time he was beginning to froth, he was drowning in froth. That was so distressing for him because he couldn't tell us what was the matter and he couldn't get rid of it. And [the doctor] apologised profusely and said he was terribly sorry and went away. And then of course at 8 o'clock in the morning I called his own GP. And he came and he got the nurses and they put the line in and they put in the proper infusions of Hyoscine and, and diamorph and everything but by then.... K1, wife, age 63, colorectal, CA(B)

This carer went on to recount how her husband remained somewhat agitated, despite medication, until near the end, when he seemed finally to be calmed by his son's voice (on the phone from America):

Female carer: But then, strange things happen, a strange thing happened really. Because my older son and my two daughters were all there, and obviously the nurses had said keep talking to him because [hearing is] the last thing that goes - he may not be able to talk to you but he'll be able to hear you. So we were all talking to him at various times and I, I don't know whether he was upset because he couldn't hear [our son in America] as well, we didn't know what was making him still so uneasy. And at about 12 o'clock S. rang up from America, he's a minister over there, and said, 'I've been thinking about dad, and praying about dad and I've got something I'd like you to read to him.' [My husband had] been searching a bit after the meaning of religion and faith all the way through his illness, but he'd never gone too far into it with S [...] And I said, 'Well I don't need to read it [to him], you can read it because you know he'll be able to perhaps still hear, the nurses and doctors say.' So I put the phone to his ear and I heard S. start to talk and it was quite miraculous really because his breathing calmed and his face relaxed, and S. went on talking for a while, and then he said, 'Mum,' and I took the phone back. And I said, 'I'll give you a ring in a little while.' [My husband] stayed quite relaxed, quite calm, and about a quarter of an hour later he died. And evidently S. had said, 'Don't be frightened, you feel you're walking into the dark, but you can turn to the light and God will take you through and you'll be fine, don't be frightened.' And he, he read The Lord's My Shepherd to him. And then he just took a few more breaths and died. So it was quite miraculous in a way... we just saw such a change come over him as he heard S. talking. I don't know whether it was because he heard S. talking and he thought he was there, or whether it was what he said. But whatever it was, it just took him calmly. K1, wife, age 63, colorectal, CA(B)

The social and environmental context also played a part in perceptions of pain, both for patients and carers. One carer noted how a holiday setting eased them both, despite the patient having pain:

Interviewer: How was he on holiday, did he manage that all right, or was that difficult?

Female carer: He was still in pain, but life seemed to be easier. It wasn't as stressful, we could just chill out, we didn't have the 'phone going constantly, you know, to see how he was. It was just a lot easier. I wasn't worried that when he'd gone up to bed for a rest the door bell was going to go and wake him up, and then he'd come down just to be pleasant. And the weather was a lot warmer. L2, wife age 40, thyroid, CA(B)

### **Dealing with the loss of bodily control and the need for intimate care work**

It was noted in the discussion of patients' perspectives on body matters that patients had concerns about a loss of bodily control, such as the onset of incontinence, and that they sometimes did not want carers to have to engage in intimate care work in such circumstances. Carers, too, sometimes expressed their unwillingness to undertake such caring tasks. This was particularly evident in situations where the relationship between the patient and carer was not spousal. Intimate nursing was less likely to be discussed by spouses as a matter of concern. These matters had a bearing on both patients' and carers' views on the appropriate location of care. There was one case where a male patient did not want his wife to have to deal with 'unpleasantnesses', although she was willing and did support him at home until death. In another case, the carer felt he could probably manage, but his wife was adamant she wanted to spare him from dealing with any distressing symptoms:

Male carer: For myself – well – I've always been a bit of a loner and I can cope with anything that Margaret can – I think having seen death many, many times and actually physically handled bodies, I have no worries in that way [...] – her personal hygiene I can cope with, I think. But it depends on what it looks like at the end, but she doesn't want me to have that. She would then say, 'I'm going to the hospice', and there's no way I could stop her, when she says she's going, she's going – so – but until then I can cope. K5, husband, age 67, colorectal, CA1.

Most spouses shared a view that they would cope, and did not speculate on the details. This was sometimes reflected in patients' accounts. For example, this female patient who wanted to, and did, die at home, had said of her husband:

Interviewer: If you get to a point where you can't fully look after yourself?

Female Patient: Oh I don't know, it would have to be me hubby I would think because he can cope, he'd cope. L12, age 70, colorectal, lives with husband.

In non-spousal patient-carer relationships, however, it was a different matter and both parties expressed concerns about intimate nursing.

Female carer: Well it was difficult you see, because with it being me brother, I was limited as to what I could do as regards his hygiene, so this is why I got him going to the hospice once a week, but he managed his stoma all right. But then again, once he started having the 'accidents' he hadn't the energy to put his pack on right - put - what I call the towel on. And of course, we had all this waterproof bedding which the social services had put on the bed, so I couldn't do it. Fortunately my daughter works at the hospital, so she would come round and see to him on a personal hygiene level. This was the awkward part with him - he didn't have a wife, and if you have a wife I suppose you have children, you might have a son that can help, but he didn't have anyone, so I found it that hard. That was the difficult thing for me - I suppose - but some people take it different than others. Well personally, I don't like it, I don't like that part of it - I don't mind passing his laces when he could put his shoes on, I don't mind combing his hair and I don't mind - but I says, when it comes to anything else, I can't. L15, sister, age 66, bladder, CA(B).

Female carer: Now, this blip [incontinence] that he had last week happened twice and he was beside himself, and I just made light of it, I said, 'Oh forget it, it's nothing don't worry about it,' but I thought I can't cope with this. I'm not a nurse, it's not your child that's been sick this is a man and he's full of cancer. And you somehow get this smell in your house that you-. Now that's what hospitals are for. L4, sister, age 58, pancreas, CA1.

However, there was one case that demonstrated the opposite perspective on intimate nursing. Here it was a daughter who was a nurse. She was willing to nurse her father if that was what he wanted, but she was never sure whether he did want this, and in the event he went on holiday and died in a hospital:

Interviewer: So he never really expressed any particular preference for where he'd like to be looked after when he got bad, or – you picked up that he didn't really want you to be-?

Female carer: I don't think he wanted me -

Interviewer: Doing his physical care, perhaps?

Carer: I don't know, I mean he was never sort of shy about his body, I mean certainly when I was at the hospital, you know, he'd never mind using bottles in front of me or anything like that, I mean it never bothered him, things like that. B2, daughter, age 33, leukaemia, CA(B).

However, this carer had nursed her mother at home with cancer a few years before and been very clear that she would attend to intimate tasks as her mother wanted:

Female Carer: The district nurses came in, and I specifically asked them not to do any care for her because I wanted to do it, because I'm sure she wanted me to do it. I got up there the next morning and they'd got her out of bed on the commode and she was just looking so upset by everything and it still hurts that they actually did anything when I'd asked them not to. I know they were trying to help me – sorry. B2, daughter, age 33, leukaemia, CA1.

### **Benefits of a speedy deterioration**

Where the patient had deteriorated quite quickly, and not needed much nursing, there was often some comfort to be found in the preservation of their dignity. As with the patient quoted earlier (K5), who was relieved that she wasn't going to end up in an old people's home, a female carer expressed her relief that her husband did not lose his independence:

Female carer: So there was a sense in which it could have been any time. And also some considerable sense of relief for him that he wasn't going to actually need to be nursed and dressed and washed and all these things. It's bad enough if you're in your 90s, but if you're 56 it's kind of – you know, it's not right. You want to be up and about and doing for yourself. L10, wife, age 52, renal, CA(B).

For another carer, whose father lived alone, his sudden death had some compensation in relieving her from worrying about him in the winter, stuck in his remote, country house:

Female carer: But, you know, I can see that for him it was far better than getting back [home] and sitting there, you know, in the winter. Actually the winter hasn't been so bad, so far, but we were worried about him being up there on his own in the winter, if we couldn't get up to him or whatever, you know, how things were going to happen once he was up there. So for him, probably for us as well, it was the easier way out, that it was all over quickly. B2, daughter, age 33, leukaemia, CA(B).

## Being at the death

Being present around the time of death was important for nearly all the carers. It was viewed as a precious, almost sacred, time. Where this was denied by circumstances, carers expressed hurt. In one interview, a carer recounts her experience in the hospital where her father had been admitted. She was taken aside to give a detailed account of his history:

Female carer: It wouldn't have happened at a hospice, and it wouldn't have happened anywhere else. [...] I felt cross because I just thought, 'This isn't relevant, he's dying, you know, it doesn't really matter about all his history and what medication he's on, and when he's been in hospital, and what for, and' – and I spent so long doing that with [the doctor] that by the time I'd gone back to see Dad – it was only outside the curtains, but when I went back in they'd given him his diamorphine and he was unconscious. Even that, that precious time with him, the last few moments of him being conscious, you know. But that's hospitals [laughs], and as I say, it wouldn't have happened in a hospice, they'd have done things a lot better, wouldn't they? [...] I'm sure I did know very well when I left the hospital there was a good chance I wouldn't see him alive again. I didn't, I was [at home], and my little brother rang me as soon as it happened – I went back through, I laid him out. B2, daughter, age 33, leukaemia, CA(B)

This carer had nursed her mother at home with cancer some years previously and the experience was very different:

Interviewer: Did you feel she had a good death in the end?

Female carer: Yes, yes, because she was at home. She was in bed with dad and two of my brothers were there and I was there, most of us were there that night. She died at twenty past seven the next morning. She was pretty unconscious by then, but I went into her that morning, dad was asleep and my brothers were asleep, and I went in, so she'd been unconscious then for about 20 hours, got no response at all from her. But she put her hand out to me, opened her eyes and looked at me, very strange, but she seemed to look right through me, I don't know what she saw. I always wonder. You hear all these near death experiences and things, but I don't know what she saw. But she held my hand and died, so I think, yeah, for her it was right. B2, daughter, age 33, leukaemia, CA(B)

In one case the fact that a patient died calmly, after his son spoke to him over the phone (see extract K1 discussed above), was described as 'good fortune' by his wife. Despite a very difficult few days, the manner of the actual death was seen as very significant and carried through by the family into the mourning phase, as marked by the funeral reference:

Female carer: We all saw, apart from the peace, the calm come over him, we also then saw the fact that one minute he was there and the next minute you could see that whatever was there has gone. Apart from how horrendous it had been, I think in the end it was such good fortune that I managed to give the phone to him [to hear his son talking from America], you know. I rang S. to say that his father had died, and told him what had happened, and he said, 'Are you just telling me that to make me feel I did some good?' And I said, 'No, talk to your sister,' because he knew J. wouldn't be telling him any fairy stories, and she said, 'Mum's absolutely right S., whatever you said to dad just calmed him and just took him through. He just calmly relaxed at that point and he stayed calm and just died.' And S. was able to say all that at his funeral. He told the congregation what had happened and what he'd said to his dad. K1, wife, age 63, colorectal, CA(B).

One carer was upset with the hospital for not contacting her in her husband's final hours:

Female carer: I came home because he couldn't speak to me and he looked at me and he didn't know me. So I decided to come home - give them my phone numbers, I give them his son's phone number. The Tuesday morning, at 6 o'clock, I got a phone call from his son - I said, 'I'm afraid your dad's in hospital, love'. He said, 'I've got news for you, Dad died at 4 o'clock this morning, they rang me. They said they tried to ring you, but they couldn't get hold of you.' I said, 'Well, they must have dialled the wrong number, because I had the phone at side of me'. [...] So [his son] picked me up and we went to the hospital and saw him. Terrible - well, you know what he was like, a big fellow, but this poor chap in the bed was thinned right down - his eyes were wide open - oh, my god, but at least he's not suffering now.

Interviewer: So it sounds like you were a bit annoyed that they didn't manage to phone you?

Carer: Well, they said they couldn't get any answer - I said, well, you must have dialled the wrong number. But thankfully, I'd left his son's phone number, because they contacted him, so he contacted me - because he lives in [Yorkshire]. It's quite a way from here.

Interviewer: So, would you have liked to have been with him at the end?

Carer: Yes, I would - none of the family were with him, in fact, he just slipped away - when I talked to them at the hospital, I talked to the sister of the ward, 'Oh,' she said, 'That was it, he was gone'. L1, wife, age 77, oesophagus, CA(B).

This carer's description of events suggests that his corpse was not properly laid out when she saw him, something that added to her distress. However, she seems to find ways of comforting herself through noting that he just 'slipped' away - the implication being, perhaps, that she would have missed his passing even if she had been there - and through recognising that that he no longer suffers.

## Summary: key findings

This discussion of body matters, from the perspective of both patients and carers, has drawn attention to a range of factors that affect both preferences for place of death, and actual place of death. These can be summarised as follows:

### Factors shaping preference for, and actual, place of death

- Patient's accounts indicate that uncertainty about what would happen to the body as death drew near, and about the signs and signals to be expected, could mean that a place of death preference was not firmly held to, was conditional, or had not been formulated at all. That is, lack of knowledge about how the body was likely to change could give a place of death preference a contingent character: 'It depends on what's going to happen'.
- However well defined preferences for place of death were, these were sometimes overtaken by events bound up with symptom management and bodily deterioration. Not infrequently, a home-death preference was unfulfilled because a hospice or hospital admission (followed by death) was necessary for symptom control.
- Especially in 'crisis' situations involving a sudden or rapid worsening of symptoms, carers often found the witnessing and management of the patient's deterioration very difficult, particularly if pain or cognitive deterioration was involved. In such circumstances, carers usually called upon health care professionals for assistance and this could result in a hospital or hospice admission. This could mean that the actual place of death did not match the patient or carer preference.
- Looking ahead, most patients did not wish to 'burden' their carer(s) with the management of their deteriorating body, especially if 'loss of control' and culturally sensitive or censured symptoms such as incontinence were involved. This was particularly the case when the relationship between the patient and carer was not an intimate couple relationship. In such cases it was usually seen as unacceptable for a carer (sibling, son, daughter, other relative or friend) to have to engage in personal care tasks such as toileting and body cleansing. A minority of carers concurred with this assessment, not wanting to take on such care work. These factors oriented some patients and carers towards hospice or hospital locations for end of life care.

- Some patients reported not wanting to leave a legacy of unpleasant and unhappy memories of their dying and death in the house of their spouse, offspring or other relative. This orientated the patient towards institutional locations for end of life care.
- Mental deterioration was a symptom particularly feared by patients, and was especially difficult for carers to deal with where it occurred. Carers were usually unable to cope with challenging behaviour (violence, aggression, serious disorientation) on the part of patients, and were likely to call upon assistance from services, usually resulting in a hospital admission and hospital-based death.
- The personal biographies of patients and carers shaped their perspective on dying and thus played a role in determining either a particular place of death preference or a lack of preference ('I don't mind where I die'). Key biographical characteristics were found to be: having themselves been close to death earlier in life; having seen a loved-one die of cancer, and perhaps having nursed them; having seen death at close quarters, for example in their occupation; having a religious outlook.

## Chapter 8

### Social matters

#### Introduction

The theme explored in this chapter is the significance of the social context of dying cancer patients, using the data generated in the patient and carer interviews. It brings to light the factors that shape the nature and type of informal care received by patients. This, in turn, illuminates place of death options and preferences of patients and carers. Patients' perspectives on their social context are examined first, though some carers' accounts are concurrently drawn upon. This is followed by a more focused discussion of carers' perspective. Extracts are used from both the pre- and post-bereavement interviews with carers.

#### Informal social support

End of life care is embedded in pre-existing social circumstances. One of the main predictive factors for people dying at home is the presence of a willing and able carer (e.g. Cantwell et al 2000). Clark & Seymour (1999: 33) remind us that

‘caring’ has been identified as both the range of activities involved in giving personal aid and support to someone in need, *and* the emotions associated with an interpersonal relationship.

Care activities are interpreted as evidence of affective ties between people, especially where those involved are related by kinship. In the interviews, personal social setting and informal support networks were centrally placed in patients' talk about preference. It has been noted that family responsibilities are fluid and variable, rather than fixed, and that reciprocity and dependence will have a range of meanings depending on negotiations within specific interpersonal relationships. Clark & Seymour (1999: 39) indicate that ‘Problems of role conflict between the demands of caring, employment and other pressures may be differentially interpreted and resolved’ in the situation of terminal care. It was noticeable in our data that issues of ‘being a burden’ and the appropriateness of the relationship with the carer/s figured as highly important in preferences.

#### Patients' perspectives

In the previous chapter we saw how patients often talked about body matters with the interests of carers in mind. This was particularly noticeable where there was a co-resident carer, usually a spouse. End of life care is thus embedded in, and shaped by, pre-existing social relationships, and takes account of how these might be altered. The patient usually considers how the carer might cope.

The health services are nearly always involved to a greater or lesser degree, but, as has often been noted, palliative cancer patients spend the vast majority of their remaining life at home (Cartwright 1991). This means that while relationships with health personnel are important, and were certainly discussed in the interviews (see the following chapter), patients' personal social setting and their informal support network, were uppermost in most of their minds. Even those who lived alone were concerned about any family they had, and sometimes about friends. This concern coloured consideration of preferences for place of final care and death.

Most patients did not want carers to have to deal with 'unpleasant' features of bodily deterioration (see the previous chapter). Nor did they want to become 'a burden' on family and friends, to impose their problems on the lives of their relatives, particularly those of grown children, who were cited as having other responsibilities (children, jobs). Linked to this was the issue of maintaining and managing self-care and independence as much as possible for as long as possible. There were several situations in which carer-related issues became more acutely implicated in place of death preferences:

- Where the patient lived alone,
- Where there was a carer who was elderly or frail

These circumstances are considered in detail later in this chapter.

### **A treasure chest: sources of support**

One man described his informal social network thus:

Male patient: I would say I have unlimited resources. I have a treasure chest of friends and family. B8 age 63, Prostate, Lives with wife PT1

This was the case for most of our participants. Family, friends and neighbours rallied round in the context of cancer. People already in some kind of relationship to the patient performed different supportive tasks, relevant to their position in the patient's world. Offers of help were frequently mentioned and many people drew on the support available. However, there was a strong sense of wanting to remain independent, to manage the situation as much as possible

within the closer bounds of the immediate family, especially as the situation worsened. Not wanting to be a 'burden' was an issue which permeated the interviews. For those without close family resident or close by, there was more use of wider informal networks, but even here there were indications that it would be the formal supportive services that would take over in lieu of family when the patient became incapacitated. The pre-existing roles and relationships tended to remain in place, although they were often 'stepped up a gear' in the cancer situation.

### **Family**

Not surprisingly, it was clear in many interviews that family and friends were very important to patients. Carers were described, and indeed described themselves, as performing practical, emotional, and administrative supportive tasks, as we found in our previous project on the psychosocial needs of cancer patients and their main carers (Thomas et al 2001, Morris & Thomas, 2001).

A few patients described the value of having a large family:

Female patient: I think this is maybe why they can't understand why I don't want this and other, because I've got all the family. See they're never away – some part of day there's one or other here, you know.

Interviewer: Right, yes, so you wouldn't be left on your own when, when your husband's out?

Patient: [...] That one – she's always here – thought she'd have been here this morning. The other two daughters – that's another one, and that's her again – you know. So they're always somewhere.

Interviewer: Do they work, or -?

Patient: Yes, they work – she's a nurse, and she works at school, a cleaner at school. But they don't work full-time – well, they do, but you know what I mean. [...] They work funny shifts at the hospital, don't they. You know, like this one that's a nurse, she works 7 till 3 one day and then 3 till 9, I think it is, another day. So they're round some part of the day. She only lives over the road, over through the Park. And that one that lives round here. The other one's moved round here now, she's come round here now, so it's not so bad. L12 Age 70, colorectal, lives with husband, PT2

Female Patient: We've got two daughters and two sons [...] my youngest daughter [comes and cleans]. The eldest daughter I mean she's does a lot of chauffeuring about doesn't she, hospital and -

Carer: She's taken us twice and she wouldn't allow me drive you see. She usually takes me.

Patient: Oh no, she'll come up and jump about, but they have a shop and she has a family you know, but if there's anything I want her to do I just need to ask.

Interviewer: And you rely on your daughters more than your sons for practical things?

Patient: Well you do don't you yes, yes.

Carer: Our oldest son just had a baby hasn't he? He works on council and has two or three jobs [...] he hasn't really got time has he?

Patient: No.

Carer: And our A. he's at farm and he's quite busy [...] he comes

Patient: Oh yes. He visits and I mean when I'm in hospital he's, he's always coming down, but as far as, well, if there was anything more to do then yes they would do it.

Carer: Yes they would definitely.

Patient: yes but you manage if you can because everybody's got a busy life haven't they.

K3, age 67, ovary, lives with husband (age 67), PT1

Worries about impinging on 'busy lives' were, however, widespread, especially in talk about grown children, and even large families were not always felt to be able to offer what the patient needed:

Male Patient: And my second daughter [...] they both work, so I'd just be staying in the house and I'd be sat in the house on my own. And it's at the top of a big hill, so I'd be stranded, so you know –. My youngest son has got two young children, he's a trainee nurse at the moment, so – and he's got his work cut out with two young children, he wouldn't want me. And my eldest son, he works. He's off the coast of Africa at the moment with his job, he lays telephone cables. But he's got a house, and he said, 'Stay in my house. Because the stairs weren't as severe and he's got a three-bedroomed house. But again, I'd be staying on my own, and you're stranded, you're isolated where he lives, so you'd be living on your own. So when I sat and had a chat with my partner and her mother, and she said, 'You can stay here as long as you want and we'll look after you, as well as everybody else coming down'. And this was the ideal situation because I'm getting 24-hour cover, or attendance, and I've got – it's a flat facility for me – no stairs to climb, and you're very, very central here, in the middle of the town.

B7 Age 57, Lung, Lives with partner PT1

Even where practical help was not possible, or not desired because of not wanting to be a burden, or because of wanting to maintain independence, talk about family was often linked with 'keeping going', and emotional support:

Male patient: And my family were smashing – family and relatives – some were coming up and nobody knows what to say or do when you get told news like that, but fortunately they were taking the mickey out of me more than anything else, which is a good thing because you don't dwell on the matter then and think, 'Well, you know, get on with life'. So again, touch wood, I've had my odd moments where I get a wee bit upset and you tend to think to yourself, 'Well why me?' Or, 'How come that's happened to me?' But basically you put it to the back of your mind and do what you can do and get on with your life really now. B7 Age 57, Lung, Lives with partner PT1

Male patient: The emotional help I haven't needed so far because I've got my mum and my brother who I can bounce things off and complain at, moan at, if that's the way I feel. K4 Age 50, Lung, Lives alone PT1

Female Patient: I wasn't looking forward to Christmas and New Year because I just didn't think I'd get through Christmas and New Year to tell the truth. But going to my daughter's did help. [...] And they looked after me really well. And I think I came back stronger in my mind, as well as my body. B12 Age 82, Bowel, Lives alone PT2

Female patient: I feel strong enough that, if there's anything out there, then we ought to try it rather than - I know it comes to a stage where it has to be about the patient and the patient's care and how, how they're responding, i.e. it's time to start looking after the patient rather than trying to cure the patient as such - but I don't feel we're at that junction. I know the chemotherapy has come to that sort of junction, but I feel that there's- it's developing all the time- there's going to be something that comes along. And because I'm only 43 and I've got a lot to go on for - I've got a fourteen year old son, loving family- that I'm not just going to sit by and let it take over. There are things out there that we can sort out and just keep very positive about it. L3 Age 43, Breast, Lives with husband and son PT1

However, in a very few cases, patients described unsupportive behaviour from a family member, and this was a great cause of concern, leading to questions of how they would manage their worsening state, and considerations of location of care. In one case a woman described her husband thus (more detail on this case is given below in the 'Needing people' section):

Female patient: You see my husband has never been to the hospital with me to see a specialist. He's never been to the doctors to see him. He'll take me down in the car but he won't go in. I've had friends go with me, and my Sister go with me. My daughter's gone with me, because I always think that if there's two of you listening to what they're

saying, if you miss something, they can say, 'Oh he said so and so.' And last time my daughter-in-law went with me and she's a nurse and she spoke up and asked a few questions. But you see R. [my husband] won't even do that with you, so I'm relying on other people sort of to go with me as backup. [...] and I mean well what are we going to do at the end? So I just think well I hope I end up in the hospice at least they look after you, you know I mean you don't want to but I think well I won't get any support here. B6, age 61, breast, lives with husband, PT1.

Another way in which family might be around, but not very available, was if they had problems of their own. One elderly widower who lived alone had a daughter in America and a son locally, but the son's wife had recently been diagnosed with MS and he felt he could not ask him for help:

Interviewer: But there wouldn't be anyone like that to help you, if you were more poorly?

Male patient: I don't think so, no, I don't think so. Oh I'd have to be in hospital I think.

Interviewer: Your son, or daughter or-?

Patient: No there wouldn't be nobody here.

Interviewer: No, no.

Patient: I mean, I don't expect my son to spend all his time here, he'll have enough on his plate when hers gets [going]- with this MS. L9, age 88, Lung, lives alone, PT1.

Nevertheless, families were clearly the most important source of informal care, and there were many examples given of the kind of help they provided. Daughters were mentioned most often, but two patients lived with their sons, and they were cited as important:

Female patient: [my son] does what I need. We get ready meals, so we just get them Wiltshire farm foods. Because he doesn't cook. I've tried, but it's a disaster. I used to like cooking and baking and now I don't any more, well, I can't. So we just have something that's 8 minutes in microwave and that's it.

Interviewer: And you've had to move your bed downstairs.

Patient: Well, he brought it down, because he didn't know what I was going to be like when I came home. So he brought it down and I was mad. Because his dad finished up in a bed downstairs and I had him to nurse. But, was I glad, because I just can't get up stairs, I struggle. K6, age 75, lung, lives with son, PT1

Female patient: Oh he does all the heavy work for me, he does. He's got me now a little Hoover, it just more or less picks dust up, just a small one, but about three times a week

he goes through the house for me. Well, with my eyes and that – he more or less peels the potatoes and you know he does all that. K7, age 72, lung, lives with son, PT2

But neither of these patients wanted their sons to nurse them if they became bedridden. Although they did not say it directly, the implication was that of it being inappropriate for a son to nurse his mother, as it for a sister to nurse her brother (see previous chapter):

Female Patient: I don't honestly know. I suppose if I come to be bedfast, he couldn't do it, could he? K6 Age 75, Lung, Lives with son PT1

Female patient: I said well I just you know be at home as long as- but if I got as though I couldn't manage I don't want to put on him, you know. K7 Age 72, Lung, Lives with son PT2

Other familial relationships also furnished carers with support. One woman described help from her elderly nephew, which supplemented help from a female neighbour:

Female Patient: My nephew does a lot. Yes, he's 73 nearly. My sister's 93, but she hasn't got her sight and she's very frail, you know. And, you see he cooks, cleans, and everything for her home and he does the shopping for home and looks after his mam, he puts her [eye] drops in and everything, you know. He really is - I think he's great. And then he comes two or three times a day, some times, four times a day to see that I'm okay. L17 Age 81, Stomach, Lives alone PT1

Another described help from her sister-in-law:

Female Patient: I have my sister in law she cleans for me and does my shopping and my big wash, changes my beds. I get an allowance so I can afford to pay a bit. She's played hell like. She didn't want any money, but I said, 'That's what it's for'. She's been brilliant from me first starting to be ill - her and my brother - so they've both been marvellous. She's got a cold now so she can't come in case I get it. No she rang yesterday, she said, 'I can't come,' unless we have a pulley up the window you see to get my shopping up. She is very good that way she does my shopping, she'll do my washing, she runs me to infirmary, she runs me to doctors, she telephones me every morning without fail. Half past 9/10 o'clock she's on the phone, 'Are you all right? Are you sure? Are you telling the truth?'. She's been brilliant so I can't fault-. I've got sisters but she's the one that sort of took over from beginning. I've four sisters. But she

sort of took over, so I let her and she enjoys doing it. L16 Age 70, Lung, Lives alone PT1

## **Friends**

Friends were mentioned much less often than family members as main supports, and there was some sense of drawing into the family in extremis. Friends often helped with practical tasks, and emotional support, but there was no indication that they were involved in more intimate care, even where they were cited as the main support of someone living alone.

Female patient: A friend from Allerthwaite, she comes more or less every day. I mean she's been filling my ice water, and the hot water for coffee etc., and she'll make my bed for me, because it's a duvet and it gets on the floor, and if I walk round I could fall. So she does that, and she keeps the curtains pulled across, so I haven't got to walk round at night. She empties all my rubbish, hovers.

Interviewer: She sounds like a great friend.

Patient: Wonderful, wonderful. Yes, and her husband put the rail in the bathroom. She's wonderful, wonderful. K9 Age 84, Lung, Lives alone PT1

Interviewer: Who else might help you if you needed it your wife wasn't here or something?

Male Patient: Well we've a variety of people. In fact, for instance, I have got to the stage where I feel insecure if there isn't someone in the house overnight because if I need doctors or something like that in a hurry I might not be able to let them in or that sort of thing. Now my wife is regularly away and, for instance she's away five days in Geneva about two or three weeks ago and for that period one of my research students came and lived in the house with me. She's going away again for a week at the end of July and we're arranging a series of visits from people. So it's that type of support, it's friends and it's just a matter of making the right arrangements we have had no problem other than people's dates. L10 Age 56, Renal, Lives with wife PT1

Male Patient: Now these friends of ours don't do that. They know what I've got and they never mention it.

Female Carer: But they're so supportive.

Patient: In fact, they take the mickey out of me, you know, so –

Carer: Well B. does, doesn't she?

Patient: She writes poems about me (amusement).

Carer: Funny ones.

Patient: Funny ones.

Carer: They're really – we're blessed with those friends. L14 Age 72, Gastric, Lives with wife (age 70) PT1

Female patient: I've got a very good friend that I worked with, she only lives over the road, and she comes every – she was here three times yesterday. Because I did get a prescription off the doctor for some Paracetamol and she's bringing it round for me today, and some drinks that they give you, and she's been for them. She'll do anything for me. And the neighbours are good. That one neighbour and the neighbour over the road, she'll be here this afternoon. Company, you know, so I'm not lonely – just in the morning, you know, and at night, that's when you feel it, night time when you're on your own – you get the curtains drawn and you feel just a loner. B5 Age 76, Colorectal, Lives alone PT1

## **Neighbours**

As indicated in the patient account just cited, neighbours were also mentioned as providing good support. The people who mentioned neighbours as steady sources of help, rather than simply as well-wishers, tended to be retired people who lived alone in a setting where there was a sense of community (often a rural locality or an urban working class estate).

Here is an elderly man living alone in a Lancaster council flat:

Male patient: Well I have a good neighbour next door – what do you mean, as regards shopping, things like that? I have a very good friend who does my shopping, and anything I want. This young lady next door, she's often popping in and wanting to do this, that and the other, you know, but I'm independent, you know. L9 Age 88, Lung, Lives alone PT1

And here is a woman who lives with her son in Kendal on a council estate:

Female patient: I mean girl across [the street] this morning. It was 9 o'clock when I got up and I thought, 'Oh, pay day, how do I get some money?' Anyhow I saw her car was there, so I phoned her and she said, 'Yes, I'm doing something, but then I'll come over,' so that was sorted. I've got good neighbours. A couple of really good ones and that's all you need, you don't need dozens, so I just asked her to go to Pound-stretcher and get me another pair of slippers. I can't get shoes. Sandals don't fit. You can see what [my feet]'re like. K6 Age 75, Lung, Lives with son PT1

Neighbours were usually configured as providing help located outside the home, such as getting shopping, picking up prescriptions, and going to the library. It was less common for neighbours to enter the home and, for example, clean or cook. Where this happened there was usually some mention of informal payment:

Female patient: [My daughter helps most] and I pay J. [my neighbour] to do the hoovering and I mean I've got a washer and a dryer so just pop the washing in. B4  
Age73, Ovary, Lives alone PT1

The question of 'paying' people who helped was most likely in less affluent areas, and the extra financial benefits that people received were noted as useful in allowing this kind of informal reciprocation.

Female patient: [my neighbour] she's been like an angel, she does my shopping – most of it – and I trust her with money – so I make sure that she always has something. Mind you, she gets a bit stroppy, but I cut her to size – (laughs) I say to her, 'OK, you're not going shopping for me then.' She knows all my business, I told her, because then she knows what to do and how I'm situated, and I would tell her anything. I would trust her with my life. And she's always having a giggle. So I said to her, 'If you don't take it, you don't go!' And she said, 'All right, but I feel awful.' So I slip her money like. L17  
Age 81, Stomach, Lives alone PT2

There were no references to neighbours helping with intimate or nursing tasks, although emotional support was indicated. One carer described how she called on her neighbours to help her through a crisis, and in this case they did actually stay in the house. After a medication problem and admission to the hospice against his wishes, her husband had become suspicious and very dependent on her, and would only be left with certain people while she nipped out. One of these was a neighbour. These neighbours had helped her when he first came home from the hospice:

Female Carer: Our neighbour [...] was quite sweet, because the first night, when I got in a panic about [my husband] being like that, and I thought, 'I'm never going to cope with this I'll let him down,' our neighbours came across in their pyjamas and slept. I just was frightened not to have somebody around, you know, it's funny isn't? But really I felt quite out of it, out of control. I didn't feel I could cope with it at all. P16: K1, wife, age 63 CA1

Other neighbours just provided some company:

Interviewer: Do you ever have any kind of need for emotional support, someone to talk to or – you know, share your worries with or – I don't know that kind of thing?

Male patient: No, well the gentleman across the road comes to see me sometimes. He's 81, and he's on the corner with me like. He's perhaps about the same as I am, and he stops about half an hour, and I've been across to see him once, and he's all right. He comes perhaps twice a week, he makes calls all round, he's pretty fit, he's just got a bit of a bad back, and otherwise I'm quite happy on my own, you know. I've got my television, it's easy. [...] I don't feel the need. I can talk to [my wife] 's pictures or things like that, you know, which you do do. And you're always talking to yourself when you're on your own, so it's the opposite, when you were younger think, 'Oh, he's talking to his-self', but you do, because there's no other way. L13 Age 77, Lung, Lives alone PT1

### **Social support in rural and urban locations**

Some patients and carers spoke of the changes they had observed in rural areas, changes that had sometimes undermined the sense of community and availability of help. One woman who had recently moved from a hamlet to an urban flat regretted what had happened to her former area of residence:

Female patient: There were four houses and if you were ill you could always send for somebody and they'd pop up. We'd help each other out. Well, all those houses have gone now they're all holiday homes and private and everybody's moved away...

In her present residence, reliance on support from neighbours was not a possibility:

My neighbours here, they're nice neighbours, but up there's an estate with big families. A. [in the flat] underneath has had a stroke, so he doesn't work, there is one big lad who's thirty and on his own next door upstairs, there is an old man who's not very good downstairs. Next to him is a deaf and dumb lady, and she comes and tries to make contact with and talk to you, and then a young lad on his own. They're very quiet and you don't see people at all. A. comes up and just has a chat on Sunday before he goes to church. Bless him, he always says 'how are you?' because he says prayers at church for me, so somebody's praying and trying hard. But apart from that we don't see anybody. They're not neighbours like we used to have at G. [hamlet]. You couldn't expect single lads to come in and give me a hand, or an old age pensioner, so-. B6 Age 61, Breast, Lives with husband PT1

Another couple who had lived in the same hamlet all their lives saw changes, but still felt very involved with the local community:

Female patient: The neighbours have been very good. I mean they're always coming in with baking and one thing and another aren't they?

Interviewer: So is this quite a well settled village of people, have people been here a long time or have you known the people a long time?

Patient: Well no, some of them are what you call in-comers, but they're all alright.

Male carer: We know everybody. I went to school there where you parked your car. There used to be a village school.

Patient: We know everybody but it's a very scattered place is K. you see. It's quite a few little settlements, where there'll be as many houses as there is here, with these barn conversions and one thing and another. P 2: K3 Pt1.txt Age 67, Ovary, Lives with husband

One woman who had lived in a medium sized village for 20 years also noted the helpfulness of neighbours:

Female Patient: They're absolutely over wonderful, if that's the word.

Interviewer: Over wonderful? (laughter)

Patient: They pop in, they see a bit of ironing there it's whipped away, they don't ask, oh I've taken it, and what shopping do you want, you know. They're just wonderful.

B10 Age 63, Unknown primary, Lives with husband PT1

However, it did not seem necessary to have lived in a place for a long time for neighbours to be helpful in the right setting. This woman had only moved the year before from London to a small village in the Lakes, where she lived alone:

Female patient: I just plan my day and just kind of manage somehow and I have got good neighbours really who pop in. B1Age 50, Lung, Lives alone PT2

Only a few people in the whole sample did not feel their neighbours could help, either through not knowing them, or the neighbour being elderly or frail, and these tended to be located in a town:

Male patient: We don't really know them very well. I mean they've only just been in a month or two and D. next door's not so good at all, so-

Interviewer: Have you been here a long time?

Patient: Seven years. L1 Age 69, Oesophagus, Lives with wife (age 77) PT1

Location in a town, however, did not preclude involvement with the neighbours. For example, a comfortably retired couple described the quiet close they lived in thus:

Male Patient: But all the neighbours, all the neighbours are very good and all. Even though everybody in this street is retired now. They've all lived here - just one family across there, who's moved in about six or seven months ago - but everybody else has lived here over 30 years. Like J. across the road there, they'd just got married, 'This is our first house, we've bought this, but we're looking for something better later on'. Well they're still there, the two sons are grown up and married and they've got grandchildren. So we all know one another, and we keep to ourselves most of the time, but when anybody's in trouble –

Female Carer: They're there.

Patient: And it was me first in hospital. H. across the road went a couple of weeks ago, now he's got cancer, so he's getting treatment, and J. went because he had a man's thing a fortnight ago – so the three of us have been getting together and having a bit of a laugh about it at times (amusement).

Carer: We've got good neighbours this side. This side of us are really good neighbours. They've been very supportive – very. And if anything's wrong, they will come to us, and if there's anything wrong we will go to them, or without asking they've been coming, all the neighbours have. L14 Age 72, Gastric, Lives with wife (age 70) PT1

Another comfortably off couple, however, described less of a sense of community with the neighbours. They lived in a large village, which was situated on either side of a main through road:

Female carer: The neighbours, they're very good. It's a strip of road and if you ever have to go to any of the others, it's not - people said to me, when I moved here, the neighbour next door said we've been here over 10 years and we've hardly got to know anybody at all. Very, very self-contained, compared to living on an estate where everybody would know each other better, I dare say. They are very good next door. We don't know the folk further down. I wouldn't even know them if I met them. But you say, you nod to everybody you meet in the street generally, but I don't know their names and that.

Interviewer: But locally, it's more the community that's been - the church community that's been important?

Carer: Oh yes, for that. It's not their faults. They all seem to just be people that don't like to - it's not proper to intrude and go and invite your neighbours. They're friendly enough, but they have this inhibition that they don't like to appear that - it's downgrading for them to not call at a house for a specific reason - they wouldn't drop in to say how are you - it's just their way. B11 Age 72, Bowel, Lives with wife (Age 70).

## **Where the patient lived alone**

Nineteen of our sample of patients lived alone, although at the time of interview two were living in residential/nursing homes and one was staying with his sister. Their average age was 75 years (range: 44-88). Living alone was one of the main factors that impinged on preference. Those who lived alone were often particularly pragmatic about their choices, and often tended to be somewhat resigned to having to enter an institution if their condition warranted it.

For one retired nurse, the need for care had already overwhelmed her and she had moved into a nursing home after a fall. Prior to that her friends had been helping her, and she had been putting her affairs in order for some time. For her the choice was guided by her strong religious faith.

Female patient: I'd no extra help, no. Until the 16th I'd managed up to a point, but not very well. I'd friends coming in to give me bits of help, but no permanent help, you know, in from 4 to 6 or 9 to 12, or bring my breakfast. But M. [my friend], who's looking after M. [my cat], she came in every morning to bring me a cup of tea, let the cat out, looked after M., so that was no problem. It was after I came back from the hospital she did this, and she's been looking after M. ever since, and with a bit of luck we've found her a home, isn't it lovely! [...] [After being in hospital] I couldn't cope when I got home, so there was only one thing to do was to stop and see what was happening, and I think, being quite a religious sort, I think that the push, falling onto the floor, was God saying, 'Right, we've got you now. Push - this is it, where you go now is where you're stopping.' B9 Age 85, Oesophagus, Lives alone PT1

Knowledge about whether there could be a home care package appeared to be limited among patients:

Interviewer: Would you prefer to stay at home if you could?

Female Patient: Well I would really, mmm. But you need help don't you, you see, you need somebody to nurse you.

Interviewer: So if there was a kind of a nursing team who would come in and help you at home would that be something that you would-

Patient: Yes that would be all right wouldn't it. B4 Age73, Ovary, Lives alone PT1

One woman who had nursed her husband through a long illness had knowledge of the social services. However, she was fairly clear that she didn't want to burden her family and would prefer the hospice for her final care:

Female patient: I'd like to go to the hospice.

Interviewer: You'd like to go to the hospice?

Patient: Yes, because I don't want it to happen in my daughter's house, and if it's here – well they'll all – you don't – . I feel that I could be supported at home, but it would be an awful effort, wouldn't it? I don't know, when the end does come, I either want to be in my own house or in the hospice, because I don't want to be in my daughter's house, if it's possible, you don't know, do you? B12 Age 82, Bowel, Lives alone PT1

A younger woman who lived alone, and had no family or close friends nearby, also favoured the hospice, but was unsure whether they could take her:

Female Patient: Obviously, because I live on my own, there will be a time when I won't be able to manage.

Interviewer: And what do you imagine happening?

Patient: Well I don't know really. I mean I think at the end of my life I would like to go to the hospice. I don't want to sort of struggle around managing on my own. I'm not that interested in staying at home if it's terribly, terribly inconvenient. I mean I don't even I don't really know if that will be possible. B1 Age 50, Lung, Lives alone PT2

Having people come into the home was viewed with ambivalence by some who had been used to living on their own:

Female patient: I tend to push it to the back of my mind at the moment. But yes I would, if I had to have care, I'd choose to go into a hospice. If I had to have care. But I do, as I say, I tend to put it to the back of my mind. Not because I'm frightened. I don't want that day to come but you've got to face up to it haven't you. And I think the atmosphere would be helpful. So I think it would be if the time came.

Interviewer: So do you think that would be preferable to being at home and having people come in to look after you?

Patient: Well I've thought about that as well. And I'm so used to this friend of mine over here. She has a live in carer. She's had a lot of carers but this one lives in. She's had every care and attention. Because I've always said – because there's somebody

else I know and she's, no I'm not having anybody in my house, etc. I said, don't be silly. But I understand. To have somebody completely strange come into your house. But I think if I got to that stage most probably I wouldn't mind. K9 Age 84, Lung, Lives alone PT2

Female patient: My sister, she said, 'Our S. shouldn't be on her own', and I don't think I should, but what else can I do? I don't want to live with anybody, I'd sooner be on my own, because I feel I'd be a nuisance with somebody else. L16 Age 70, Lung, Lives alone PT2

A few preferred not to think about the future too much and make plans, or found they could not decide on what was best. Some people found it quite difficult to articulate what they wanted for the future. The woman in the following extract, despite talking freely and in detail about her present circumstances, became less fluent when asked about the future.

Female Patient: I don't know what I'll do.

Interviewer: You've thought about it, but you haven't - ?

Patient: Yes.

Interviewer: You can't think what's the best thing?

Patient: No, no. No, I have thought about it, because it is getting harder, I can feel it now. Getting about.

Interviewer: Yes – so are you just sort of leaving it up to fate, sort of thing, really?

Patient: Yes, yes.

Interviewer: Yes, you're not making any kind of plans on what you think would be best for you?

Patient: No, no – no.

Interviewer: OK. But you would like to carry on living on your own - ?

Patient: As long as I can.

Interviewer: As much as you can, yes.

Patient: Yes, but I think I'm going to have to move, although I don't want to. I don't want to move at all, but I think I'll have to do.

Interviewer: Have you thought about – you've thought about possibly nursing homes, you've thought about relatives - ?

Patient: Yes, I've thought about a relative - .

Interviewer: But not felt keen on that?

Patient: No.

Interviewer: Have you thought about the hospice and what they have to offer, or - ?

Patient: Well, I suppose I could ask, couldn't I, but no I haven't thought about it really, I've no idea what it's like inside. P57: L16 Age 70, Lung, Lives alone PT2

Another patient who lived alone also had problems envisaging future care:

Interviewer: Do you have any feelings that you might be able to stay at home if you were poorly, or do you think - ?

Male Patient: Well, if I was that bad, I wouldn't be able to, would I, really? But, if things don't get any worse, I can manage now as I am.

Interviewer: Yes, sure – yes, I can see that, yes.

Patient: That's if I don't get any worse.

Interviewer: Yes – I was just wondering about if they did get worse.

Patient: But how do I know if it's not going to get any worse, or not? L9 Age 88, Lung, Lives alone PT2

However, others were much clearer about what they wanted. One widow, who had family nearby, was certain she wanted to stay at home and had discussed this with a health professional:

Interviewer: Now if your illness gets worse, how would you like to see things change, how would you like your care to be organised, if it got much worse?

Female Patient: Well my carers, I'd like them to come to me. I wouldn't like to go into a home or anything. I'd like to stay in my own house and that.

Interviewer: Right. And do you think that help would come from Social Services, or from the nursing services, or –?

Patient: Well both, I would have thought, wouldn't they – I would have thought.

Interviewer: Have you talked to anyone about that possibility, you know, if you had to have nurses coming in?

Patient: Yes, one of the Macmillan nurses, she asked me, and I said, 'No, I don't want to go, I want to stay home', you know, all the time.

Interviewer: Yes.

Patient: She did ask me that.

Interviewer: And did she say that would be OK and she could organise it?

Patient: Oh yes, yes, she said yes it should be possible, yes. P67: L7 Age 60, Endometrium, Lives alone PT2.

Another younger woman described her vulnerability at home alone and had enquired as to how things might be managed, and what the possibilities were, which she had found reassuring:

Female patient: Because I live on my own and I feel quite vulnerable when I'm at home. I guess that's the major part of it, as you suddenly change from having nursing on hand day and night to flying solo and it's a big transition. Once or twice I've found that quite hard, but I guess I'm getting more used to it now. When I had a 6 week spell in hospital just recently, the transition home was eased because some friends had arranged to come and stay at my house. So there was actually somebody there when I went home, so that really eased it on that occasion, but otherwise I think I would have found that one quite difficult when you've been used to continuous care for 6 weeks, suddenly being on your own it's a big change. [...]

Interviewer: So, would it be better for you if you had someone around at home?

Patient: Oh, I think if there was someone else there that would be easier for me, but it's just not been my circumstances. When I was talking with [the hospice social worker] I got a bit concerned as to whether I would be able, whether I would come to a position where I wasn't well enough to look after myself at home. Well, I know the hospice don't like to have you for a long period of stay, so I wondered if there was an in-between situation which I needed to be thinking about. And I contacted certainly one nursing home, only to find that they only take people that are over 65. So I talked to [the Macmillan nurse] again about that and said that it was concerning me, and she mentioned one or two places that take people under 65, [...] and she also mentioned something called Country Cousins, where people actually come and live in at your home for a fortnight at a time, come and join you basically. So that gave me some reassurance, but she further she said that what would happen would be that I would come into the hospice as a first line of care, and if it was proving to be a longer stay than the hospice could manage, [the hospice social worker] and others here would talk with me about where I could move to. So that reassured me that I didn't need to worry about it immediately. I was talking with [the hospice social worker] just this morning about it and she said there's no point worrying too much about it because we don't know what the circumstances are going to be, but that they would be able to help me find somewhere if it became necessary, if things proved to be more long drawn out than short term.

Interviewer: So what would your preference be, to be in the hospice if you could?

Patient: My preference would be to be at home as long as I could, but after that yes, the hospice I suppose would be my next preference. It's difficult to say when you've not experienced any of the other places. I've only experienced here and I know it's a lovely place. I'm very happy here. K8 Age 44, Breast, Lives alone PT1

This was echoed by another younger woman, who came to feel very vulnerable as her condition deteriorated, and who did not want social care in the home, but came to know the hospice and felt safe there.

Female patient: Just from the practical viewpoint really and sort of feeling secure in there's somebody there all the time. Whereas I think if you're very ill and on your own it can be quite frightening, but apart from that I don't know what will happen, and I mean I will cross that bridge when I come to it. B1 Age 50, Lung, Lives alone PT2

### **Where a carer has chronic illness, was elderly, or frail**

There were eleven carers in our sample of 18 who had serious health problems of their own. Three had had, or developed, cancer themselves, three suffered from heart problems, and two had skeletal problems. Of the others, Parkinson's disease, depression, and ME were noted. In addition, patients whose carers were not interviewed often mentioned the carers' health problems or frailty through age. The carers' ability to care for the patient at home was thus sometimes a matter of concern and influenced thoughts of preference:

Female patient: Having been in the hospice, I mean I would be quite happy to go there.

Interviewer: It was nice there-

Patient: Yes, I would but, you know, it hasn't reached that point yet so we haven't really got to discussing that but, there's no way you could cope with me is there?

Male carer: No

Patient: No. K3 Age 67, Ovary, Lives with husband (age 67) PT1

One patient with an elderly husband said:

Female Patient: I think he might find it very hard at the end, physically as much as anything. I don't know, might surprise me but I know he looks tired sometimes. B10 Age 63, Unknown primary, Lives with husband PT1

And a woman who lived alone noted that her sisters were all somewhat incapacitated:

Female patient: What can I do, my sister, she wanted me to go and stay with her, my other sister, she's not so well though now, she's having gallbladder troubles,

she wanted me to go and live with her, but now she's badly, so -. I've got another sister that's younger, she had breast cancer two year ago, now it's flared up again, so she's not so well. So we're all – I think we're all ready for being shot really. L16 Age 70, Lung, Lives alone PT2

However, even where both the patient and the carer were somewhat limited in their functioning, there was often a determination to manage by themselves as long as possible, as the following extract illustrates:

Interviewer: And the two of you sort of help each other out you said you know, you kind of do it together perhaps?

Female patient: We do yes. Well I used to help him with his shower. Well you see, I got that I couldn't do that so that's quite a help when somebody comes. And because he's got the elastic stockings on now with this blood clot, well he can't get them on, and I can't get them on, and it all got a bit much in that sense. But no we muddle along between us at the moment and we'll just have to ask for a hand if we need it, for more help if we need it.

Interviewer: Yes and you'd know, you'd decide when that was-?

Patient: Oh, yes, yes, you would know when the time came yes.

Interviewer: Would you discuss it between you or would you just know?

Patient: Well I think we'd just sort of know if we need it. I mean I would know if I couldn't get myself sorted in the morning sort of thing and at night you know. K3 Age 67, Ovary, Lives with husband (age 67) PT1

Turning to a carer's account, here she describes how she managed the physical care of her husband at home until his death, despite her own ME.

Interviewer: And you said that your ME wasn't so bad at that time so that was fortunate.

Female carer: It had been bad before but it was – I don't think remission is the right word - but that's the only way I can explain it. It does come back and I was told it would, you know. It does come back but sometimes you have a spell. I think I probably said I am Christian and I do believe that I get help in another way. I know I do actually, I know I do. So that was just – it didn't just happen. I think that was planned, that I wouldn't have the pain, that I could look after [my husband]. [...]

Interviewer: Yes because he wasn't completely – he could get into a toilet and things?

Carer: No I could – I mean he weighed so little, you know.

Interviewer: But you're not very big either are you?

Carer: No.

Interviewer: So lifting him?

Carer: But I think sheer love makes you do it, doesn't it make you do it. Sheer love gives you the strength to do it. L14 wife, age70, gastric CA(B)

Another carer's narrative illustrates how a frail carer could have extra burdens in the form of anxiety, even where physical care of the patient, her brother, was not a factor:

Female carer: I didn't find him hard work. It was getting me down to the extent - because I have got a bad heart, I've got a dicky ticker- so when I had to go out to the town or whatever, I was stressed out because I was rushing to get back. I was coming back with half I hadn't got, I'd gone for, to see if he was all right. I didn't like leaving him, he wouldn't have anyone sit with him, and on the Saturday - prior to going into the hospice, before he died, the previous week - I had to go for the flu jab and I said, 'I won't be long Tommy, stop in bed till I come back', because he did smoke and I found he was dropping asleep. He didn't smoke in the bedroom, he never did, but he were dropping asleep and he couldn't roll and the energy had gone, so to be on the safe side, I said, 'Stop in bed Tommy, I'll only be an hour till I come back'. L15 sister, age 66, bladder, CA(B)

## **Self care and independence**

As some of the extracts already presented suggest, self care, being independent of outside help as much as possible, and for as long as possible, was a recurrent theme. Both patients and patient/carer dyads presented self care as an aim, and one which they often managed, as they described the ways in which they adjusted to limitations. Self care was related to the issue of uncertainty about how things would progress, a theme discussed in the previous chapter, because several spoke about 'managing somehow' until the end, or very near the end.

Patient: I don't like to ask. As long as I can do it, I'd like to do it myself, always been independent. B4 Age73, Ovary, Lives alone PT1

Female patient: It's been very good. I've found it very good. If I wanted anything I can ask for it. But I've got to ask for it and I - you know - I'll have to be desperate to ask for things. B12 Age 82, Bowel, Lives alone PT2

Male patient: The [family] would [help] if we asked.

Carer: I think they would do but we don't ask. As long as we can be independent we will be. K11 Age 79, Gastric, Lives with wife (age 76) PT+CA1

Interviewer: At what point do you know that you need some help?

Male patient: When I've struggled and struggled and struggled and can't do. K4 Age 50, Lung, Lives alone PT1

Female carer: We feel confident that [the hospice is] there for us if we – I mean we wouldn't call on anybody unless it was desperate, would we? We're a bit independent. But – um – who knows what we may-

Male patient: We've to keep that independence as long as we can.

Carer: Yes. L14 Age 72, Gastric, Lives with wife (age 70) PT2+CA2.

Interviewer: If you did get worse who would you like to be looking after you?

Female patient: Myself.

Interviewer: If you get to a point where you can't fully look after yourself?

Patient: Oh I don't know, it would have to be my hubby I would think, because he can cope, he'd cope L12. Age 70, Colorectal, Lives with husband PT1

These extracts suggest that asking for help is not an easy thing to accomplish, and many of the interviewees related their 'independence' to their histories and identities:

Male patient: I'm relying on a wheelchair at the moment for the bulk of my travelling, but I walked about 120 yards yesterday which was quite a feat really and I was quite pleased with myself. And then my partner plays bowls, so I went down to the bowling green, I thought I'd sit and watch that, and scored a couple of games, I marked a couple of games for them, so – because you feel a bit useless because you can't do just simple things – you can't sort of think, 'Well I'll run round with the Hoover, or do a bit of dusting, or' – because with being divorced, before I met my partner – spent five years living on my own – an ex- serviceman, so I can look after myself. But simple things like standing doing the ironing, or doing the washing, or even washing the pots, can be quite tiring now. So when I do something I get quite over the odds. I get quite chuffed with myself. B7 Age 57, Lung, Lives with partner PT1

Female patient: I'm a very determined person, I won't be put off if I can possibly help it, and they keep saying to me, 'Oh, I don't know'. I said, 'You don't know what?' 'Well you won't let us help you'. I said, 'No, I won't – as long as I can do it myself, I'll do it one way or the other'. So I think some of them get a bit annoyed. See they think they're helping me – well I'd much rather do it myself – because after all, you can do a

thing much better yourself than somebody else doing it for you, so -. B3 Age79, Breast,  
Lives alone PT2

In addition, continuing to manage was linked to relationships with others (also see next section on 'not being a burden'), even though at times it was a struggle.

Male patient: I need my independence. I could have stayed living in my mum's, but that really wasn't an option. When I'm having a bad day, what's the point of inflicting that on somebody who you care for very much who doesn't really want to see you sit there wanting to throw up or whatever. That wasn't an option and never was. It wouldn't be good for her and it's not good for me and as I say I'm an independent so and so. K4  
Age 50, Lung, Lives alone PT1

Male patient: All my shirts and stuff I take to the laundry, my daughter would wash, but I don't want her to, you know, she's got enough to do. But apart from that, I mean I'm pretty self-contained. A bit of a struggle, but I can L13 Age 77, Lung, Lives alone PT1

Female patient: Not like being nasty, but I wanted to do things on my own and I can't do that if I'm going to push onto somebody. And he said, 'What about upstairs E.?' I said, 'It's okay I'll, I'll stop on settee if I can't get upstairs.' He said, 'I'll bring your bed down.' I says, 'You won't, had enough of that,' I said, 'I don't want it down here, thank you, love.' I reminded myself that I was being ignorant and I did get upstairs. Even doctor said, 'Do you go upstairs?' And I said, 'Yes, course I go upstairs,' I said. 'I didn't think you'd make it.' I said, 'Oh yes.' I said, 'I went up hands and knees.'  
(laughter) L17 Age 81, Stomach, Lives alone PT1

Female patient: But, you see, even if you have your daughter trying to dress you or undress you, it's embarrassing. I'd sooner try and do it myself, but as I say, I am absolutely knackered when I've done it. I flop on the bed, but I think 'I'll have five minutes.' L16 Age 70, Lung, Lives alone PT2

It is acknowledged that advanced disease will bring changes to people's lives, and 'managing loss' is a factor which has been identified for people in this situation (Watson et al 1988). However, there were some patients who had acknowledged that they did need help, but even after the fact this was presented as difficult and frustrating.

Female Patient: That's the trouble, I get frustrated I can't do things like I used to do. I used to be very independent, you know (amusement). Because I've been disabled all my life, you know – My legs and that, but it didn't stop me doing anything.

Interviewer: No, no – but this is different, this has stopped you doing stuff.

Patient: This has certainly B-ed me up well and truly (amusement). L7 Age 60, Endometrium, Lives alone PT2

Male carer: Well, what I mean by hard for her, she's seen these jobs she wants to do and she can't do it.

Female patient: Oh heck, I mean I can sit and see something on the clothes rail and think all I want is to put them in the airing cupboard and a week later they're still there and it's just too much effort to do it. Things like that, or throwing some dead flowers out and that sort of thing. K3 Age 67, Ovary, Lives with husband PT1

Female patient: And it gets me so frustrated, I could scream, because when you've always been used to, you know, dashing around and doing everything yourself, it comes terribly hard after 75 years to not be able to do it. B3 Age 79, Breast, Lives alone PT1

Female patient: All I'd love to do is get in my garden. B4 Age73, Ovary, Lives alone PT1

Female patient: It's just annoying when normally, I mean, before I was ill, I could spend all morning cooking and baking and things like that. And now I have to do so much and then come back in here. It's giving me backache if I do too much. K10 Age 77, Breast, Lives alone PT2

Male patient: My beloved Zimmer frame has come into its own. I had because of, many years ago I had a major heart problem and I had issued to me a mobility car to allow me mobility. Again because of the cancer I am not going, I am not allowed to drive now, the strength is not there in my legs. And so S. drives me virtually everywhere now. Everything that I do basically is supported by an outside, shall we say, influence in that one of the greatest joys in my life was my garden. I now have to back off on the garden and do the little bits I can, like doing weeding and potting and so on via – well my wheelchair really. I do a lot, quite a bit in my wheelchair and I do quite a bit standing against my frame. But, you know you can get through with that. I certain can manage it, yes. But I do miss being able to jump up and down so quickly. B8 age 63, Prostate, Lives with wife PT1

Female Patient: I want to be independent, but I'm frightened to be on my own.

Interviewer: Right, yes, yes – I can understand that.

Patient: I'm going to cry –

Interviewer: Go ahead, it's all right, if you want – I'll turn this off.

Patient: I've been more weepy lately, and this isn't me, I've always been able to cope, but I can't cope anymore. I can't cope. I just wish to the Lord would take me, it would be easier for everybody, but I must be here for a purpose – oh, that's better – that's better. B12 Age 82, Bowel, Lives alone PT1

## **Not being a burden**

The aim of managing self care was fuelled by a desire to maintain independence and identity, but was also closely tied to 'not being a burden'. This was an especially strong issue for those with adult children, and there was much talk of not wanting to make demands or impinge too much on their lives. A related theme was that of not wanting to put their loved ones 'through it', to spare them the difficulties of the situation.

In some cases the parent felt that their family could not really help because they had too much to deal with already, as already outlined. Respondents tended to list their family's commitments and emphasise their desire not to put too many demands on them.

Female patient: the only thing that bothers me is if I got to as I just can't look after myself [...] well if it just got as I couldn't-I mean you do, don't you? I mean my daughter couldn't nurse me full time because she's got two children and she's working and her husband left her five years ago, so I mean she's up against it I don't want to knock her up. [...]

Interviewer: right but your daughter couldn't manage to-

Patient: she couldn't possibly and look after two boys and run her home and go to work she couldn't do it. B4 Age73, Ovary, Lives alone PT1

Female Patient: I'd sooner let them get on with their own lives. I don't want them stuck with me. L16 Age 70, Lung, Lives alone PT2

Male patient: [My daughter]'s all right, she does her best, [but her husband has Parkinson's disease]. You can only get so much out of a person. She's only got one pair of hands. L13 Age 77, Lung, Lives alone PT1

Talk about spouses in these terms was less common, but it did occur:

Male patient: I wouldn't mind, whatever is most convenient.

Interviewer: You wouldn't mind OK right. So that would be mainly to allow your wife to carry on working?

Patient: Yes, so that she doesn't, as it were, have to give up everything just to look after me. L10 Age 56, Renal, Lives with wife PT1

Both the male patients being cared for by their sisters, and the mothers living with their sons, wanted professionals to manage their final care:

Interviewer: And why would you want to go into the hospice?

Patient: Really I wouldn't burden her.

Interviewer: Your sister?

Patient: Yes.

Interviewer: You think it'd be too much for her?

Patient: Yes, I should think. L15 Age 63, Bladder, Lives with sister PT1

As well as practical difficulties, the emotional strain of cancer was a factor that affected people's preferences. Patients' thoughts were for their family, and their desire to continue to look after them.

Female Patient: If things got sort of distressing to the family then I want away yes. K5. Age 67, Colorectal, Lives with husband PT2

Female Patient: I think I'd rather go in the hospice, I think it would be easier for people.

Interviewer: It would be easier for your husband and - ?

Patient: And family, yes, yes. B6 Age 61, Breast, Lives with husband PT2.

One woman who had nursed her husband with cancer, and knew what it had been like for her and her children wanted to protect them:

Female patient: If I was really sick, I mean sick sick, I wouldn't want my kids to look after me. I don't think I'd want that, I think I'd sooner go somewhere to be looked after. Yes I think I would sooner that. I mean I hope it doesn't come to it, well I mean something's got to happen some time, but I don't think, because they was so good with their Dad and they went through so, much I wouldn't want that again.

Interviewer: Yes, yes so they were quite involved with him as well?

Patient: Oh yes, yes. I wouldn't want them to do that again. If I could spare them that well I would. I mean I had it to do as my husband, but it was too much for them I think and I wouldn't want it again so we'll have to see. L16 Age 70, Lung, Lives alone PT1

Street (2001, p99) indicates that "wanting to protect a loved one from the emotional burden of watching an undignified death can lead to requests for assisted suicide." There was one case in our study where a real intention for suicide (unassisted) was stated. This man wanted to protect his elderly mother and brother and himself from the strain of advanced cancer.

Interviewer: Have you thought what if it did turn out that the treatment wasn't working well? Have thought about your situation if you got much iller, if you deteriorated?

Male patient: I refuse to answer that question on the grounds it might incriminate me. OK I think you understand the answer to that, OK. K4 Age 50, Lung, Lives alone PT1

This desire to care for those who would carry on after them sometimes extended to thoughts about the legacy of memories they would leave.

Female patient: That's my personal feeling that I think the family suffer more than the one with the illness and I think it's up to us to make sure that they don't suffer as much, they're going to have to live with this aren't they? [...] I think it would be easier for all of us. I really do. K5 Age 67, Colorectal, Lives with husband PT2

Male patient: I wouldn't like to put that on my sister. I wouldn't want her to come in one morning and see me there you know what I mean? L4 Age 57, Pancreas, Lives alone PT1

Female patient: I did say to him I'd prefer to go to the hospice but that is to save J. [my son]. I don't want him to come down here and find me dead.

Interviewer: Oh right.

Patient: Do you follow what I mean?

Interviewer: Yes, yes.

Patient: I might have a silly attitude, I might have a silly outlook to it I don't know.

Male Carer: I don't want to find you dead eh! K6 Age 75, Lung, Lives with son (age 36) PT2+CA1

Clark & Seymour (1999: 39) indicate that "Problems of role conflict between the demands of caring, employment and other pressures may be differentially interpreted and resolved" in the situation of terminal care. This hypothesis is supported by Finch & Mason (1990,1993) who

conclude from their study that while family histories and relationships led to differing ways of acting upon obligations, certain principles were followed and preserved. In our study there were many examples of familial relationship being worked out. However, there were some parents who felt they had to address cultural expectation that children should take care of their parents and justify their children's lack of closer involvement with their care to other people.

Female patient: [My daughter's] moving [down south] a fortnight tomorrow. So hopefully I will get a holiday or two down there. And she is worrying more about what people will say, being the nurse, and going now when people know that I am terminally ill.

Interviewer: What, she thinks people will say she should have stayed and looked after her mother?

Patient: Yes, and I said, it's not applicable that at all, it's me, I want to see where you are. I don't want to die thinking, oh she's going to London or somewhere, I want to see where she's settled. The other daughter's buying a house, well I want to see her settled too in there, and then I feel at peace, you know. And there's nothing for her to do, nurse at all, because I want to go in the hospice if it's necessary. K5. Age 67, Colorectal, Lives with husband PT1

Female patient: [My son lives in America]. I think that some people really can't believe that he hasn't been to see me, and I say, 'Why should he? He knows, I've told him, and if I felt he ought to come I would tell him.' I mean he's no fool. He had to come over when his father had cancer, and he knows I can cope, and if I really wanted I would ask him, but he's got his life and his job, and it would be more of a hindrance than a help if he came. I'd have to think about food for him and that sort of thing. Even Dr Norman has said, 'Well, I think your son should come and see you.' And then a friend of mine, he said, 'Isn't he coming?' So I said, 'No need to'. He said, 'Of course, every son should go and see his mother.' So I said, 'The time may come. If I have to go into hospital and I become terminal, fine then, but I don't need him.' And I mean he's been away for -he came back for his father, twice - he's been away nearly 30 years, so it's not like a youngster, is it? K9 Age 84, Lung, Lives alone PT1

## **Needing people**

Despite patient's protestations that they did not want to 'burden' carers, it was clear that having their family and friends around was valued. The 'treasure chest' was appreciated and managed through paying attention to the level of demand they placed on those close to them. Most did

their utmost to avoid burdening family, but were very glad to know they were there, and would help if needs be, as this carer testifies:

Female carer: And of course, going out and leaving him, because I'd say, 'Do you want me to go and get so and so to sit with you?' 'No, no, no, I don't want anybody' - very, very independent.

Interviewer: Yes, yes - so his independence in a way, made it a little difficult for you, in other ways?

Carer: It did, in other ways. I don't think he realised it, but I don't - . He was very frightened, because he kept: 'Oh, I don't know what I'd do if I didn't have you and the family round, I don't know what I'd do, I think I'd have gone and committed suicide,' he said, 'I wouldn't have - I couldn't have coped. I didn't want to go in a home or anything'. And of course, you'd say to him, 'You're not going in a home, you've got family, we're all here to look after you T.', but he always had that fear that I would get ill and what would happen to him? That fear was always there at the back of his head.

L15 sister, age 66, bladder, CA(B)

Unsupportive carers and family were few and far between among our sample, but where this happened it was very difficult. There was only one case where a patient felt her husband was not supporting her, but it was clearly distressing:

Female patient: Well [the Macmillan nurse] said we could have a talk to him but he just said, 'I don't want to see anybody.' The Doctor said the same, we'll sit him down and we'll tell him the seriousness of it, but I don't know if he's burying his head or what. You know when I say I'm bad and I've got all the pain, 'Well there's nowt I can do about it,' he says. So I have to get up and make myself a hot drink and take my Morphine stuff and just go back to bed until it's gone, and he's come home and I'll say, 'Do you know, I never got so and so done.' 'Well what do you expect if, he said you're on the settee all afternoon?' So I got this three-seater settee for when I do have a bad day I can lie down, but I don't get that many bad days, but I seem as though I can't see the full day out without having an hour, you know what I mean. But that's the only answer I get and I think well my friend has Radium from Preston and her husband's took semi-retirement to take her down and it hurts me to feel that mine, and he's a lot younger, there's no care about it. And I think what's going to happen later on? And I don't know. This is the thing, where will you end up and this is what I'd like to know. I'm sorry about crying but I get so upset about it. B6 Age 61, Breast, Lives with husband PT1

Fortunately, by the second interview she had come to accept her husband's attitude, and despite her feeling that he wouldn't be closely involved in her final care, her relief was palpable:

Female patient: [I told my husband] I could have [my funeral] in the chapel here and be buried, and do you know, he was so pleased, as though a relief has been taken off him. I thought, 'What a funny thing to do.' The way he said, 'That'll be nice, that'll be nice.' And I thought, 'Yes, he's thinking when I'm dead what's going to happen to me?' But in the meantime nothing, you know what I mean - ?

Interviewer: Right – OK.

Patient: But it was comical, I couldn't help but laugh at the way it seemed so – oh, he was so relieved about that. Never mind, it's his way, he's a country lad and he takes things just as they come and doesn't think about things. [...] I mean I've been bad in the past with different things, and the doctor's had to come out and give me injections, and he's come home, and he's sat with me for an hour, and he'll say, 'Well, are you feeling better now?' I'll say, 'Yes.' 'Oh well, I'll go back then.' He's that type, he's a workaholic, and he just – I think he just doesn't know how to cope, he's never had children, because it's my second marriage, but he loves my grandchildren and we take them out, but he doesn't see danger of what could occur. You know what I mean, and I think he's – that's just him, so I've accepted it now, at first it did upset me a lot.

Interviewer: Yes, I think you were quite upset about it last time I saw you.

Patient: I was, but I've decided now, you can't change him, it's just how he is, and I mean if I did say to him, 'I'm ill, R., don't go to work and leave me on my own,' he would stay at home, but he wouldn't offer, you'd have to ask. But he's a very gentle person, but he just doesn't know how to cope, I don't think. B6 Age 61, Breast, Lives with husband PT2

In another case the carer recounted how he had given up work due to his wife's illness. Initially they had paid one of their daughters to look after the mother during the day, but she had neglected her duties:

Male carer: There's me – someone that's in the house that's looking after her now, because I would be at work and I wouldn't know. I could come home and she could be flat on her back, because no-one would say anything, and J. wouldn't – the other daughter - she'd be out at ¼ to 7 in the morning till 5 o'clock at night [working], so anything that happens in-between that time we wouldn't have known anything about it.

Interviewer: Yes – so if you got poorly, and also because you were on your own perhaps, that was a consideration?

Carer: Because the daughter was supposed to look after her, and she didn't do anything, so I thought to myself, 'Well, what's the point of that, I could be doing all this'. L11  
Husband, age 49, breast, CA1

## Carers' perspectives

In this section, attention turns to the informal carers, examining their perspectives on some of the themes explored above from the patient's point of view. Extracts are used from both the pre- and post-bereavement interviews with carers.

### Carers and the patient

In the foregoing discussion, several interview extracts have already suggested that a patient and carer dyad, usually a married or cohabiting couple, often constituted themselves as a unit, who were supported as such by family and friends. Many of those in our carer sample were willing to shoulder the 'burden of care' and indeed *wanted* to do this:

Female carer: [A nursing home would be the] Very, very, very last resort. Yes. While I had breath – while I could breathe – let's put it that way – I would look after him myself. I mean [a home is] for people on their own obviously, it's the ideal thing isn't it. Or people that perhaps can't cope as a carer or to look after people. I haven't found it difficult.

Male patient: I mean there are people our age that can't cope, isn't there?

Carer: Yes. We're in our 70s. I mean we're not young, are we? But no. I feel it's my duty to look after him. It isn't a task. It isn't a task at all. Not – whatever I do, I'm pleased to do it – because I love him so much, and it isn't a problem. I will look after him as long as I can breathe. And if that sounds sappy I don't care. That's how I feel. [...]. L14 Age 72, Gastric, Lives with wife (age 70) PT2+CA2

Interviewer: Did you sort of plan to just carrying on keeping him at home?

Female carer: Oh I would've done if it was possible, if it was at all possible. I mean, if he was comfortable and not in pain then that would have been no problem at all, I would've preferred him to have stayed here. B8 wife, age 60, prostate, CA(B)

Interviewer: And how about you, how did you feel about having to go [to the hospice] to be with him?

Female Carer: I would have preferred him to be at home. Because I've been a long-time carer for me daughter, and I consider myself to be a very good carer, and I wanted him to be at home with me, because I was just as good as them at giving him his medicine and making sure he got the right drugs and everything. So I would have preferred him to go on a daily basis just to check with them that – how he was doing and progress and everything, and then to have him back home. L2 wife, age 40, thyroid, CA(B)

As the last two extracts suggest, there were often uncertainties about how the disease would progress and several carers described 'sudden' deaths (see the previous chapter), which altered their plans to care at home. The desire to care was often accompanied by worries about whether particular eventualities could be managed, for example, the patient's pain or distressing symptoms, and by whether professional support in the home would be available.

Female carer: I would want to do [the care] if I could get enough support, but my two daughters work and my two sons are away, and I don't know whether the nursing provision would cover all the times that would be needed, depending on what will happen to him. It's a bit of an unknown. So that's what I'm planning. K1 wife, age 63, colorectal, CA1

Female carer: I think I probably had lots of worries about what was going to happen and, you know, how we were going to provide the care, and obviously all those issues just disappeared in the end, because it was over so quickly. P15: B2 daughter, age 33, leukaemia, CA(B)

Some carers described adjusting to the situation, where thoughts of preparing for the future were not to the forefront. One woman was at work when her husband collapsed unexpectedly. Although she knew that the cancer was terminal, she describes being lulled into a sense that the end of life was not imminent:

Female carer: So I'm convinced B. thought for a long, long time he would still be soldiering on and maybe I did too. Probably because I saw him every day and some days were better than others and you just grew to accept that kind of life. You accept the restrictions, you accept you can't go here or do that or, and things aren't the same but perhaps you don't really notice just how far it's gone. B8 wife, age 60, prostate, CA(B)

Carers also had to consider the patients' preferences. In a few cases the carer wanted to support the patient at home, but the patient wanted to spare them some of the distress:

Female carer: Oh I desperately wanted to keep him at home. I wanted to keep him at home from the start, and he asked my youngest son when he came from America to ask me to let him to go into the hospice when he was near the end, because he wanted to be looked after where it wasn't distressing for his family. And I was upset about that, but I said I would go along with what he wanted. Then of course after he'd gone in for his assessment and medication he said, 'I've changed my mind I don't want to go back in.' And I'd said to him, 'I promise you, you won't.' K1 wife, age 63, colorectal, CA(B)

Female carer (daughter): I would like to think he could die at home if that's what he wants, and I would like to think I could help him do that if that is what he wants or to be here or wherever is right for him. [I nursed my mother through cancer at home] ... we'd done everything for her and we didn't need anybody else. I suppose because of that I want to do the same for dad but I know I've got to stand back and think, you know, is that right for dad? It might be what I want to do but it might not be what he wants or might not be appropriate. So I think we'll just have to wait and see. [It depends on] whether he'll ever talk about it or whether it will just be whatever happens, and how much you can plan and how much it's just the circumstances that you have at the time. So it depends whether he ends up in [hospital] with some overwhelming infection or... I don't know whether at that stage he would be able to be transferred to the hospice, we'd have to look into it. That would be an option, we'll just have to wait and see. B2 daughter, age 33, leukaemia, CA1

Carers were also aware that patients did not want to be a 'burden'

Female carer (daughter): But as to looking after – I don't know. I mean [dad] never wanted to be a burden. He always felt I should be with [my husband] if he was at home, and I should be with the children if the children were around, you know, he didn't want to bother me, and I think he wouldn't have wanted me feeling I had to do all the looking after him. B2 daughter, age 33, leukaemia, CA(B)

Male carer: M. wants to go in, she hates to be a burden, and M. wants to go into the hospice when the time comes, without any hesitation she will ask to go and I think she's already booked a place, as it were, she keeps telling me! Excuse my voice, it's a throat problem I have but it's nothing serious.<sup>16</sup>

Interviewer: And how do you feel about her, if she wanted to go into the hospice, do you want her to go in or -?

Carer: No problem at all, the hospice is a wonderful place, my sister-in-law went there and one of M.'s friends went in there and the change from the pain when they were outside to the peace and tranquillity when they were in there was overnight virtually and that's what I want for M. K5 Husband, Age 67, colorectal, CA1

A patient's 'independence' sometimes caused problems for carers, and several mishaps and falls were mentioned. Here is one vivid example:

Female carer: Nobody in the bed! So when I come in, he's sat in the chair - what a mess! He'd cut all his arm, he'd cut all his head and of course, the shock, he was crying. I said, 'Whatever happened?' 'Well I thought I'd try and get the milk in,' and he went dizzy. He said, 'I can't even fetch a bottle of milk now without making a mess of it', and then it all came together for him. I think it did - and I said, 'I'll ring the doctor.' He said, 'No, no, it's Saturday', and I said, 'No, I'd rather ring for somebody to come and see you if you've had a fall. Did you knock yourself out?' He said, 'No.' I said, 'Well, I'll still get somebody,' and it was Dr. [X] - he came out. Course they all knew his condition at the surgery so I had no problems him coming out and he looked at him and he said - trying to laugh it off - 'I don't know, you won't do as you're told, T., you won't do as M. tells you, will you?' 'Well, I was trying to help'. I think he was trying to think, 'Well, I'll beat this,' but to no avail - but you had to let him get on with that, if he thought that way, well, let him think that. But deep down, I knew, I knew. L15 sister, age 66, bladder, CA(B)

However, there were also cases where the patient became very dependent on the carer:

Female carer: There were times when I was totally exhausted and also because of the areas he had tumours I couldn't lift him and on two occasions he fell and I had a real struggle to do anything with him. And on the last weekend if my son hadn't been there... And he had a couple of 'accidents' which he was appalled about because even

though he couldn't communicate with us he realised something was going wrong and he couldn't get out to the loo. If M. hadn't been there I wouldn't have managed to have sorted him on my own. So although you're willing and although you want to do it somebody a bit older than me wouldn't have been able to do it. And I mean, I really feel awful because one particular night I'd done something to my back and I was trying to hurry him a bit to use the commode and, and each time I tried to lift him, poor chap, he sort of said, 'Oh leave me a bit, leave me a bit.' This was before the very end. And I was guilty of saying, 'Oh J. come on will you please, my back's really hurting, and I'm really tired.' And I thought I should never have made him feel guilty like that because he obviously was trying as hard as he could within his ability, his strength and yet I just at that point felt totally, absolutely zapped. Because you don't sleep, you know. You've one ear on their breathing, if they move you're awake, and it was what I badly wanted to do. And you see our bathroom was inadequate as well because it didn't have a shower and it was all a big tussle, and with the nurses in there with him there wasn't enough room. So, and he wouldn't even go to day care for a bath. He got so frightened of the hospice that - they persuaded me to take him to see [the consultant] and she said to him, 'You need to stay now for a couple of hours to let A. have a break.' And I didn't want her to say that because I didn't want him to feel that he was, the obligation was on him to stay when he was frightened of staying. And she said to me quite firmly, she said, 'You must go and do a bit of shopping and get a bit of a break and J.'ll be fine and he'll have a bit of lunch and he can have a massage and he'll be fine.' And it was like leaving a child at school, it was desperately miserable. He didn't move from where I left him. K1 wife, age 63, colorectal, CA(B)

## **Carers and other people**

Sometimes carers had to 'manage' other people in order to protect the patient:

Female carer: It was mainly his parents, they would phone during the day, and quite often he'd gone to bed for an hour for a rest, and I could tell they were getting agitated, because I'd say, 'He's asleep.' And sometimes I just think they just didn't believe me, and they'd phone up again a few hours later and if he was still asleep they'd phone up again. And I said, 'Look, I'm just not going to go up and wake him up, I'll tell him you've called when he wakes up and then he can give you a call right back.' So that caused quite a bit of tension for me. L2 wife, age 40, thyroid, CA(B)

Sometimes other people intervened to help the carer.

Female carer: Oh, he preferred to stay at home, I mean he did.

Interviewer: Yes, because when he fell, you didn't phone the ambulance straightaway.

Female carer: I said to him, let me phone for some help. 'No, no [he said]. So I stayed up all night with him. [...] He fell on the Saturday, he fell about midnight on Saturday, well, he lay there all day Sunday. I managed to move him so I could get to the bathroom, and I was up with him the rest of Saturday night, I was up with him all Sunday night. Then, as I say, this insurance agent came on the Monday.

Interviewer: So you felt you couldn't phone the ambulance because he didn't want you to, but it was fortunate someone else came along and sort of said, right, well, this is it, this is what we're doing.

Carer: I never said anything [to my husband] till after [the caller] had phoned – I said, 'Look, he's phoned.' I said, 'The ambulance is coming for you, I can't move you, you can't move yourself, so the ambulance is going to move you – oh, my.'

Interviewer: So he was quite with it when he was lying on the floor?

Carer: Yes, oh yes

L1 wife, age 77, oesophagus, CA(B)

Unwritten rules were referred to by some carers, in terms of how much, and what kind of, support they could ask of other people:

Female carer: I think the care overnight would be something that I would have been having to investigate further, like having nursing care overnight, or paid care overnight, if I did need to go away. You can't rely on friends all the time. It becomes a bit more than you can ask people. L10 wife, age 52, renal, CA(B)

Male carer: I'll pay for anything that's necessary, but I'm sure locally there's all sorts of people available, from what I know of what's been happening. People come in morning and evening and get her up, put her to bed, that sort of thing. I'm sure I can do that. I don't want my daughters to do that. One of my daughters who lives a long way away, she's a nurse, she would do it willingly but I don't think M. wants her to do it, so I will do it, or whoever's here. We've actually got a carer living next door as well but I wouldn't ask her to do it. K5, husband, Age 67, colorectal, CA1

In the following extract, a woman caring for her brother was able to ask her daughter to help out with personal hygiene:

Female carer: [my brother had an accident with his stoma] so anyway, that was all right and my daughter [who works at the hospital] came. I rang her and she came round and

she cleaned him up and got him settled. [...] And on the whole, he was quite a good patient, but I think what I'm trying to say - every situation is different, every family's different. And I think when you come to maybe the situation I was in, where it was the male, the brother, with no wife, I started to worry then what would happen to him. I can't do - if he won't accept the hospice, going in more often and he won't accept help - what am I going to do? That was my worry. L15 sister, age 66, bladder, CA(B)

However, in another case the carer notes that her husband would not have wanted his grown children helping with personal care, even though one of his daughters was a nurse:

Female carer: You didn't get 24 hour support and towards the end I needed it. You needed it, because of the lifting, I couldn't do the toileting and the lifting, you know. And if you've got someone who's very prudish and very private like J. was, he wasn't going to let his family do it, you know. He was, fortunately he was unaware that it was M. [his son] that was helping me towards the end, at least he may not have been but he'd gone passed the stage where he could object. But earlier on in those weeks he wouldn't have wanted his daughters or his sons to have done it. K1 wife, age 63, colorectal, CA(B)

Carers could be 'independent' too:

Female carer: [we've got good neighbours] and good friends as well.

Interviewer: So could you get out to get the shopping?

Carer: Yes, just rush really. I just went and got what I wanted and back again. I suppose yes. I mean A. and E. would have got the shopping, but I'm a highly independent person. I mean they did get some things for me that I just couldn't - he wasn't well enough to leave to so I couldn't get them, and things he fancied. If he mentioned anything I was there and got it. To try, you know, to see if he could eat that. But with the shopping I used to go, sort of get him washed and settled with the paper, and just dash off in the car and get what I needed and just come straight back again. But not out for any other reason no. L14 wife, age70, gastric, CA(B)

## **Support for carers after the death**

After bereavement, carers spoke of support from family, friends and neighbours:

Female carer: Some days I get very weepy, other days - well, all right.

Interviewer: But you've got those services and you've got your family presumably?

Carer: Oh yes, oh yes. Fortunately, eldest daughter lives just round the corner, I've got two sons on [road name], the other daughter's over on [road name] - I've got M. next door, she's a pensioner, but she'll ring me every other day to see if I'm all right. I have the warden, P., to talk to if I've got any problems. [...] I'm quite happy with all that, everybody's been ever so good and Mr. M. there he said, 'If I ever see your curtains still shut at 11.00, I'll come across.' So people get to know, don't they, with you being on your own. L15, sister, age 66, bladder, CA(B)

Female carer: But everybody's been marvellous. The phone's been red hot, - or it was then, and I had people calling. I had letters, cards - it was marvellous

Interviewer: So was that just from people around that you know since you've lived here?

Carer: All over the country, Scotland right down to southern England - yes - oh, they were marvellous. [...] There's two or three of his friends that still contact me, they still come to see me, and they're the ones that have bought his stuff. [NB She had financial problems after his death and sold the car and many of her late husband's possessions in order to pay the rent] L1 wife, age 77, oesophagus, CA(B)

Membership of a church was important to a few:

Female Carer: [The church is] where I swear I got the strength from and I get the strength each day, each day I get the strength to live through that day without him. It doesn't ease the pain really, I think that's going to take some time. But I've got this friend to do things that I have to do, I'm not sitting - sitting crying. I've cried a lot and still do, but I keep myself busy and I do things that I would do. I'm fanatical for cleaning. Mind, I haven't touched this place today because I've been out. I wanted to get some bits in for the garden because that takes up a lot of my time. L14 wife, age 70, gastric, CA(B)

Interviewer: How important has [being a Quaker] been, over and above the health services and your friends and family?

Female Carer: A lot of them [have been supportive]. Not all by any means. It is important. It's a very safe kind of space is a Quaker meeting when it's happening, and the actual worship is where I think I have let go most often of defences and allowed myself to grieve most obviously as it were. I don't cry easily, but I can in meetings sometimes. And the people are friendly and supportive, and they will go on being there. It's not something they'll offer for a few months and then they'll sort of forget. You know, I can say, 'Can I take up your offer of supper next term?' Because it's not kind of

short term. It's going to be there, kind of supporting underneath without being too noticeable. It's going to be there to be called on if I wanted it. So yes, I think it's important. There's a level of trust between people that allows you to say what is going on quite easily. You don't have to answer, 'Yes, I'm fine,' to every inquiry. You can actually say what it's really like. L10 wife, age 52 CA(B)

## Summary: key findings

This chapter has examined the social context of dying cancer patients. It has highlighted factors that shape the nature and type of informal care received by patients. This, in turn, tells us a great deal about what determines actual place of death as well as patient and carer perceptions concerning place of death options. Patients and carers are generally realistic about the potential capacity and limitations of the informal care resource in their particular social setting. This moulds their place of death preferences. It means that a sense of 'What will probably have to happen' generally replaces more abstract notions of 'what I'd like to happen in an ideal world'. Key social context factors that influence place of death preferences and outcomes are as follows:

- Patients' place of death preferences were formed with close reference to the network of social relationships in which they are embedded. Pre-illness social networks and relationships were taken account of by patients in their assessment of the how and where of end of life care. In fact the nature of the informal care resource available to patients was generally of primary significance in patients' assessment of how their support can be met.
- The majority of patients described very supportive informal social contexts. The care received often included both practical and emotional support, though individual carers in any network may not be able to provide both types of support.
- The key informal carers were family members, especially spouses, daughters and sons. Friends and neighbours also played a significant, if generally lesser, role in patients' support networks. As noted above, there was a strong sense that intimate care needs could only be met by particular carers, and that aspects of the illness management needed to be kept within family boundaries. However, those of 'second order' closeness could and did provide important practical and emotional support. Variations were reported in the nature and quality of neighbourly support both within and between urban and rural locations.
- The assistance offered by family and friends was usually taken up and much appreciated. At the same time, patients did not want to be a 'burden' – physical or emotional - on carers, and were especially mindful of the other imperatives in carers' lives - for example, the childcare and/or occupational demands on their adult children. Thus patients drew boundaries around what was 'acceptable dependency'. Also associated with the desire not to

be a burden was a wish to 'spare' loved ones excessive emotional distress. This could influence place of death preferences. In particular, some patients expressed the desire for a hospice death because this would decrease the burden on their intimates.

- Despite a willingness to accept offers of support, maintaining a significant measure of independence and self-care for as long as possible was thought to be important by most patients. In some cases, asking for help was seen as a last resort. Loss of independence was a matter of considerable regret for all, tied in as it was with a sense of loss of 'who I am', of one's identity.
- Patients sometimes expressed their concern for the long-term (that is, post-death) well-being of carers by wanting to protect them from any lasting emotional effects of 'finding me dead in their/my house'. This oriented a few patients towards a preference for a hospice death.
- Patients made an assessment of a carer's physical and emotional capacity to care. For example, a spousal carer may also have serious ill health and/or frailty, or, in a minority of cases, the quality of the relationship may not support a sense of 'being safe' or loved. This influenced patients' place of final care preferences. Further, an assessment of the roles that could be played by a carer were influenced by beliefs about what kind of caring it is 'proper' for a particular relative or friend to perform. Thus, social mores may rule out intimate caring by a male relative, by an offspring, or by a friend. This impacted upon place of death preferences, again directing patients towards professionally provided end of life care in an institutional setting.
- Carers' narrative accounts testified to the physical and emotional stress of caring.
- A number of carers were determined to care for their husband/wife/ parent/sibling at home but acknowledged their worried uncertainty about how they would cope with particular eventualities, especially with pain episodes and other distressing symptoms. There were uncertainties about what formal care support might be forthcoming in such circumstances. However, some carers also acknowledged the requirement to 'go along with' the patient's wishes about place of final care and death in situations where these wishes did not match their own.
- Patients who lived alone (n=19) tended to have given thought to their future care arrangements, though not in all cases. For most, there was a resignation that 'when things get bad' they would have to end their days in some form of residential care, with the hospice being the favoured option. Most did not see a home death as a possibility. However, in Chapter 4 we saw that, of those in this group who had died by the end of September 2002, 8 died in hospice, 3 died in hospital and 3 died at home.
- Our study has underlined the importance of different dimensions of the patient's social context. In assessing the patient's need for formal health and social services, health and social care professionals need to gain a fuller understanding of the contours and dynamics

of the social relationships involved in patient's social setting. The informal care resource has to be assessed so that it can be worked with, to the benefit of both patients and carers.

## Chapter 9

### Service matters

#### Introduction

This chapter examines the nature and quality of the relationship that patients and informal carers have with individual health and social care professionals and with services in general. We have found that a number of dimensions of the user-service link are important in shaping both preferences for and actual place of death. It is the perspective of patients and carers on these matters that is of relevance here; the data presented is from the interviews with these service users.

The dimensions of the user-service link that are examined are as follows:

- The knowledge that patients and carers have about services.
- Patient and carer service experiences.
- The type and quality of relationship that patients and carers have with individual health professionals.
- Patient and carer evaluations of how trustworthy, reliable and 'safe' services, service systems, and practitioners are.
- The perceived accessibility and availability of services

These dimensions are considered in relation to particular service domains in turn: hospices; community oriented services; hospitals; and nursing homes.

#### Hospices

Seventeen of our patient sample (41%) expressed a preference for final care and death to take place in a hospice – either as the sole preference (n=8) or as an equal preference with a home death (n=9) (see Chapter 4). However, both those living alone and those who lived with others wanted to stay at home for as long as possible and only enter a hospice at the very end. As discussed in the previous two chapters, this preference was often associated with, and tempered by, other concerns, for example concerns about symptoms or carer resources.

Female patient: I think when the time's right, that you can't be looked after anymore at home, I think it's a good thing, and I'd be willing to go in. B6 age 61, Breast, Lives with husband PT2

Female patient: My preference would be to be at home as long as I could, but after that, yes, the hospice I suppose would be my next preference. It's difficult to say when you've not experienced any of the other places. I've only experienced here and I know it's a lovely place. I'm very happy here. K8 age 44, Breast, Lives alone PT1  
[interviewed in the hospice]

Several specific factors were related to the hospice being the preferred place of death:

- Knowledge of a hospice (through their own illness, or through contact when someone they knew was dying).
- Experience of a hospice.
- Perceptions of what a hospice has to offer.
- A sense of safety (having access to medical help, and to emotional support for themselves and carers).
- Comparison with a hospital.

### **Knowledge of hospices**

Thirty patients in the sample (73%) had encountered one of the two hospices in the MB area during their illness, either as a day-care patient or an in-patient<sup>17</sup>. Thus most patients had personal knowledge of what the inside of a hospice was like. In the majority of cases this personal experience was positive, but it was common for patients to recount that their pre-conceptions of hospices were negative:

Male patient: Everybody's got the same thing with St. John's hospice, once in there's one way out. You walk in and you're wheeled out, but it's not the case.

Interviewer: Yes, but did you have those thoughts?

Patient: I had the same feelings, yes. L2 age 41, Thyroid, Lives with wife PT1

One patient had a strong negative reaction when it was suggested he see the palliative care consultant at the hospice:

Male patient: When they said, '[the consultant]'s at the hospice', it really threw me. As I say, I've got over it now, but for other people who are not as strong-willed as me, it might really upset them. [...] When he said it's in the hospice, I thought, 'My God! they're getting me in there very quick.' [...]

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<sup>17</sup> This high percentage reflects the fact that our sample was recruited with the assistance of specialist palliative care nurses. See chapter 3 for a discussion of sample bias.

Female carer: But it's a lovely place. Inside it's a lovely, lovely place. People have – you know, the very word, as B. said, the very word 'hospice'. But people go for respite, don't they? All sorts of things. Don't just go to die. And it's –.

Patient: Well, people don't know that till they've been a few times, do they? L14 age 72, Gastric, Lives with wife, age 70 PT1+CA1

Only in one case in our sample did contact with a hospice work in the opposite direction, wherein a benign pre-conception became negative reaction. This case involved a man who had been willing to try the hospice and felt it might be more dignified for him, and kinder to his carer, if he died there. However, a hospice admission changed his mind:

Female carer: [My husband]'s visit to the Hospice was really for palliative care to assess his drugs. And the building and the staff and everything were absolutely superb, but sadly the people like J., going in for respite or palliative care, are in with the people who are in being very, very terminally ill and about to die. So instead of it being a separate block where you're in one side having your palliative care and you're walking about and being upbeat and as you are at home-. Even with your single room you're made very aware of the last stages of the sort of illness that you've got, and J. came out quite depressed and down.

Male patient: The best description I can give you is that I found it a bruising experience, and that isn't to say I wouldn't go again, but I would be less keen to go than hitherto. K1 age 67, Colorectal, Lives with wife PT1

According to his wife, he had subsequently asked her to promise that he would not go there again, but a further admission due to a medication crisis occurred, which left him upset and 'hostile' (see also excerpts from this interview in the Chapters 7 and 8).

Seventeen of our sample attended hospice day-care at least once, and the majority, especially if they were of retirement age, enjoyed their visits. However, there were a few examples of people maintaining a resistance to hospice services after attending day-care. One woman, for example, places her situation firmly outside the need for such services, while indicating that another patient (whom we also interviewed) gained a lot from attending. Her image of the hospice as a 'good' place for some people to die, especially those living alone, remained unchanged:

Interviewer: You also mentioned that you tried the day-care, at the hospice?

Female patient: Yes, but that was it, I'm not going no more.

Interviewer: You didn't like it?

Patient: No, no way. I think that place, it always gives me the – I don't know, I think you're never going to come out. I don't know what it is, I think it's because I've lost two brother-in-laws in there, you see, and then J.[across the road] – I know he was 88, but he kept saying, 'Oh, I don't care, as long as I get better', but I knew he wasn't getting better, I could see it. And as I say, I was with him – he went [in to the hospice] on the Thursday and he died on the Saturday. [...] If you live on your own I think it's a good thing, it's a really good thing. Like J., I mean he's on his own all day, he's nobody in the house, and it's a good thing. He couldn't wait for Monday and Thursday [day-care visits], you know, because it was a break. L12 age 70, Colorectal, Lives with husband PT2

This respondent wanted to, and did, die at home. Another married woman echoed this assertion that day-care was good for people living alone:

Female patient: I think if somebody was alone, then I think probably they would be very glad of it. And if I was alone, I'm sure I would be very glad of it, but I've got J. and I'd far rather be with J. than go and sit in the day room in the hospice or wherever. L5 age 76, Bowel, Lives with husband PT1

There were indications that the hospice image was changing. Even those who had had no direct contact were often aware of the current wider role of hospices:

Interviewer: So you don't know much about hospices?

Female patient: No. I've no idea what – no – what it's like.

Interviewer: What do you imagine they're like?

Patient: Well, now I've seen that [hospital] Macmillan Unit, I imagine it's much the same, only that there are people that – most of them will be in bed, won't they, I suppose? But I've heard them say that's it's a very cheerful place. It's not – it isn't anymore – you know – enough to put anybody off. Yes. K10 age 77, Breast, Lives alone PT2

Only a very few people knew nothing about hospices when asked what they thought a hospice had to offer. Some had a resistance to finding out too much, due to the connotations of death:

Interviewer: How about hospice services? What do you know about those?

Male patient: We don't.

Female Carer: Not a lot. I think we're shutting our minds to that for the time being.

Interviewer: But for other people, what do you think hospices do?

Carer: They help.

Patient: Well, we haven't had experience.

Carer: They help you to die with dignity and without pain, but apart from that, I don't know. K11 age 79, Gastric, Lives with wife, age 76 PT1 + CA1

Some patients who had no prior knowledge of the hospice, and had some resistance to it, were encouraged to consider taking up its services by others. This man was encouraged by a hospital palliative care nurse to see the palliative consultant:

Male patient: She came to see us first and she told us about what they did at St. John's. She was the one who convinced me to see doctor, so if it hadn't been for her, no I wouldn't have probably come up here. L2 age 41, Thyroid, Lives with wife PT1

For some, only actual contact with the hospice would change their minds. Despite a knowledgeable niece, it was only the experience of the hospice that persuaded this woman that hospices were not places to fear:

Female patient: As I say, even though I've got a niece who's a Macmillan nurse, I still had it in my head that you go there and it's beginning of end. And once you've talked to them you realise that no, it's not. They are there to help you. They're not there just for your dying, they're there to help. Quite a lot of us that were down there – there must have been at least a dozen of us – we were all there for same thing, to have tablets and medication all changed. K6 age 75, Lung, Lives with son, age 38 PT2 + CA1

Another man was encouraged to attend by his son. When asked how he overcame his resistance to the hospice he said:

Male patient: Took a bit of notice of my son.

Interviewer: OK. How did he persuade you then, what did he say?

Patient: He used his power of persuasion.

Interviewer: Right, he just said 'you're going, dad', or something - ? (Laughter) Did he know what they do there, and explain it to you more?

Patient: Oh aye, yes, oh aye. Oh, he doesn't miss a thing, what goes on. L9 age 88, Lung, Lives alone PT2

A carer explained that in private her brother had not been at all keen on going to the hospice:

Female carer: I mean he was asked last Tuesday to go to the hospice, and he's sort of like a lamb to the slaughter when the doctor was here and, 'Yes, yes. I'll go for a couple of days.'

Interviewer: That would give you a break as well if he did that, yes?

Carer: But when he'd gone he cursed me to my husband fit to burst, 'She wants to f'ing get rid of me, she f'ing this and f'ing shot of me.' A different hat altogether when the medics have gone. L4 sister, age 58, pancreas, CA1

## Knowledge of the hospice through others

In addition to personal experience of hospice services, many patients and carers had known someone who had used them, and had thus had an earlier introduction (in person, or by reputation) to the hospice environment. Of the thirteen patients who had had a close relative die of cancer (see Table 23), six mentioned their relative's use of a hospice. The hospices were described as: peaceful, good at managing pain, recognising carers' needs, having good facilities, comfortable, offering a range of services and very caring. One carer said it was 'the most caring place' he knew [K5 husband, age 67, colorectal, CA1]. Here is just one example:

Male patient: [my wife] went in there for 10 days. [The doctor] said, 'Would you go to the hospice?'. You see, you get such bad instructions about the hospice, they say it's where you go to die and all that sort of thing, you know. But it's nothing like it at all. I thought, 'Well, it's just like a hotel,' and J. was as happy as she could be. They washed her hair, which I couldn't get to do, give her a nice couple of baths while she was in, which you will appreciate, because my bathroom was upstairs. I went in one day and she was fast asleep, so you can't be more content if you're asleep, can you? So I had a good impression of the hospice. L13 age 77, Lung, Lives alone PT1

**Table 23: Patients who had a close relative who had died of cancer: relationship of relative to patient**

<i>Relationship to patient</i>	<i>n</i>
Spouse	7
Sibling	3
Parent	2
Adult children	1
Total	13

In addition, some patients talked about the involvement of a friend or more distant relative with a hospice. Comments from these people were similar to those who had closer experience, with 'caring' as the feature most mentioned. Here is one example:

Female Carer: We've been to see friends two or three times, think it's great, think it's a wonderful place. They're so caring in that place, very, very caring. L8 age 79, Colorectal, Lives with wife, age 82 PT1+CA1

## **Personal experience of hospice services**

As noted above, almost three quarters (n=30) of our patient sample had some involvement with a hospice as either as an in-patient and/or a day-care attendee. The number of admissions per patient ranged from 1-12, with five of these patients only having one admission close to death. Seventeen had attended day-care at least once. Of the 11 (27%) who did not have involvement with a hospice at this level, one mentioned attending as a day patient once for a blood transfusion. Five of the 11 used CancerCare services (a support service closely linked with the two hospices), ranging from attending a drop-in centre to having complementary therapy sessions.

Personal experience of a hospice in-patient admission was often very reassuring and comments were made on how good the service was, often better than people's expectations:

Female patient: I went in a ward on my own. I did get moved later, because somebody very ill was coming in so they asked me if they could move me. You're well looked after, you're well taken care of, nothing is too much trouble for them. I mean they came down, it was late at night-

Male carer (son): I was going to say, it was a quarter to 9 at night when we'd finished work and got washed and presentable you know. We got down there and thought, 'Well, they won't let us in.'

Patient: And they did, didn't they?

Carer: And that was quarter to 9 at night and they left us there till 10 o'clock did the nurses, and one of the nurses said, 'Oh, the door will be locked when you go out, unlock it and make sure it's locked when you go out'. They were really nice with us you know.

[...]

Female patient: No, I'm not afraid, no.

Interviewer: And if it did come to it at some point?

Patient: If it came to that, I would go.

Interviewer: You would go there?

Patient: Yes definitely I would. I was amazed just how good they were. He was more amazed than me. K6 age 75, Lung, Lives with son, age 38 PT2+CA1

Experience of day-care was frequently described as reassuring:

Female patient: I know I might be in bed a while, because if it did get to the stage where J. [my husband] couldn't look after me, I wouldn't mind going in the hospice at all, now I've seen how good they are and how capable they are. And they look after you so well. I wouldn't mind going in there. B10 age 63, Unknown tumour type, Lives with husband PT1

Interviewer: Yes, right – so what do you think the Hospice has to offer someone in your situation?

Female patient: Oh everything

Interviewer: Everything?

Patient: Everything – the care and everything – you've only to look at their faces and you know they're not just doing it for any reason only because they love doing it – their faces show that. I mean, well, you feel wanted.

L17 age 81, Stomach, Lives alone PT2

However, as noted in the previous section, day-care was not everybody's preference. In the following case a man in his 50s noted that he was not yet ready for day-care:

Male patient: They asked me if I wanted to come in for a couple of days as a day patient, not to stop, you know. And I just said well at the moment I don't fancy sitting here all day with old women, because you can't take anyone with you. I mean it wouldn't have been so bad if I could have taken my daughter with me. You see my daughter comes up Tuesday to Saturday and I can't very well go to the hospice for a couple of days and leave her stuck by herself, because she's trailed up from London. It's not very fair really I don't think. So when I feel I need it I'll go. I've no problem with it you know. I mean I do these crosswords and they're very hard, but I'll sit here today until I've done that, it keeps my brain active. I do a lot of quizzes and books and stuff like that to keep myself busy. [...]

Interviewer: So for someone like you there's nothing that you particularly want out of that sort of situation?

Patient: Not at the moment, no.

Interviewer: When you say not at the moment, do you think that there might be something in the future that they might offer you that-?

Patient: Well, if I get that weak or whatever, or I need to give my sister a break or something like that. L4 age 57, Pancreas, Lives alone PT2

As noted earlier, the association of the hospice with death was off-putting to some people, but one man found that seeing people die in the hospice held some reassurance in terms of his own anticipated care.

Male patient: There's three people died since Friday and I know them all. We've all been in this same room, all talking, and in fact one of them was related to me, that was yesterday, so er- .

Interviewer: That kind of makes it hard being in here?

Patient: Yes, sometimes it makes it hard. Sometimes it makes it easy, because at least you get to talk to them, you know, and you do understand what they're going through. The worrying thing obviously is, when your turn comes, is there going to be somebody there for you, you know. L2 age 41, Thyroid, Lives with wife PT1

### **'The hospice looks after you'**

Many positive comments were made about the hospice services. Our interviewees, both patients and carers, felt they were well cared for by staff in, and associated with, the hospices. The physical surroundings were praised along with the food (especially at day-care) and equipment. It was the 'atmosphere' of and inside the buildings, together with the attitude of staff in both hospices that were highly appreciated. In addition, there was a theme of 'safety', which came through in talk about hospices. Safety, or 'feeling safe' was a particularly important factor with regard to place of death preference.

Hospices were frequently noted as having the following valued attributes:

- One was given time and treated with respect.
- One encountered a caring attitude
- The ambience was pleasant.
- It engendered a feeling of 'being safe'.

### **Time and respect**

Patients and carers frequently reported that the hospice had more time for patients than other services, and that people were treated with greater respect. People felt they were not just a 'number', and that the service was more 'civilised'. Questions were answered more thoroughly.

Male carer (son): I was quite impressed, but rest of doctors and nurses that come they aren't worth a shite if you want my-

Female patient: He hasn't a lot of time for them.

Interviewer: So you really only think the people at the hospice are very good.

Carer: Yes I do, they're the only people who have got time. K6 age 75, Lung, Lives with son, age 38 PT2+CA1

Male patient: There's a sensitive side to cancer. I think the GPs and some of the nurses don't actually- . It's not actually till you get into places like Cancer Care, and St. John's [hospice] and Christies [specialist hospital] that you see that people do understand why it's a specialised thing. L2 age 41, Thyroid, Lives with wife PT1 [interviewed in the hospice]

Female Carer: They will actually hold the patient's hand - .

Male Patient: Yes.

Carer: And sit close to them and talk to them with nobody else around.

Patient: Yes.

Carer: Whereas in hospital, the consultant sweeps in, surrounded by a gaggle of – you know. K2 age 64, Prostate, Lives with wife PT1

## **Caring attitude**

As the previous extracts suggest, a generally 'caring' attitude went along with time and respect. This was often described in detail by those who had experienced it, for example:

Female patient: I didn't feel uncomfortable [in the hospice], I didn't feel pressured, I didn't feel they were sort of in on my face all the time. If I was on my own, they would come in and chat and it was a general chat to find out how I was and what was going on. And sometimes you would hear the feedback of that maybe the next day via another nurse, where they obviously networked in their meetings. And maybe they were a bit concerned about something I'd said or whatever, and that would be relayed back to me via another nurse so you knew it was being talked about. I just found it very, very pleasant, and I was very pleasantly surprised at how, how, caring and relaxing it was to be in there, and really just to get me sorted until I could cope with the pain side of it. L3 age 43, Breast, Lives with husband and son PT1

## **The ambience**

The whole atmosphere of the hospices was also found to be comforting by many. Peacefulness and cheerfulness were frequently mentioned as part of this ambience:

Female patient: There are people around all the time. And, there again, you're not allowed to suffer, from what I could see there. And they talk to you. It was just – and there was a certain amount of peace. I mean children would come in and they'd be quite happy. There were toys for them to play with. Yes, it was a wonderful place. I would feel that if the time ever came I would choose to go there. But I understand from [the Macmillan nurse] that I could have a week in the hospice – R&R, isn't it – rest and relaxation - tender loving care you might say, for a week. And I think that time may come sometime. But not at the moment, because as I keep saying, there are people far worse than I. K9 age 84, Lung, Lives alone PT2

## **Safety**

The hospice was frequently constituted as offering a place of safety, where symptoms could be controlled, pain avoided and carers supported. Relief from pain was a major component of this perception:

Male patient: I've got no pain, and pain doesn't bother me, doesn't bother me in the least does pain, but I'd hate to be doubled up like this all the time. You want to die with a bit of dignity, and if I've got to go into the hospice I'll go into the hospice. That doesn't hold a problem for me. L4 age 57, Pancreas, Lives alone PT2

In addition speed of access to help and relief was viewed as an advantage of the hospice:

Female patient: Just from the practical viewpoint really, and feeling secure in there's somebody there all the time, whereas I think if you're very ill and on your own it can be quite frightening. B1 age 50, Lung, Lives alone PT2

Male patient: Well, you can't do it alone. I've tried and I know I got myself in such a mess [with my medication] and knocked myself out for two days. [...] So in that respect you've got to be careful in what you do. See, you could make a mistake like that, because I don't really want to go any quicker than what I have to. L2 age 41, Thyroid, Lives with wife PT1

Even where the preference was strongly for death to occur at home, the patient and carer felt some security in the knowledge that they could contact the hospice for advice:

Male patient: [the hospice consultant] has said, 'Anytime you feel something is wrong, give us a ring and just come down and see us'. So it's all right, the backup on that. [...]

Female carer: Well it offers you, again, a lifeline. They're only at the end of a phone. We know that we can ring at any time with a problem. And I feel that we could ring up and something would be done to help us. We feel confident with them. L14 age 72, Gastric, Lives with wife PT1 +CA2

The desire to protect carers from the 'worst bits' (see Chapter 7 on Body Matters chapter) was seen as supported by the hospice.

Female patient: That's my personal feeling, that I think the family suffer more than the one with the illness and I think it's up to us to make sure that they don't suffer as much, they're going to have to live with this aren't they? And I think it's better for them if I'm, or any patient, is in a hospice being taken care of. Because I think they would see me as being better there than they would if I was upstairs in the bedroom waiting for a doctor to come and change the medicine. I'd rather be on the spot, and I think it would be easier for all of us. I really do. K5 age 67, Colorectal, Lives with husband PT1

Carers were also perceived by patients to benefit from respite care:

Female patient: Because she [daughter] works so hard, and she's so tired, you know, so I went in for a fortnight just to give both of us a break. [...] although she came to see me every day, twice a day some days, it would be a break for her. She could settle without thinking to herself, 'I wonder if my mum's all right.' She'd know that I was, I'd been cared for there, so she could go to bed and think, 'Oh well, I can sleep, because I know my mum's going to be all right.' L6 age 72, Oesophagus, Lives alone PT1

Although the hospices offered places of safety, for some it was only 'home' that could offer such a sanctuary.

## **Reciprocating**

The theme of reciprocity was discussed in the previous chapter in connection with patient-informal carer relationships. Even in the situation of terminal illness, patients often felt that they wanted to give something back to those family members who were caring for them. This desire to reciprocate extended to formal carers in hospice settings. The literature on chronic illness suggests that part of the 'work' of sufferers is to contend with 'formal and informal disenfranchisements' in their illness experience (Conrad, 1990: 1260). Positions of dependency threaten identity as a socially competent adult. Lawton (2000) highlighted the importance of emotional reciprocation by patients in hospice settings, arguing that this is one way in which patients are able to mediate and negotiate "the potentially unequal relationships between 'carers' and 'cared for'" (p. 64). Our data support this line of reasoning. Patients in our sample described

behaviours that fended off ‘social death’, with reciprocation being one of them. This was tied to the patient’s sense of identity and personal history, as the following extract suggests:

Interviewer: Would you go [to day-care] more often if you could?

Female patient: Oh rather – but if I did that I would want to pay, because I don’t think it’s fair. I mean the state the Health Service is in, I don’t think it’s fair to take all that and not give anything back, because that’s me, because I’ve been brought up that way.  
B3 age 79, Breast, Lives alone PT2

Patients and carers frequently expressed gratitude for the extremely ‘caring’ nature of hospice services. Some described actions which provided tangible expressions of thanks, such as taking a box of chocolates to staff, or in this case, arranging a concert:

Female patient: And it’s surprising, you can ease yourself if you try to help somebody. So as I say, I was sat there and I thought, I know what I can do. I can get the concert group together, we can give them a concert [at the hospice]. So I got on the phone to D. [...] I said, ‘Just to give a concert.’ And I explained I’d like to do something for them. I said, ‘I think it would give them a break.’ So she said, ‘Yes. I’ll get in touch with M. and I’ll get in touch with so and so.’ And I said, ‘Well, I’ll get in touch with S. and J.,’ that’s the pianist and her husband, and he’s got a lovely voice. And when we’d finished I’d got ten of them. L17 age 81, Stomach, Lives alone PT1

### **Bereaved carers**

Both hospices offered some support for carers known to them after the death of the patient. Several bereaved carers described how hospice staff had got in touch with them and offered them the chance to talk, or more formal counselling. This was generally appreciated, although not all bereaved carers had taken up the offer.

Female Carer: I’ve had a letter from her and I rang the hospice and she wasn’t there at the time, but I said I was all right at the moment, but sometimes it can hit you, as they said, months after. I’ve had a letter from the hospice only last week actually, to go to the United Reformed Church on a Tuesday between 10.00 and 12.00, they have this bereavement - and meet other people that-. I haven’t taken that offer up yet either. Very supportive, very, very supportive, couldn’t fault them at all.

Interviewer: Right, right, so you think you might take up those kind of services, if you felt you needed it, or you think you will anyway?

Carer: I think I will. L15 sister, age 66, bladder, CA(B)

Timing seemed to be an important factor in several of these interviews. The offer of help was appreciated, but the decision to attend was related to other factors at particular points in the bereavement. For example, one woman felt the need for help more acutely when her father died three months after her husband's death.

Female carer: I've only been the once. I feel probably I ought to go again or a bit more because of losing my dad, it's funny isn't it. I thought I was coping until, until my dad died. K1 wife, age 63, colorectal, CA(B)

For one woman whose daughter had died a few months before her husband died of cancer, the need for help was already acute, and offers were snapped up instantly:

Female Carer: I didn't have anything for when my daughter died.

Interviewer: Right – so no-one offered you any support after she died?

Carer: I was too angry, I couldn't.

Interviewer: But after he died you felt you could?

Carer: Well, after G. had died, I knew I wouldn't get through anything without everything that everybody was going to offer me, which I took.

Interviewer: Right. OK, so what things have you been offered?

Carer: Aromatherapy, which I took. Hypnotherapy, which I took. Bereavement counselling, which I took. [...] and I ended up seeing a psychiatrist.

Interviewer: So, do you think those things have helped you at all?

Carer: Oh, they must have done, because I'm a lot saner. I'm not as distressed as I was. I was just utterly and totally distressed, I couldn't concentrate and I just couldn't focus on anything – and I just found it very difficult, but I'm – I'm a lot more saner, I would say. L2 wife, age 40, thyroid, CA(B)

Another carer suffered from ME, which made it very hard for her to attend a bereavement group, even though she felt the need:

Female carer: Tuesday and Wednesday I didn't go to either one. I did ring them up and explain but I felt too bad to go, not only because – and they're the times I need to be massaged really I suppose when the pain's so bad - but I felt this black cloud had come right down over me and I couldn't go out. I didn't want to see anybody and I couldn't go. L14 wife, age 70, gastric, CA(B)

Another bereaved carer, whose husband had not been involved with the hospice, nevertheless had been in contact with the CancerCare services during his illness and was carrying on with this. She also described how she might seek help from her GP:

Female carer: I'm not aware, or I don't think, I'm going into a depression or anything. But that too could be coped with with help from the health services. A couple of years ago I was [suffering from stress]. Because I think obviously it's stressful now dealing with all the extras that come after a death – the paperwork and the money arrangements and all that kind of thing. But it was stressful before in a totally different way, watching someone getting so ill, and being kind of on duty all the time, in a way. Being a carer is kind of stressful because it's so continuous. [...] If I needed anything it would probably be a bit of help sleeping myself, because I'm finding it quite stressful, so I'm waking up very early and not getting to sleep early, but that's my own fault for reading too late. I'm having short nights and eventually it becomes cumulative and you feel you're not coping. So I'm managing it myself but that would be the sort of thing I would probably go and ask for.

Interviewer: Who would you ask for that kind of help?

Carer: Well I'd go to the GP and ask for some mild sleeping tablets or something like that. A friend has already given me some homeopathic sleeping remedies, so there's always that sitting there that I haven't actually used. So there are routes I could follow. [...] And I think that's up to me really. L10 wife, age 52, renal, CA(B)

The fact that death was located away from home was described as helpful by one carer. One patient spoke of her husband's death in the Lancaster hospice several years earlier, and how this had given her a lead in to her widowhood, as she was more used to him not being at home.

Female patient: He died there, which made it – I don't know if it's right to say – easier. Because he hadn't been at home, and I was so used to him not being here that when he actually died it was easier to cope.

K9 age 84, Lung, Lives alone PT2

### **Comparing hospices with hospitals**

In many of the interviews, talk about hospices involved comparing them with hospital services. Several of the extracts already presented have demonstrated this. In all instances, hospices were felt to be superior, providing more sensitive and individualised care. In two cases where the patients concerned had died in hospital, the female carers felt that the hospice would have been

a better place for their relatives to die. One felt it would have offered a more peaceful end for her husband, whose symptoms were difficult to control in the hospital.

Interviewer: So, you would have been happy if he'd managed to go to the hospice say?

Female carer: Probably, I feel, I might be totally wrong, but I feel he would have been more, more – what's the right word – I don't mean peaceful, that sounds though he's already died – but I think their pain control would have been better. Plus the fact that the hospice, it's almost one-to-one care. And I'm quite sure they wouldn't have let me fight to keep him in the bed, I'm sure they wouldn't. B8 wife, age 60, prostate, CA(B)

The other carer recounted how time had been wasted - the last few precious moments with her father, by the hospital routine:

Female carer: We got up to the ward and the registrar presumably, or the SHO, whoever it was, had come along and wanted to clerk him in. So when I got back from phone calls she was busy trying to ask my little brother all these questions about Dad's history, which my little brother couldn't answer, so you know, 'Well M. [my sister] can answer those'. So I said, 'Well you should get all this from his notes'. 'Well we can't find his notes because they must be locked away in the consultant's office and it's the Bank Holiday', and all the rest of it, 'Can you give me his history?' 'Well how long?' 'Well, we want, you know, the full history of the illness'. And looking back, that was just such a waste of time -. And it wouldn't have happened at a hospice, and it wouldn't have happened anywhere else. And working in the profession I know well that presumably what she wanted was all this written down so that on the ward round the next morning she could stand there and say, you know: 'This is G.D., age 65 and he's had leukaemia for the last 12 years, he's had these problems.' I mean you know what it's like, but it didn't help at that particular time because I felt cross, because I just thought, 'This isn't relevant, he's dying. It doesn't really matter about all his history and what medication he's on, and when he's been in hospital, and what for.' I spent so long doing that with her by the time I'd gone back to see Dad, I was only outside the curtains, but when I went back in they'd given him his diamorphine and he was unconscious. Even that, that precious time with him, the last few moments of him being conscious. But that's hospitals (amusement) – and as I say, it wouldn't have happened in a hospice, they'd have done things a lot better, wouldn't they? B2 daughter, age 33, leukaemia, CA(B)

One bereaved carer and her husband had lost a daughter in her twenties through cystic fibrosis, about a year before the husband died. He had died in the hospice and the daughter in a

Manchester hospital. The carer described the huge difference she perceived between the two deaths:

### **Daughter's death in a hospital (Manchester)**

Interviewer: So you've had these two huge shocks, but the hospice picked up on your distress and offered you some help. But [Manchester] did they offer you support, but you were just too angry at that time to take it?

Female Carer: No, no – they didn't offer me anything. I was furious with them, because I found out they lied to us. Yes – we'd taken A. [our daughter] through to [Manchester] on the early hours of Monday morning, which was Sunday night, and I had to go to work Monday morning, so we took her through and we checked her in and we left her, and we were in touch all week by telephone, and on Wednesday [my husband] phoned her up and the nurse said, 'Oh, she can't come to the phone, she's on her oxygen.' And then what actually happened – she died during the night, sometime after half-past nine, they phoned us up after midnight. They were that concerned about her during that night they phoned a doctor at home for advice on what to do. I think that was sometime around half-nine, and they'd found that she'd died, I think, about eleven-forty that night. It was a bank nurse who had gone in to check on her and they found that she'd died, and they phoned us up, ten-past-midnight, that night, and led us to believe she was still alive, and the state that G. [my husband] was in, they knew how poorly he was.

### **Husband's death in the hospice**

Female carer: When he actually did take a turn for the worse, and he had to be sedated, it was just so sudden, because we weren't expecting that. I didn't even think to give the hospice my phone number for work. I wasn't even worried enough to think to give them my number, because on the Sunday before he'd been home and he'd been chopping me some kindling wood for the fire. [He went into the hospice for pain relief]. So I'd got up as normal and gone to work, and then he'd got up in the morning, according to the hospice, and he was chatting, then all of a sudden it just seized up and he panicked and they had to sedate him. And I think that was just after nine o'clock, and they managed to get hold of me at work, and I went through straight away, so it was – you know, quite a shock. [...] And that afternoon, after he'd been sedated, and I'd come to terms with it in my head, that's when I realised things had taken a turn for the worse and they weren't going to get better. So I asked my father-in-law to come home with me to round up all the cats, and I took them to the cattery, so I could just stay with G., and I didn't have to come home and feed the cats or mess with the cats. I could just stay with him constantly then, which I did. [...] He was a big lad and I loved him very much and there's no way I wanted him lingering. So I just kept asking for more and more drugs. So he ended up

being connected to three syringe drivers, and he had quite a lot of extra injections, and he would have wanted that, and that's what I asked for, and I'm very pleased I got it. L2 wife, age 40, thyroid, CA(B)

### **Problems with hospices**

As we have seen, the hospice services were highly praised by the users in our sample.

Complaints were few and far between, and none were of a very serious nature. One woman felt somewhat abandoned by the hospice once she had gone home, but this was perhaps as much to do with the community services not recognising her vulnerability as it was a fault with the hospice:

Female patient: I suppose my biggest concern has been when I've gone home. Mostly I've gone home from the hospice and I've felt suddenly there's not much support. Once or twice I've almost deteriorated when I've gone home and I've phoned the hospice, and it's almost as if, well, you've left us now, and the community has to care for you, but I didn't feel as if the community were really picking up. As I say, [the Macmillan nurse]'s been very good and the district nurses have been very good, but the GP wasn't really picking things up, he didn't come to see me at all. [...] both times when I've rung the hospice and the hospital, sort of half hoping that they would readmit me. They've said, no, we can't, we've not got a bed or we can't do that. So, I've felt this sort of cut off, 'No, you've gone home, you're on your own now.' K8 age 44, Breast, Lives alone PT1

### **Distance**

Travelling what were sometimes quite lengthy distances to hospices was rarely mentioned as a problem. One patient in Kendal had thought that if she went to the hospice she would save her son distress, but then worried that it would be too far for him to come and visit her:

Interviewer: So, you feel that [the hospice] sounds better than the hospital if you were really poorly?

Female patient: Yes, but I'm beginning to have doubts now. I thought well if I do get bad, it's well out of town, and [my son] wants to come and see me, you know. I never thought of that you know. K7 age 72, Lung, Lives with son PT2

Two patients who lived in Windermere (almost equidistant to both hospices) mentioned distance and how it would be good to have a hospice closer to home. One had a dream of

building a hospice in Windermere if she won the lottery, and the other noted that quite a few people from the Lakes used the Lancaster hospice, despite the distance.

Patient: I haven't won the blessed lottery, but that's what I would do if I won it. That's exactly what I would do because it's perfect, that house. And it would be so much nearer for everyone. You see there's one at Ulverston isn't there and there's one at Lancaster, which takes in Langdale, Grasmere, Ambleside and it's such a long way to visit. And I think perhaps if you're in a hospital visitors are very important. They're your contact with the outside world, aren't they? I don't know, I haven't been a patient in a hospice, only a visitor but I know it is a long way to go. K5 age 67, Colorectal, Lives with husband PT1

Female carer: It wasn't just us. I mean if it had just been a complete one-off, just us from Windermere, but there were quite a few people in the hospice from this area, and most of them finding it quite trying, especially in the winter.

Male Patient: They provide a wonderful service, don't they?

Carer: Oh, they're very good. The staff are very, very - .

Patient: And people – and people want to use them.

Carer: But it's only a pity – you see, there is another one in Ulverston, but there's only eight beds. And it's a good distance as well. K2 age 64, Prostate, Lives with wife PT1+CA1

## **Hospice capacity**

Patients were often warned that hospice beds were not always available at the time they might need one, and they understood that this might not allow the fulfilment of a preference for a hospice death.

Female patient: In terms of the hospice, I don't know how often places are available.

Interviewer: Have you talked to anyone about this?

Patient: I've talked to [the Macmillan nurse] about it, yes. I think that she said that it can be a problem. I don't know. B1 age 50, Lung, Lives alone PT2

Female patient: Right away I told them to book a bed. I think they'll put me in the garden shed if necessary! (laughs) If they want to!

Interviewer: They've virtually promised you -?

Patient: Virtually – you can come and interview me if they let me down, I'll jump up and down. (laughs) K5 age 67, Colorectal, Lives with husband PT2

Female carer: When they explained to me at the hospice that there is a waiting list for beds, I thought, 'Yes, well, I can quite imagine.' They just can't willy nilly nip out, plus T. [my brother] wouldn't admit to how ill he was. L15 sister, age 66, bladder, CA(B)

Many in our sample also realised that a hospice was not a long term solution to care needs.

Male patient: But a hospice, they don't like you long-term, do they? I mean a hospice wouldn't take me. If they had a definite – if the doctor was to say, 'Well he's only got a couple of weeks left' - yes, they may. But if they said, 'He could live up to two years', they're not going to look after me for two years, because a hospice is not designed for that. B7 age 57, Lung, Lives with partner PT2

Nevertheless, patients were very happy with hospice services. Several pointed out how lucky they felt that to be able to receive the services:

Female patient: That's me main focus point. Yes. I'd been very lucky, you see, to get the hospice service.

Interviewer: Yes. What makes you say that you're lucky?

Patient: Well, they can't take everybody, can they? B12 age 82, Bowel, Lives alone PT2

## Community oriented services

We turn now to patient and carer experiences of services delivered at home or in the community. Death at home is considered the 'gold standard' among many palliative care practitioners (Stajduhar & Davies 1998). However, home is often viewed as a homogeneous and unproblematic location. In the palliative care literature, home care is configured as cost-effective and more inclusive of patients and their family, and seen to contribute to the overall quality of people's lives. In support of the latter point death at home is seen as facilitating a sense of normality, security and personal control (Stajduhar & Davies 1998). Yet home can be a place of struggle and physical, emotional and organisational labour (Williams 2002). Several studies have suggested that families caring for dying people at home frequently experience increased stress and pressure, even where there is support from community services (Cartwright & Seale 1990; Stajduhar & Davies 1998, Leich 2000). Home may be a site of shared symbolic meaning, but that meaning may not always conform to the idealised home which will succour quality of life. Williams (2002) suggests that home care may impact on perceptions of the meaning of 'home' and this was the case for some of our respondents.

## Trust

A key theme to emerge in the data analysis was that of trust - patient and carer trust in services and in individuals delivering those services. Closely related themes are the degree to which services and practitioners engendered a sense of reliability and safety - that care would be 'sorted out' when the situation warranted it. These themes impacted upon place of death preferences and actual place of death outcomes. Like other studies (Seale, 1989), our research suggests that the quality and nature of interpersonal relationships in the patient-service link are critical influences on the delivery of care to dying people, whatever the health care setting.

It should be clear from the preceding section that virtually all patients and carers who had knowledge of the hospice services were very trusting of them, even where they preferred death in another location. This theme was also apparent in talk about other services, but trust was not so straightforwardly secured. Various health professionals were cited as occupying the role of trusted advisor, but most frequently it was the GP or the Specialist Palliative Care Nurse (SPCN) nurse:

Female patient: We've got a very good, a very good doctor.

Interviewer: Right, yes, he'd sort it out for you?

Patient: Yes, I think so, because he always says to me. 'If you want me, don't wait, just ring up, and if [the receptionist] says 'next week', say 'no, today.'" And he'll sit you down and talk to you, and you can be going out the door, and he'll say, 'I haven't finished with you yet, sit down.' He doesn't rush you, and he talks to you and you can ask him anything and he'll explain it, and he's very, very good that way, and I've a lot of faith in him – yes. B6, age 61, Breast, Lives with husband PT2

Female patient: I've got implicit faith in [the SPCN]. K9 age 84, Lung, Lives alone PT2

Here is an example of a younger woman who lived alone and who had clearly been worrying about managing, but had had her concerns allayed by discussions with health professionals:

Female patient: I know the hospice don't like to have you for a long period of stay, so I wondered if there was an in-between situation which I needed to be thinking about. And I contacted one nursing home, only to find that they only take people that are over 65. So I talked to [the Macmillan nurse] again about that and said that it was concerning me, and she mentioned one or two places that take people under 65, [...] and she also mentioned something called Country Cousins, where people actually come and live in at your home for a fortnight at a time, come and join you basically. So that gave me some reassurance, but she further said that what would happen would be that I would

come into the hospice as a first line of care, and if it was proving to be a longer stay than the hospice could manage, [the hospice social worker] and others here would talk with me about where I could move to. So that reassured me that I didn't need to worry about it immediately. K8 age 44, Breast, Lives alone PT1

While for some the trust in professionals allayed their worries and meant they could get on with their lives while they could, other people were more insecure about how they would manage the future. Uncertainty and lack of knowledge concerning the kind of services they could receive was a factor for some people.

Interviewer: What about the community services, like the GP and the district nursing, the Macmillan nurses?

Female patient: Well, my GP's good, but I don't know about anything else. I'm just hoping when the time comes that they'll offer things that I don't know about, you know? B6 age 61, Breast, Lives with husband PT2

Where there was a loss of trust, however, it could be very difficult for patients and carers. One male patient had trusted his GP, but there had been a problem with medication that had meant an unwanted admission to the hospice and a sense of broken promises, which was difficult for both the patient and his wife:

Female carer: I'd said to him, 'I promise you, you won't [go into the hospice].' And the GP had said the same, you know, that we can manage you. And that was something that I was very glad about, but of course he was quite upset with me over ending up in there, thought I'd let him down. And he wasn't very happy with the GP because he had a bit of an idea that it was him that gave him the medication (laughter). He was never as friendly again which was a shame because the GP had been really, really caring with him, really caring, he'd got very fond of him. He said he'd learnt a lot about the way people can handle terminal illness from him. K1 wife, age 63, colorectal, CA(B)

### **Specialist Palliative Care Nurses (Macmillan<sup>18</sup> Nurses)**

The SPCNs were central to many of our respondents' negotiations with services. As discussed in Chapter 4, our sample was mainly obtained through the assistance of four of these specialist nurses with community remits. The community-based SPCNs in the MB area had different

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<sup>18</sup> We frequently use the term 'Macmillan nurses' for Specialist Palliative Care nurses in this chapter, as it is the term most commonly used by patients and carers.

bases across the district, some in the hospices, some in district nurses' offices, and some in community offices.

In our sample, only two patients had had no contact at all with a SPCN, but degrees of involvement varied among the rest. Some patients mentioned seeing a 'Macmillan' nurse frequently, and others only once or twice. Some mentioned regular home visits, occasionally weekly, sometimes fortnightly, but intermittent visits and phone calls tended to be the norm while the patient had no particular problems. Carers also used the service.

In this section we focus on respondents' experience, knowledge and understanding of the SPCN service. Patients described what they perceived the 'Macmillan nurse' to be available for, outlining the kind of help provided. Patients and carers commented on the nurses' support, attitude and expertise, which were almost universally praised. Their accessibility was discussed, and their place in the scheme of things was considered, especially where they appeared to offer connections between services. Several patients considered the Macmillan nurses to be the mainstay of their care. This woman described how they are accessible and skilled at relieving burdens:

Female patient: I think the most important are the Macmillan nurses. To me they are the basis of everything. They're there when you want them. They know exactly what to do to help you. You don't even have to worry - like you make an appointment with the doctor and go and sit in the waiting room - you know. And that's what you want, less hassle now, at least that's how I feel. I just don't want to be hassled with anything. Not that I'm depressed or anything, don't get the wrong impression, it's just, I ring the Macmillan nurse and she just takes everything off you. K5 age 67, Colorectal, Lives with husband, age 67.

The Macmillan nurses were described in their many roles, and provided respondents with a sense of security, and with support which made things easier, potentially extending patients' and carers' ability to manage at home for greater lengths of time or even up until death. The following sections give examples of participants' descriptions of the help they received from these nurses.

### **SPCNs: an information and emotional resource**

Female patient: I can talk to the Macmillan nurses, and the nurses at the hospice, they'll sit and talk to you and that, I can get support from them. Yes, they're very helpful. B12 age 82, Bowel, Lives alone PT1

Male patient: If I had a problem with my dressing, I'd get my normal district nurse. If I had a psychological problem, I'll turn to the Macmillan nurse first. B8 age 63, Prostate, Lives with wife PT1

Female patient: I phoned my Macmillan nurse because I feel they know more about cancer, you know. General practitioner's got to have his finger in every pie haven't they? No, we rang the Macmillan and she sent me straight to [the oncology consultant]. K5 age 67, Colorectal, Lives with husband, age 67.

### **SPCNs: Organisational resource**

Female patient: And the Macmillan nurse in the Infirmary is very good at organising things. She was very willing to talk to my family about my condition and they wanted to talk to her to see how they could help. And it is very good, yes. K12 age 65, Ovarian, Lives with husband PT1

Male patient: It was [the] Macmillan nurse got everything organised. When she said to me, 'How are you managing?' I said, 'It's a bit awkward in the bathroom'. I couldn't quite get over the bath into the water, I couldn't stand long enough to have a shower, so the best bet was to put a seat over the edge of the bath and then sit under the shower. B7 age 57, Lung, Lives with partner PT1

### **SPCNs: Practical and financial resource**

Female carer: The Macmillan nurse also encouraged us and helped to put in an application for Disabled Living Allowance, which we probably wouldn't have bothered to investigate because it's just another thing to do, and we aren't badly off. So we probably wouldn't have bothered. So she put things in our field that we could then take up if we wanted to. L10 wife, age 52, renal, CA(B)

Male patient: And I've had a grant from Macmillan's themselves for some garden furniture so I can sit out, and furniture that I can leave out because I haven't got the room to store and I don't want to be lugging it about. K4 age 50, Lung, Lives alone PT2

Female carer: We've got a holiday in view. The Macmillan nurse pointed us in the direction of an insurer that would cover for N. and so the holiday's booked and paid for, and all being well, we'll be going next month. K11 age 79, Gastric, Lives with wife, age 76 PT1+CA2

Female carer: The Macmillan nurse even found out for me about compassionate leave, sick leave, because I was too worried to ring my own Education Authority in case they thought, how long is she going to be off? So the Macmillan nurse stepped in and did all the enquiries. K1 age 67, Colorectal, Lives with wife PT1

### **SPCNs: Linking with other services**

Female carer: The Macmillan nurse that I contacted for his acute jaundice, it was her who initially got the ball in motion, by contacting the GP, the GP contacted the hospital, we were in within 24 hours. B11 age 72, Bowel, Lives with wife, age 70 PT+CA1

Female patient: The Macmillan nurse has given me a curriculum vitae of mine on this, which I could then hand over to somebody and wouldn't have to do all the explaining about it. I might get something wrong and it's all written down. [...] I was going to another daughter's wedding in Derbyshire and this daughter thought I should have a contact in Derbyshire while I was there because I stayed there a week. And the Macmillan nurse contacted the Macmillan nurses down there through my daughter's GP and gave me their telephone numbers and names so that I did have that contact. And this curriculum vitae was written for this but it is very useful indeed. K12 age 65, Ovarian, Lives with husband PT1

### **Attitude and accessibility**

Patients and carers commented on the attitude and accessibility of the SPCNs:

Male patient: I think the overriding thing is that the Macmillan nurse is a far more intimate, compassionate, feeling type of person, that would be my opinion. B8 age 63, Prostate, Lives with wife PT1

Female patient: I do find seeing [the Macmillan nurse] very helpful because it makes me feel there's somebody interested, and somebody I can talk about my illness. Which you don't want to do in day to day life particularly, you know, moaning about the nitty gritty bits of it. B1 age 50, Lung, Lives alone PT2

Male patient: Just the Macmillan nurse will come and pop in every two to three weeks, unless of course you want them in every week. I mean you can reach Macmillan any time you want which is, well they're very good that way. L2 age 41, Thyroid, Lives with wife PT1

## **Knowledge of SPCN services**

Although our participants could describe the 'Macmillan' nurse's role as it pertained to them, few had knowledge of how this fitted into a service structure. While this was not of great concern to them while they were receiving their services, it did suggest that the 'uninitiated' cancer patient population and general public are likely to be somewhat unaware of or unclear about this specialist nursing role, as other studies have found (Beaver, Luker & Woods 1999a). If patients and carers are to be more closely involved in decisions about their care, they may need to know more about the nature and structure of services and practitioner roles. Our sample was well linked in to the Macmillan services, but this is not the case for all cancer patients. In our previous study of cancer patients and carers (Thomas & Morris 2001), which was not exclusively about palliative care, we found much less knowledge about specialist/Macmillan nurses, and fewer people who had contact with them.

In this study most people had been referred to a SPCN, but few knew how this had happened. One well-educated couple had sought out a referral themselves:

Female carer: Initially we found out about the Macmillan service from a friend of mine whose husband had the same thing. And she said what you could do with is to talk to a Macmillan nurse and you have to get that through your surgery. And I rang the surgery and it was the receptionist who said I don't think we deal with that. The Macmillan nurse was surprised at that when we got in touch, and she said I'll make a point of having a meeting with all the GPs and tell them about our service because they should know as a matter of course. K1 age 67, Colorectal, Lives with wife PT1

Knowledge of how the Macmillan nurses received their referral was generally lacking, unless a specific conversation with an oncologist or GP was recounted. One woman speculated that it was her involvement with a hospice charity shop that got her a Macmillan nurse:

Female patient: I mean the Macmillan nurse turned up and I don't even know who got me her or what. I don't know and I keep thinking. I work at the Hospice charity shop. I have done for years except when I was bad right at the beginning, I'm back now. And when I first went in, J. [the one in charge] is fairly big at the Hospice, and I just said I can't come, well it's two flights of stairs. I said there's no way I can manage them at the moment, and she said, 'Have got a Macmillan nurse?' I said, no. Then next thing one turned up on my doorstep, so whether J. arranged it or whether the Doctor arranged it I don't know. B6 age 61, Breast, Lives with husband PT1

Another couple felt that because they did not take up an offer of treatment they were dropped from the system and did not benefit from services such as Macmillan nursing.

Male carer: When we told the Macmillan nurse that we thought that we wouldn't take any action at that time - but we would think about it, we just got the idea rightly or wrongly that we'd been dropped.

Female patient: Yes we did.

Carer: We felt that because we weren't, you know, getting into the system, they, it was as if, right well, you've got to paddle your own canoe now sort of thing, but that made it-

Patient: We both felt that, didn't we?

Carer: Yes, that may have just been in our minds, but we just had that sense. But we had a further word with [the GP and decided to try the treatment]. So we went onto the Erinidex and, that seemed to get us into the scheme of things again. L5 age 76, Bowel, Lives with husband PT1

Others made connections in their talk between Macmillan nursing services and other services:

Male patient: There's a Macmillan nurse connected to every GP in Barrow, so [my Macmillan nurse]'s the one that deals with the GP that I come under, she deals with them for the cancer patients, and liaises, plus if there's anything else. B7 age 57, Lung, Lives with partner PT1

### **Marie Curie nurses**

Few in our patient sample had experience of Marie Curie nurses, and there seemed to be little knowledge of this service:

Female patient: I thought, 'Well, what's the difference between a Marie Curie and a Macmillan?' [...] Do Macmillan just talk to you and they're for support? B6 age 61, Breast, Lives with husband PT2

However, in one case there had been extensive use of Marie Curie services. The carer greatly appreciated the help she had received from this source.

Female Carer: I began to feel I wouldn't manage it I really panicked a bit so I was glad that the Marie Curie nurse came but she was wearing a uniform and J. [my husband] wouldn't let her do anything. [...] He panicked a bit about his mental capacity and about dying and I didn't feel that I had enough skills to cope with that, so I was glad

that the Marie Curie nurse was there, just so there was another professional was around. [...] I don't know what would happen if I needed constant care. I know Marie Curie's about three times a week but I don't know how we'd go on covering otherwise and I'm hoping to keep him at home. K1 wife, age 63, colorectal, CA1

Female carer: The two district nurses that came mostly were absolutely superb and then night ones, and the Marie Curie nurse and my family, obviously. But the district nurses would come maybe about half past 9 – 10, come for an hour, go. And then the night nurses would come about 7 for less than an hour and give him a bit of a wash and sort of make him a bit more comfortable and go. And the Marie Curie assistant was only available on the whole, on the look of it, unless there was something more you could tap into, 3 sessions a week. [...] The [Marie Curie] nurses feed in their availability, the district nurses feed in their requests and the computer sends out the times to the nurse. So C., the Marie Curie nurse, fed into the computer that she was available for the Monday night. Our district nurse requested her and thought she was coming, came to us and said, 'Yes, C.'s coming tonight so you're fine.' And then when C. rang to say, 'Did you hear anything about the nursing?' And we said, 'Yes, you're coming.' She said, 'Well, no I'm not, the computer's told me that I'm off tonight. I haven't got any work tonight.' So she very kindly didn't go out but said, 'I'll ring you at 10 to 10, if you haven't heard from anybody I'll come.' So had she not been available and willing to do that we'd have had nobody on the last night before he died. K1 wife, age 63, colorectal, CA(B)

### **General Practitioners (GPs)**

We obtained the names of participants' GPs at the interview, as we wished to send a courtesy letter to the GP to inform them that their patient was involved in our research. This was explained to participants, and all gave their consent. In all, 38 different GPs were identified, covering the 41 patients. Four GPs were mentioned by two patients, but otherwise participants had different GPs.

Our respondents described a very variable service from GPs. Some GPs were closely involved in the care of the patient, but many merely provided prescriptions. Some GPs were much trusted and praised, but others were felt to be of little help. GPs were valued if they had time for patients and if they were easily accessible. Often a GP was trusted if the patient had known them for some years.

### **Helpful GP attributes**

## Giving time and showing concern

Interviewer: Your GP - you mentioned earlier saying she rang you up saying why hadn't she seen you? (laughter)

Female patient: Yes, so I have been told I have to go every month, I had to go that day and she gave me the antibiotics you see. And she says, 'We'll call this a visit and I expect to see you every month.' I said, 'Right.' K5 age 67, Colorectal, Lives with husband PT1

Female patient: You could sit and talk to him like I'm talking to you. I can talk to him although he's a man I can talk to him I can say anything to him at all. L12 age 70, Colorectal, Lives with husband PT1

Male patient: I would say there are individuals who I've come across in this last two or three months who care, full stop. I know you can go into all the works if you want, they care.

Interviewer: Yes, you feel cared for by them?

Patient: Yes, they've troubled themselves. I was coming back from Lancaster after the first session of chemo, and it was a community transport for once. Somebody was driving it and I passed my GP in [town] and he turned round and followed to ask how I'd gone on. Now, all right, it's a rural community, he recognised the car [vehicle]. He knew who was driving it and all the rest of it. How many GPs would do that? I had an appointment 36 hours later, he just wanted to know how I'd gone on. Fine, you sum it up, you can't put a description, a prize, a qualification, a quantification or whatever you want on that, and that's the way it's been. K4 age 50, Lung, Lives alone PT1

## Trust

Trust in a GP was engendered by their willingness to take time over, and an interest in, the patient.

Female patient: Trust him, yes – oh definitely. He's played hell with one or two of them and I've said to him, 'Shut up.' About the Infirmary, again he got onto them, when I was in the surgery, when he said he wanted them to see me, he's telling them. He said, 'Have you heard anything?' And I said, 'No, give them a chance,' I said, 'it's only three weeks.' He said, 'Three weeks is too long for you.' And got on the phone and he went bonkers. L17 age 81, Stomach, Lives alone PT1

Often, a sense of trust had developed over years, due to the patient's own long standing illness or that of a family member.

Male patient: Very supportive, I mean going to visit him is more usually a discussion, 'what shall we do next?', than anything else, and he leaves me to experiment with drugs regimes to a certain extent to see if I can work out a system that helps. He's been very good, they've all been very good. It's been very much a partnership. L10 age 56, Renal, Lives with wife PT1

Female patient: Oh my GP's wonderful. My GP is very good. I called her out last week because I got a bit of a sore throat. And she came to see me. And she's very good. She'll come out any time to me. Because she came when my husband was poorly, so I know her very well. And she said I can call on her any time. I can go and see her. B12 age 82, Bowel, Lives alone PT2

In some cases, however, the GP was new to the patient, but a rapport was quickly established.

Female patient: [My GP]'s very, very good and she's really on the ball with everything. In fact, from all the different GPs I've had, I feel she's the best of any. Mind, she's the youngest that I've had, and she really is very good, and I know if I want anything, I've only to get on the phone to her and, if she can possibly do it or get it, she will. B3 PT2

Male patient: I've struck very lucky I think because coming in [to the community] as a stranger and just having to meet a GP who I can relate to. K4 age 50, Lung, Lives alone PT1

### Accessibility

GPs who were easily accessible and responded quickly, were valued:

Female patient: If I need my GP I can leave a message at the surgery and say, I have a problem I'd like to talk over - with tablets, and he'll ring me back in the same day, and I can talk to him about that. K10 age 77, Breast, Lives alone PT1

Female patient: The doctor, if I felt off and I just went on that phone he'd be here within 20 minutes. I know that because I proved it, not since I've been in hospital but before, once before when I was ill, and I was really ill, and he came and I don't think he was 20 minutes, quarter of an hour. So I mean you can't grumble can you. L17 age 81, Stomach, Lives alone PT1

Male patient: Dr W.'s a 100%. He's been very good. If I ask for a call he'll come. I rung him one morning at nine o'clock, he was here at quarter to ten. It must have been near the end [of his day], but he came. And he always gives me something useful. L13 age 77, Lung, Lives alone PT1

### Support for bereaved carers

A few bereaved carers mentioned the support they'd had from the GP after the death.

Female carer: Well his GP came round to visit spontaneously, which was very nice of him, to say that if I ever needed any help I was to come straight to them, not to struggle on alone if I was having difficulties. So that was very nice. L10 wife, age 52, renal, CA(B)

### **Less helpful GP attributes**

#### Little contact

A fairly large proportion of our sample did not use their GP service very much, and when they did this was mostly for prescriptions.

Female Patient: [I only see my GP] when I'm wanting tablets. K7 age 72, Lung, Lives with son PT2

In these cases, it may have been that the participant was receiving enough support from other services, or that they trusted the expertise of the specialist services more readily, and some felt they had been 'handed over' to the specialists.

Male Patient: I wouldn't go to my local GP because I think it's out of his hands now and there's nothing – he's going to refer me to one of these people, and it'd be quicker us doing it ourselves.

Carer: There's no point –

Patient: Because they've said, you know: 'Don't go through your GP, just give us a ring and we'll make an appointment either the same day, or tomorrow, or whatever, or we'll come and see you'. So that's the situation as it stands today. L14 age 72, Gastric, Lives with wife PT1

Female patient: [The GP] came down immediately when I couldn't move on the bed and he organised the going into the hospice, but as far as anything else goes he said it's out

of his hands. He couldn't remark on the treatment or, you know, alter that in any way.  
K3 age 67, Ovary, Lives with husband, age 67 PT1

Occasionally there was talk by participants of the GP working in conjunction with other services:

Male carer: I think that anything that would be offered [by the GP practice] would be in conjunction with the hospice, and I think they would work it between them. [The palliative consultant] when we've spoken to her, that if there was any great change, she says, 'Well, no doubt you'll be in touch with your GP and the GP will be in touch with me.' So it'd just be a sort of little triangle, and really if we were really bothered – I think we could go direct to [the palliative consultant], and she would say, 'Well, come down and see me here. And I'll let Dr W. know.' Or the other way round, depending.  
L5 Bowel, husband, age 75 CA2

Some did not have a particular rapport with their GP, or felt that GPs were too busy:

Male patient: Whatever people say, I think you have to ask the GP to call, I think it's that way round, that GPs probably now have too big a load just to sort of pop in just to see how people are, but will call when asked. Which I think is a perfectly reasonable way to go about things. B2 age 65, Leukaemia, Lives alone PT2

Female patient: I suppose he'd come out if I wanted, but I don't ask him. K6 age 75, Lung, Lives with son PT1

For some there were indications that the GP did not do anything to suggest his/her willingness to get more involved.

Female patient: The GP, he got me into hospital that time when I was really bad, but I haven't seen him since then. L7 age 60, Endometrium, Lives alone PT2

But there was also a case where the GP was willing, but the patient did not seek out their help:

Female patient: GP, I haven't been near to her really, but our elder daughter was in and she sent a message - 'if mother doesn't come and visit I never see her!' So I have to – and then she insisted I go every month, not for anything, just – so she can see me once in a while, but apart from that I don't go near the surgery. K5 age 67, Colorectal, Lives with husband, age 67 CA1+PA2

There were some who felt rather abandoned by the GP:

Female Carer: [The GP] hadn't actually been to see [my father] at all. I don't know whether, whether people should, you know, get more involved. The GP knew how ill he was and was probably waiting for us to ask him to go and see him or something, I don't know. There wasn't anything he could do really, but you'd think if he had a patient who was that ill, you'd actually keep an eye on them a bit more. But the Macmillan nurse was keeping an eye on him, and the district nurses were keeping an eye on him as well, so -. B2 daughter, age 33, leukaemia, CA(B)

Female carer: He never came to visit him once - from coming out of the hospital. That was exactly a year to the day he came out of [the hospital], exactly a year. There wasn't one visit. L14 wife, age 70, gastric, CA(B)

Female patient: He seems to have been noticeable by his absence really. I don't know whether that's my fault, I've not made appointments to go and see him. But he said while I was having chemotherapy I was best not going to the surgery because of risk of infection. I've got an appointment to see him next week. I'm not sure how the liaison works between the hospital and the GP, how much information he gets back or how much it's up to me to fill him in, information on progress, or decline to him. I'm not sure about that, it's perhaps that I've not told him enough that he's not as aware of the situation as he should be, or whether that should be working through the medical channels without my involvement, I'm not sure on that, what the procedure should be, but I definitely feel that he's not really responding. K8 age 44, Breast, Lives alone PT1

Female carer: The GP came round once, which was a couple of days after B. died, but I didn't see him because I was busy doing, with somebody else doing something and he hasn't been since. But I had to go to him for a smear test or something and he said, 'I did come round to see you I., but you were busy,' and I said, 'Yes, I know and I do appreciate it, thank you very much, you're very kind.' But I really was lying because I know that if I had seen him two days after B. died I perhaps might have said something out of turn – like, you were no help to me, you were no help to B. So just as well. B8 wife, age 60, prostate, CA(B)

Male patient: My own doctor hasn't been and he knows, he were notified when this first came to light, he hasn't been. I go to the doctor's surgery on [x St], and there's four or five of them there. My own doctor, Dr. H., well, when I've been to see him he's never

been available, so I've seen one of the others, I've seen three altogether, but not one of them has been to see me. [...] I don't expect to be run after every five minutes, I don't expect that, but a visit now and again.

Interviewer: Yeah, you feel a little neglected, it sounds like?

Patient: That's right. 'Oh, he's got this and that, there's nothing we can do about it, so we'll just leave him.' That's the impression I've got. I'm not happy about it at all. After all they can't do much anyway when they come, P69: L9 age 88, Lung, Lives alone PT 1

## Attitude

The GP's attitude to their patients was criticised by some respondents:

Male patient: Last week the three of us were stood in the street there, and with it being a cul-de-sac it's pretty quiet, and the three of us have all been in hospital within the last three months [...] And every one of us, we all have different GPs and we was all complaining [...] You know, we was pulling them to bits. But I said at the same time: 'OK', I said, 'I pull mine to bits, and I think he's frightened of seeing me since this happened'. But I can understand it. L14 age 72, Gastric, Lives with wife PT1

Female patient: He's been to see me about three times. I were talking to him one time about giving up smoking, and he says, 'Why do you want to do that?' and I says, 'Because I want to be healthier than this.' And it sounded like – 'The way you are, it doesn't seem to matter whether you give up smoking or not' – know what I mean? And that upset me. L11 age 48, Breast, Lives with husband, daughters, and grandson PT1

Female carer: I was saying that I was concerned about one or two things, 'Well we can do his bloods again but it's not going to show anything.' 'Well I don't know,' I said, 'I know I'm just a bit concerned.' And when he was leaving he said, 'You know there's a really good film on, why don't you go and see it, why don't you take him to the cinema because that will take his mind off himself.' And I thought, B. couldn't walk from one end of the house to the other without his Zimmer frame and to take him to a cinema, he would have been asleep in the first five minutes. I didn't need that sort of thing, it wasn't constructive. B8 wife, age 60, prostate, CA(B)

## Slow in referring

A few respondents felt that their GP had been slow in spotting the seriousness of their illness, and this affected their feelings toward, and trust of, the GP.

Female carer: I think the worse thing really was how long it took you to get to the hospital because of the situation at the surgery. Because of the senior man who suddenly retired, with almost no notice, and our own doctor having glandular fever. And he was off sick for a long time. Also, it being summer, the other doctors were still taking their holidays. So it was difficult to see anybody, and you were stuck with a locum, who didn't really know very much. [...] I tend to think that if Dr K. [our regular GP] had been on duty all the time that things would have moved faster. K11 Gastric, wife, age 76.

Male patient: I think my doctor's still a bit ashamed that he never found it quick enough.

Interviewer: So every time you see him he wears a paper bag, does he?

Patient: 'Are you all right, gov?' I never get within striking distance, you know. L14 age 72, Gastric, Lives with wife, age 70.

The wife and son of the next patient did not take the GP's slowness quite so lightly, however, as the former describes in the bereaved interview:

Female carer: [the GP came after my husband died] He had, I can remember, he had a hat on and he never even took his hat off when he came in.

Interviewer: It doesn't sound like you were terribly happy with him.

Carer: No, I wasn't happy at all with him.

Interviewer: Would you have liked him to come more?

Carer: I would have liked him to have done more for B. before and I think he knows it, I think he knew it as well.

Interviewer: What do you think he could have done?

Carer: I think he could have done more tests on him, he was putting it down to the tablets he was taking for his back.

Interviewer: Right, so before the diagnosis?

Carer: Yes. It was 18 months before. He was going for 18 months. I mean he had an ulcer that ruptured. In that time the cancer had grown which we discovered when he was rushed into hospital. But G.[my son] was cooking and [the GP] said, 'I'm very sorry about your loss' or something. He said, 'Is your son here?' And he was very angry, G., very angry, in fact so angry he wanted to make a complaint and I stopped him. I said, 'It's not going to Dad any good now.' I couldn't have gone through it to be honest with you, I just couldn't have dealt with it at the time. And G. just came out and he's a very polite person and he said, 'Yes', just yes he said, 'I'm very sorry for your

loss about your Dad' and G. said, 'Right' and he walked back in, he couldn't talk to him he was so upset with him. L14 wife, age 70, gastric, CA(B)

### Accessibility

As with valued GP behaviour, the question of easy access and availability of GPs was an important factor in participants' talk about problems with GPs.

Male patient: I think I'd be able to get hold of [the Macmillan nurse] easier than the doctor.

Interviewer: Yes, doctors are hard to find sometimes?

Patient: Once you get past receptionist you're not so bad. L1 age 69, Oesophagus, Lives with wife PT2

### **Out-of-hours service**

There were various comments on the out-of-hours primary care services. Usually these were fairly mild criticisms to do with not seeing one's own doctor and having to explain one's situation again to a stranger. However in one case there were some considerable problems on two occasions. This is presented in the following 'case study' format:

#### **Case study: Problems with out-of-hours services**

A man in his sixties was living with his wife in a medium sized rural town, some 15-20 miles away from the nearest hospital. Initially he had thought that the hospice might be the best solution for his final care, but after an admission had decided that he preferred to remain at home for the rest of his life. His wife, although anxious about managing, was fully supportive of this decision, as was their GP and Macmillan nurse. A daughter, who was a nurse, lived reasonably close by and was supportive, and the couple had very good neighbours.

#### Episode One: Medication problems

Six weeks before he died, a problem occurred over a weekend as the result of medication. This is how the daughter told her mother to describe it when requesting assistance: "His breathing is going flat and he's in a dangerous position because he keeps getting out of bed and he's almost anaesthetised and he's in danger of hurting himself." The wife rang the primary care co-op services: "it was around three in the afternoon when I rang and it wasn't till eight o'clock at night that somebody came. By that time he was hardly breathing properly at all and had launched himself out of bed to go to the bathroom but couldn't stand because he was basically anaesthetised and it took five of us half an hour to get him back to bed, crying out with pain

because everywhere we held onto him hurt him where his cancer is, and the doctor actually who came was saying all the time, 'Poor man, this is a complete nightmare.'" It took another hour for the ambulance to arrive, and he was admitted to the hospice, where he was taken off the drug that caused the problems.

However, because the patient had been promised he would not be admitted to the hospice again after a first admission, he became very suspicious of health professionals. Wife: "And it effectively locked him away from us all at a time when we all badly needed to feel that he, he could rely on us." The wife was upset that she had to break her promise that he would not enter the hospice again, and it was also "very frightening to think that if this happens again, how will I will be certain that it isn't another five hours [wait]?" The wife felt that lack of specialist expertise out-of-hours was partly to blame for her husband's predicament: "And it's made me realise, and it's made us all realise, that once you get to a fairly late stage and you are juggling the drugs about that there needs to be possibly more expertise available. Because once 4 o'clock comes - the Macmillan nurse is not on 24 hour call and they've gone. And if it's the weekend or a bank holiday they've gone for a good while. And whereas it might be said, well if they've got patients in that state surely they should see they've got all the drug regime in place and ordered and everything's ready to be done by the GPs and by the district nurses on the instructions of the hospice or the Macmillan nurse saying, this may be needed."

#### Episode Two: Pain relief at the final stage

In the ensuing six weeks the patient was cared for at home with help from primary care services, Macmillan and Marie Curie nursing and hospice advice. The patient's condition was deteriorating and it was a Bank Holiday weekend. The night before he died was described by his widow as "a pretty dreadful night because that was the night, by that time, he was needing much more sedation. He was becoming agitated. We didn't think necessarily, we didn't know, he was also needing something for his lungs, he was beginning to fill up with fluid." There was some mix up with the Marie Curie allocation, and had it not been for the dedication of a particular Marie Curie Nurse, who sorted out the problem, the family would have been alone. The Marie Curie nurse sent for the on-call doctor who was located in a hospital approximately 15-20 miles away. He suggested she should come and pick up the medication and she refused saying (according to the carer): "No, firstly I'm not leaving my patient, he's desperately ill. Secondly, I'm not coming over for some monitored drugs without you having seen the patient." The doctor did come out but could only give him the equivalent of two teaspoons of oromorph "Because of the Shipman new regulations." The wife noted that she could have given her husband that, and had hoped that the doctor could provide something stronger.

The rest of the night was described by the widow in this way:

“He just went on through the night getting more and more distressed. So much so that at about 5 o’clock in the morning my daughter was horrified and said, ‘This is just dreadful, I want you to ring that doctor again, something else has got to be done.’ And he came again and he said, ‘I’ll give him some Hyoscine in an injection, I’ll give him another injection of,’ what he’d given him. But it wasn’t anything like enough. And of course by which time he was beginning to froth, he was beginning to get all this, he was drowning in froth. That was so distressing for him because he couldn’t tell us what was the matter and he couldn’t get rid of it. [The doctor] apologised profusely and said he was terribly sorry and went away. And then of course at 8 o’clock in the morning I called his own GP. And he came and he got the nurses and they put the line in and they put in the proper infusions of Hyosine, and diamorph and everything but by then-.” The widow felt this scenario should never have happened. This belief was confirmed by the palliative consultant who told her that the hospice could have given advice, and that there was a 24 hour duty chemist who could have provided the needed drugs.

K1 wife, age 63, colorectal, CA1+CA(B)

### **District nurses**

In nineteen of our forty-one cases (46%) the patient and/or carer mentioned having contact with district nursing. For some it was around terminal care, but others were having regular or intermittent contact prior to this phase. Since not all our sample of patients had reached the final phase by the end of the project, and a few were difficult to track for ethical reasons (see Chapter 3), we speculate that the total proportion of cancer patients in the sample who had some contact with a district nurse would be higher than 46%. However, there was a sense in interviews that district/community nurses are more shadowy figures than Macmillan nurses. Although there was little complaint, these nurses were not mentioned by name as often as Macmillan nurses, and less was said about their services. This may be partly to do with the way district nurses tend to work in teams, so that different nurses may visit the patient at different times, unlike the Macmillan services where one nurse is assigned to the case.

Male patient: I mean the district nurse has called, did I have one here yesterday, a district nurse. [...] the nurses vary but they’re all nice. L4 age 57, Pancreas, Lives alone  
PT1

The practical nursing tasks which district nurses perform is perhaps in contrast to the more psychosocial model of Macmillan nursing and this may also affect service users' more matter of fact perception of the service.

Female carer: Well if it was a nursing thing, then I would contact the district nurse at the doctor's, or contact the doctor. If it was something in that way. Something that

needed dressing or injections – obviously injections. But if it was anything else I think I would contact the social services and if they couldn't help me I would ask them who I could get in touch with for that particular thing. L14 age 72, Gastric, Lives with wife, age 70 PT2+CA2

District nurses were mentioned as coming to perform specific tasks, for example injections, adjusting TENS electrodes, dressings and physical problems. The involvement of district nurses at the end stage was mentioned by a few carers, for example:

Female carer: But it was on the last day, on the morning, the Sunday morning that I rang up because a district nurse came out – I rang on the emergency GP number 'because I could see how poorly he was and she came and made him as comfortable as she could, she said, 'He's very, very poorly.' L14 wife, age 70, gastric, CA(B)

There were also indications, however, that the district nurses also performed a supportive role, checking on the patient, supporting the carer and the patient.

Female patient: The district nurse comes. I mean, I just need to ring up and then she'd be down. Yes, they're very, they're very supportive. K3 age 67, Ovary, Lives with husband, age 67 PT1

Female carer: Probably just over two weeks before he died and the district nurse came, and again I can't praise her enough, she was absolutely excellent and she spotted that B. was getting very low, very, in himself, which was not his nature. He was very, very outgoing, very positive about things. And he, I think it was the first time I ever heard B. admit to her that he was fed-up. And she sent for our GP. B8 wife, age 60, prostate, CA(B)

Some patients described the district nursing services as 'excellent' or 'wonderful', and carers commonly gave such a description after bereavement.

Female carer: Excellent, the district nurses were absolutely excellent. There were two of them, yes, and they used to, well not take it in turns, maybe it was a day off and the other one would come. But they were both extremely excellent, kind, very, very caring. B8 wife, age 60, prostate, CA(B)

As with other health professionals, the accessibility of district nurses was cited as important:

Female patient: The district nurse is always at the end [of a phone], even of a weekend, I can contact her. And then she can put out feelers anywhere sort of thing. B10 age 63, Unknown primary, Lives with husband PT1

Only one patient described wanting district nursing services, and being unable to obtain them:

Female patient: It doesn't seem to be very much here, because when I was having such difficulty getting out of the bath, I asked my GP if they had auxiliaries on the district that came to bath you, like a lot of the big cities do, you see, because I'd been used to that. Well, I mean, I hadn't needed it, but I knew if I wanted it, it was there. And she said: 'Oh no, we don't have anything like that here'. What she told me to get was one of these bars, you know, that fit on the taps and then you pull yourself up with them. I says: 'But I don't want that', I says, 'I want somebody to' – because I got stuck in the bath one night and I was three quarters of an hour before I could get out (amusement). B3 age 79, Breast, Lives alone PT2

There were just a few criticisms of district nursing. One where a patient took a dislike to a particular nurse, but with three it was more a criticism of their surveillance. These patients felt they did not need a district nurse for any specific task and could not always understand why they were visiting if they were only sitting and talking.

Female patient: It's only since the cancer in my bones I've been having them coming. I didn't feel as though I needed it. In fact, I couldn't understand why she was sat there saying nothing. K10 age 77, Breast, Lives alone PT1.

## **Social Services**

More than half the patients and carers reported receiving some form of help from Social Services and/or social workers. However, only a few, who lived alone, were receiving home care services, and for most who had had contact with Social Services it was equipment or finances that were mentioned, and people were generally very happy with this kind of help. It was evident that in many cases, health professionals, usually Macmillan or district nurses, generally brokered the setting up of these kinds of services. Amongst those who had not been involved with Social Services, knowledge about what they did, or could provide, was minimal. A few respondents thought that they might be able to get help in the home if they needed it. Problems with home services were mainly to do with inconvenient or variable times of arrival. In addition, some had an aversion to having 'strangers' in the house.

## Having home care

Six in our patient sample talked about having a home care worker coming in to clean, cook, and/or help with bathing and dressing. Of these, four were women living alone, and one was in a retired couple relationship. In addition another couple had home care for the carer, who suffered from Parkinson's disease.

Female patient: And I have a lady comes in the morning. And gives me breakfast at 8 o'clock, and then I can – I can stay in bed till 10 o'clock or half-past 10, and that's resting - . And I find that's very helpful. B12 age 82, Bowel, Lives alone PT1

Female patient: Since October I've had somebody coming in during the morning to help me shower, because I went through a spell of being light headed when I was moving around a lot, so someone's come in every morning. I largely manage it myself, but it gives me that support to have somebody there, they can help me dry, sometimes they can wash me, depending on how I feel. For a short while I had somebody coming in doing evening meals for me, but I found that wasn't very satisfactory, because they were coming at widely ranging times. It wasn't easy to think of meals that they could cook me. So I'm just having someone come in the morning, not at teatime. I find it easier just to get ready made meals and put them in the oven, when I'm wanting them, rather than depending on somebody coming in. K8 age 44, Breast, Lives alone PT1

Home care was rejected by three patients who had been offered it. Interestingly, all three lived on council estates.

Male patient: Social services come once – young nurse – wanting me to have home help, well I don't want a home help.

Interviewer: Right, well you don't have to have one do you?

Patient: Oh I don't want anyone rummaging through my drawers, I mean, as long as I can manage. I can keep my house tidy and do my washing and all that sort of thing, as long as I can manage, that's how I'll carry on. L9 age 88, Lung, Lives alone PT1

Female patient: Yes, we manage. So, because somebody asked me again the others day, did I want, what do they call them, carers, home help or what are they called? And I said no- there was no need. If I was desperate I'd ask for somebody. [...]

Interviewer: And it was when you came out that they started offering you someone to come early in the morning to get you up and you didn't want that?

Patient: No, not at 7 o'clock [in the morning]. K6 age 75, Lung, Lives with son PT1

In a few other interviews, participants were reluctant to have ‘strangers’ come into the house:

Female patient: I’ve got a cleaner comes in and scrubs all the stairs and that for me, and the bathroom, but she started last year, she used to work where I worked, you know. [...] I mean she’d be willing to still do for me, but if ever she packed in, I think you can pay the Social Services and have their care, but I think I’d rather have somebody private that you know. B6 age 61, Breast, Lives with husband PT2

Male patient: Maybe you can open up more to a brother than you could to a stranger – not being detrimental in any way towards you – you know what I mean. Or somebody that comes in from the Social Services that maybe has been to see five other people, it comes off a bit pat. [My family] know what type of person I am – they keep shouting at me because I won’t sort of admit stuff. If I have a wee bit of pain, I won’t admit it, I’ll say: ‘No, I’m all right, it’s just a twinge.’ Well they know, and what they’ll do is pick a phone up. The next thing, I’ve got a visit from the doctor. Because they know – you can’t hide it from them - where I could hide it from you, if you were a social worker, say: ‘No, I’m all right, I’m keeping well’, or ‘there’s no discomfort’. So you say: ‘Right, I’ve asked now,’ you know. B7 age 57, Lung, Lives with partner PT1

A bereaved carer described how a care package had been arranged for her brother against his wishes, but with hers:

Female carer: The Social Services had come down and sorted it all out - ‘We’ll have this package in place for when he’s discharged’, when he comes home. He wasn’t happy about it, ‘I don’t want somebody coming in and getting me up for me breakfast and helping me to dress and wash.’ I said, ‘Well, we’ll jump that hurdle when we come to it. Get into the hospice and get your rest first’. That’s how you had to deal with him, but then it didn’t come off you see, he didn’t come home, but the package was being put in place ready for him which would have been a Godsend. L15 sister, age 66, bladder, CA(B)

In another case, a carer was trying to get her father help in the home, but he died before it became vital:

Female carer: We were trying to find more care for him. I was trying to get a home help and trying to -. I talked to the Macmillan nurse and she was trying to get social workers involved in order to get more home care for him because he obviously wasn’t managing at home. B2 daughter, age 33, leukaemia, CA(B)

## **Equipment**

Many in the patient sample mentioned obtaining equipment for the home from the Social Services or occupational therapist, such as rails, bath aids, mobility aids, and these were usually deemed to be very useful, and the service quick and efficient.

Female patient: They've been marvellous, the Social Services, very, very good. When I came out of hospital there was a commode for me – a seat round the toilet – and, what else was there – I had a Zimmer frame, sticks. And then my daughter – I got a Lifeline because I fell out of bed, you see, and I was crying, at 2 o'clock in the morning and nobody could come. They couldn't get in, no-one could get in. So as soon as I came out, I bought a Lifeline and the lady was putting it in and my daughter was making me a cup of tea and she said, 'Mam, you could do with a – something that you could put a cup of tea on.' And they brought me a lovely tea trolley – they brought it in the afternoon – you've only got to speak and you get it. B5 age 76, Colorectal, Lives alone PT1

## **Little knowledge of Social Services**

When questioned about their knowledge of what Social Services provided, seven of our participants said they did not know. Here are a few examples:

Interviewer: Have you had any contact with Social Services?

Female patient: I don't think so.

Interviewer: Do you know what they might offer you if you-?

Patient: No, I haven't a clue. Actually you've made me feel completely clueless. B1 age 50, Lung, Lives alone PT2

Interviewer: And Social Services, do you think they have anything particular that they can help with?

Female patient: I've no idea, I've never gone into it to see what there is. People keep saying there's this and there's that and there's the other, but I don't know. L12 age 70, Colorectal, Lives with husband PT2

However, others in our sample did feel that help from Social Services might be forthcoming if they needed it:

Female carer: I think I'd go to the Social Services if I thought I needed something that perhaps my GP couldn't provide. I think I would get in touch with the Social Services

then, if I needed some sort of help that they couldn't do for me. I wouldn't be afraid to contact them. You know. I think. And they could say yes or no, whether it's possible.

L14 age 72, Gastric, Lives with wife, age 70PT2+CA2

Interviewer: And if you are at home and your family were looking after you, do you think there'd be other services that you could get? Who would that be, do you think?

Female Patient: I think you'd get that through the Social Services, don't you? Yes, because I had a load of leaflets when the Social Services did come. And you can get people that'll support you in the home. So you could get somebody that would support you in the home. Not a nice thing to look forward to, is it? B12 age 82, Bowel, Lives alone PT2

Several people, when questioned about Social Services, associated them with form filling and financial benefits.

Female patient: If you can fill all the forms in, you have to go through all that I suppose, I don't know. I really couldn't be bothered with all the forms, it's just - and especially for someone with an illness like me - you look at a form like that and think 'Oh no!' Well I would, no way. I have a disabled sticker because I was having chemotherapy but [the Macmillan nurse] filled that in, she helped me do that. But you really can't be bothered with forms, when you're dying of cancer, which is what we all are. And you're faced with this great wad, and I think they say, someone said that they'll help you but - I don't know - you can't do it over the phone with somebody you don't know or anything. I just think that wants sorting out somehow, I don't know how, I don't know, but - I know how I feel with cancer and I just couldn't be bothered with those forms. I'd probably lose out on financial assistance, I might if I was hard up, I might struggle through it but, not that we're rich, but the way I feel. K5 age 67, Colorectal, Lives with husband, age 67.

## Hospitals

Most patients had experience of hospitals, associated with diagnosis, surgery and/or treatment, and many still went for regular out-patient appointments. Experiences of hospitals were varied – often these very satisfactory, but several patients reported difficult in-patient episodes. These experiences, especially the negative ones, coloured patients view of the hospital as a place of possible final care. A few bereaved carers described death in a hospital; it was usually considered inappropriate, and often upsetting.

## Good hospital experiences

Patients who were very satisfied with hospital experiences described caring staff, prompt treatment and attentiveness. Here are a few examples:

Male patient: I thought [the hospital ward] was excellent, absolutely excellent. They couldn't do enough for you, explained well, looked after well by all the nursing staff up there. L2 age 41, Thyroid, Lives with wife PT1

Female patient: Marvellous – you only had to ring a bell and they were there – they bathed me, washed my hair – put rollers in, combed it out – oh, they were really good. B5 age 76, Colorectal, Lives alone PT1

Male patient: I've no complaints about anybody or anything, and like I say, the hospital service was second to none. You know, when you watch television and listen to the radio and people slag off the NHS, in this area we're very, very fortunate or – whether it was me as an individual, but you know, no complaints at all – I've been really well looked after. B7 age 57, Lung, Lives with partner PT1

Specialist cancer facilities were especially praised:

Female patient: So they decided I'd have to go for radiography. And I had three weeks – 15 treatments. It was wonderful. They're so good and the whole place is – it's a pleasure to go into the department. Of course you realise when you're on a cancer unit how different it is from a normal surgical ward or something like that. The nursing is different. Your eyes are opened to a lot of things. K9 age 84, Lung, Lives alone PT1

Male patient: I wasn't particularly impressed with the attitudes of some of the people in [the local hospital]. Maybe they were not used to coming face to face with it, maybe I was just not ready for the answers they were giving me, maybe it's a bit of both. I certainly was less impressed with those than the people I've met in [the specialist unit]. They specialise, they have to deal with some very difficult people. I hope they don't consider that I'm one of those! But they do. It's a massive place and yet there's that feeling that you're a person. I can't put it better than that, you're not a number, you're not just a registration in the National Health Service you, you actually are a person. I'm a people too, as I used to call it. [...]. This [specialist unit] they're wonderful to me. I'm in contact with them on the phone if anything is bothering me, or I think something is not going right. They tell me well go and see your GP and get him to do a blood test, or skip your GP come straight in to see us, we'll send somebody for you. What more can I

ask for? When I'm there they keep me in touch, they know I'm not fit. I ask them what the results are of certain bits and pieces, they tell me in a language which is probably not strictly medical language but it's one I understand and I know what it means. Yes they're very understanding. K4 age 50, Lung, Lives alone PT1

One patient who had extensive experiences of hospitals due to a pre-existing heart problem noted that he would therefore be happy to have final care in hospital, if necessary.

Male patient: I wouldn't go overboard to make an enormous fuss if I couldn't be at home. I've been in hospital enough times to know how that works and always get on very well in there with the staff and so on. L10 age 56, Renal, Lives with wife PT1

### **Poor hospital experiences**

Alongside these positive accounts of hospital encounters many in the patient sample also reported 'bad' experiences. A few of these negative experiences had shaped place of final care and death preferences, placing it firmly in the direction of home or hospice:

Female patient: ... if it did get to the stage where J. couldn't look after me I wouldn't mind going in the hospice at all, now I've seen how good they are and how capable they are. And they look after you so well. I wouldn't mind going in there. But not the hospital.

Interviewer: Not the hospital?

Patient: Oh no, no, not if I can avoid it I can tell you. B10 age 63, Unknown primary, Lives with husband PT1

Bad hospital experiences tended to focus on feeling 'abandoned', being in the wrong place, with nothing happening, for example:

Female patient: Last year I didn't go into hospital, after my first experience I decided it wasn't a good idea. [...] I had to go in for a week but it's very difficult with the medical ward up here, because sometimes it can sort of turn into a geriatric ward which is, it's all right when you're very ill but then as you come around a bit it's quite depressing really. So this time I just thought no way I'm going into hospital, so I had a few friends came up but then I just learnt to manage really. B1 age 50, Lung, Lives alone PT2.

Female patient: The week I had in [hospital] I really was very disappointed, as I set off on one ward – well, I set off in a little room on my own, you see. After three days they said: 'We'll have to move you into the big ward because we need this bed'. So I said: 'Well, fair enough'. Well, it was a big ward, and there was three in, they were all a bit -.

I thought, 'Oh Jeez.' They didn't speak. I know one was deaf, but the other two, one just got up and sat and looked out of the window, and I thought: 'Oh my God'. And then two days after that, they said, 'We need this ward for males'. She said, 'We're moving you down to the gynae ward'. I said, 'Good heavens, I'm a medical case, not a surgical case'. She said, 'I know, but you're the only one with enough intelligence in the ward to know why we're doing it', you see. Well, I got my meals and that was about all I could say really, because I never saw anybody, and as I say, I was nothing really to do with them. B3 age 79, Breast, Lives alone PT1

The woman in the extract above had a particularly difficult experience. She had been in hospital for six weeks, on a gynaecological ward due to bed shortage when she felt she should have been on a medical ward. She felt that the doctors did not know what to do to help her, and offered little in the way of treatment. She also described having little support from the nursing staff:

Female patient: Speaking honestly, they were so rushed off their feet looking after the old people there were no beds for, and things like that, they certainly didn't have time for me who was still capable to go and get me own dinner and see to me self and everything. And so I just sat there for six weeks, which is a bit much. [...] They did say I could come home for the odd day if I wanted to, but my husband's elderly and I thought there's no point me making him come for me all this way, pick me up, take me home, start to make me meals, because I wasn't that well, just to take me all the way back again. And also I didn't want to lose my bed (laughter). I was in the system at least, I wanted to get somewhere so I thought I was better where I was at that stage. B10 age 63, Unknown primary, Lives with husband PT1

She then went on to describe how her legs swelled up more and more, but nothing was done to alleviate the problem:

Female Patient: It was definitely over long in the fact I never got any treatment, and the things that the little bit of the cancer led to. They could have been doing something. Well, I feel they could. I suppose they gave me treatment for being jaundiced because they gave me the steroids to help the inflammation and that did help a lot. So yes they did give me that, but nothing for my legs. I feel they should never have got into the state they got into in the first place. B10 age 63, Unknown primary, Lives with husband PT1

When she finally came home she found, through the community services, that there were things that could be done to ease her swollen legs:

Patient: But since I've come home I've been on water tablets and they've taught me how to massage all the lymph system to get things moving again. And I've got them down, I mean they were, they were out here. [...] They can help me. I think that should have been avoided myself. I didn't know about these treatments. B10 age 63, Unknown primary, Lives with husband PT1

## **Deaths in hospital**

Several bereaved carers described how patient deaths had occurred in hospital, usually due to an emergency admission. Some of these cases have been discussed in the previous two chapters, since these deaths sometimes involved considerable distress and regret (see cases B2 & L1).

One case (also discussed in Chapter 7) involved a 'horrific' few days. The carer described seeing her husband in great distress, with the doctors unable to sedate him. The difficulties were compounded by the attitude of some of the nursing staff.

Female carer: They just did not seem to be able to do anything for him and that was distressing. And when I saw [the consultant] I said, 'You've got to do something, it's awful.' And he said, 'Well, the amount of medication I've given him, ' he said, 'if it was me I would be out for a week but he seems to be fighting it.' And he was coming out [of sedation] every 20 [minutes], and you couldn't touch his legs, he would not have you touch his legs. And all the time, and he couldn't speak, and he, it was awful because he was throwing himself over the bed and, and putting his arm round my, like this, and looking at me as if to say, 'Please do something.' And I was so disappointed in them and the nursing staff. I know they can't work miracles. I know they can't but silly things when he's got drip in here, something in here, something in here and, of course he had to be catheterised and every half-hour we were wrestling to keep him in the bed. And if we went to ask for help – 'oh we'll be there in a minute, we'll be there in a minute'. It's not good enough when it's one of yours, you know what I mean. I know they can't do individual. [...] And when you get nursing staff coming in, you send for them, 'Can you help us?' and they come in and they pat him on the head and they say, 'Oh come on you're not helping yourself.' I said, 'I don't believe you said that.' So eventually on the Friday evening [the consultant] said he was going to put a line in here so that they could get drugs in that were faster acting blah, blah, blah – fine. So he settled for about two hours. Then it started again. So I said to [my son], 'Go and get one of the, go and get somebody he'll need some more.' Well [the consultant] hadn't authorised anybody to use the drugs so that was an hour's wait before they found a doctor. We are physically fighting because he was a big man was B. And I thought, it's not right. Probably I expected, and in fact have been told when I asked the question, oh

months before this, what is going to happen when we get to the final stages? What am I faced with? Is this going to affect his internal organs, is he going to be vomiting? Am I going to have to, just tell me what to expect so that I am prepared for it. 'Oh absolutely not, no, he'll just get weaker and he'll just sleep.' B8 wife, age 60, prostate, CA(B)

There were some staff who she identified as helpful in these circumstances, however, such as the ward sister and a particular staff nurse:

Carer: And they rang on Saturday morning at 7 o'clock to say there was no rush but if we wanted to go in B. had deteriorated. And then a staff nurse came on and he was a man, A., he was called, and he was excellent, he said, 'My job this morning or tonight while I'm on shift, is purely to look after B. So if you want me, you just shout and I'll be here.' And he came in every half-hour and every time we asked for him he was there. But by this time of course B. wasn't in pain then. B8 wife, age 60, prostate, CA(B)

## Nursing homes

In their recent BMJ article, Carrese et al (2002: 128) suggest that housebound elderly people tend to describe a 'world view that does easily accommodate advance care planning: they live life a day at a time, preferring not to consider problems until they occur'. Although the problem of cancer with a poor prognosis had already occurred in the lives of people in our sample, there was evidence among many patients of a resistance to considering their future need too closely (see also Chapter 7). Questions about nursing homes particularly evoked a 'worse case scenario' for many patients in our sample, both younger and older. Only two patients in our study entered nursing homes as a result of the cancer, and only one death occurred in a nursing home (see Chapter 4). Few claimed much in the way of knowledge about nursing homes, and most resisted the idea of considering them as a place of care.

Interviewer: The next thing [to ask you about] is nursing homes - ?

Female patient: Oh, shut up – for goodness sake. (Laughter)

Interviewer: Not much to say about them – but not for you, but perhaps for someone in a similar situation, or do you think they would have anything to offer?

Patient: No, I've no idea.

Male carer: No.

Patient: Where are the nursing homes, or who are they, or - ?

Carer: Well, that's something one would have to meet at that particular time.[...]

Patient: Oh God, I hope I don't need that, ever. [...] With all the old dears sitting with white boots.

Carer: That's right – that's right.

Patient: Oh dear God – God preserve me. [...] Was it yesterday we were talking, and I said to J., 'If I hadn't had J., I doubt I would have been able to stay here on my own.' I would have needed a lot of care coming in, do you understand me. I mean I've got family, but I mean you can't expect family to be driving up here every day and staying for – I mean they've got their own families. So I suppose one would have to consider that sort of thing. I mean you obviously wouldn't want to. L5 age 76, Bowel, Lives with husband, age 75 PT2+CA2

Female Patient: If I had to, and I was saving somebody work, then I would go, but it wouldn't be with a smile (laughs). Well, I don't think it would – oh gosh, no, and you can get some horrible people - not running them- the people that are in them can be horrible too. L17 age 81, Stomach, Lives alone PT2

Male patient: [I'd] not want to be put into a home anyway.

Interviewer: No, it doesn't sound like you'd like to go into a home if you-

Patient: No, no.

Interviewer: Unless you were really dragged there?

Patient: Well, there might come a time when I've no option, but I don't know. If I can feed myself I'd say no. L9 age 88, Lung, Lives alone PT1

Male patient: I don't think that I'd go in a nursing home, I don't think I'd like that, I put my mother in one and I saw what it did to her. But Doctor P. at [the hospital] said if you don't want to go in nursing home or hospice, I'll always have a bed here for you at [the hospital] you know, he said if you don't want to go. I said hospices don't bother me but I wouldn't like to go into a nursing home I don't think. I'm not being, I don't think I'm old enough to go in a nursing home, I'm fifty six year old, I don't want to be sat with eighty odd year olds. That would demoralise me. L4 age 56, Pancreas, Lives alone PT2

Even where the respondent felt a nursing home provided good care there was still a reluctance to consider it as an option:

Female patient: Well – I don't know. I've got a friend who's got a husband in a nursing home, and they're very good. You know. If you needed that type of care. If I – me friend's husband who's in a nursing home, he's very well cared for. Better cared for than the hospital really. Because they've got more time. So the homes are very good. I wouldn't mind going in there if I've got to. But I'd

have to. I would have to be – I don't think I'd mind going in if I had to, but I don't want to. B12 age 82, Bowel, Lives alone PT2

Female Carer: Yes, if it got to the point when you couldn't possibly manage at home. But it would have to be dire.

Interviewer: Right. Sort of last resort.

Carer: Very, very, very last resort. Yes. While I had breath – while I could breathe – let's put it that way – I would look after him myself. But no, I mean it's – and for people on their own obviously, it's the ideal thing isn't it? Or people that perhaps can't cope as a carer. I haven't found it difficult. L14 age 72, Gastric, Lives with wife, age 70 PT2+CA2

In addition, respondents often placed their identities as at odds with the kind of person who went into a nursing home:

Female patient: Well, to tell you the truth, the ones I've been in I'm not very happy about. To me, I've been to a few, but every one I've been in you walk through the door and smell urine, and I just cannot do with it, you know – and the old people – I know I'm not young myself like, but –. B6 age 61, Breast, Lives with husband PT2

Female Patient: Well, I've been in a few lately, I've seen me mother in a few. They're all very good, I think, mind you, they're like – more mental, where my mother is, but the staff do seem very nice, and they're all nice and clean, but I mean the sort I would want – well, I don't know - . I've never been in one that would cater for such as me [...] so I don't know what sort I would need. L16 age 70, Lung, Lives alone PT2

One patient we interviewed had moved into a nursing home due to her worsening condition. She already knew the place as her sister was in there. She made the decision aided by her spiritual beliefs and was happy to spend her remaining days there (although she actually died in hospital due to an emergency):

Female patient: I couldn't cope when I got home, so there was only one thing to do was to stop and see what was happening, and I think, being quite a religious sort, I think that the push, falling onto the floor, was God saying, 'Right, we've got you now. Push – this is it, where you go now is where you're stopping.'

Interviewer: So you imagine now you're going to stay here until the end of your days?

Patient: I've told them all. I've sat here about 1 o'clock in the morning, this is the Monday evening – at 1 o'clock, I'm sitting here and I look up and round there there's

like a squiggle – there isn't, but there was. It went round and round a whirly thing and then it went out through the door, and a voice said, 'You are now here. We're leaving you all our good will and good wishes and spiritual help for the future.' B9 age 85, Oesophagus, Lives alone, PT1

One respondent lived in a retirement home and felt she might need a nursing home at some point, having no close family to help her:

Female patient: Well, it'll depend how bad I get really, you see, I mean I've always said I know I'll end up in a home, I've said this for years now, and I quite think I will, because my back is not really getting any better. I had an operation on it eight, between eight and nine years ago, and they were supposed to be taking three vertebrae out to try and straighten it up B3 age 79 Breast Lives alone PT1.

A few younger patients had enquired about nursing homes, and discovered that there were few that took people under retirement age. One man aged 64 did enter a Cheshire home near where he lived, and died there. At a tracking interview his wife said he was happy there, although she was finding it hard to be on her own.

#### Other service matters

Some respondents spoke of matters pertaining to the co-ordination of their care. Two cited lack of care service co-ordination as a problem.

Female patient: You just get three different versions. There's nobody seems to be co-ordinating, you know. I think, well, who is the main person in charge of this? For example, Dr. [hospital doctor] because I was having problems sleeping prescribed Diazepam and then Dr. [Consultant] suggested something else. Actually the one who was most helpful about that was my GP who suggested having a ventolin nebuliser. It just seems daft in a way. And then there are the sort of practical problems, which I suppose are specific to me, because most people drive or have someone else who can go and fetch and carry things. As I say there's all these-. It seems to be a very bitty kind of system. And then you get offered something like aromatherapy and I just think, 'Why? Why that?' I mean it could be anything couldn't it? Counselling or reflexology or astrology or something, and I just wondered why really. B1 age 50, Lung, Lives alone PT2

Female carer: If someone chooses to die at home, which in fact you are told you can do, and you are also told you will get all the back-up, if you are going to feel confident with that, you are going to need some better bridge between the expertise of the Macmillan service and the hospice and the medical people who are dealing with the patient in the home - in order for them not to have that sort of scenario occur where mistakes can possibly happen, through the fact that the response is not adequate from a duty doctor, and there's too many patients, and there hasn't been the medication put in place. You know, it fell down badly on certainly those two occasions. K1 wife, age 63, colorectal, CA(B)

But in the main, patients and carers were impressed with how the healthcare team in cancer tended to work together. One woman, whose husband had long standing heart failure, noted that she wished there was such good support for other diseases:

Female carer: I'm not quite sure how it all jigsaw puzzles together, but it worked very well for us on the whole I think. And I think it's a pity there isn't the same kind of response to what is obviously a very serious and terminal heart condition. Because most of his problems were due to his heart. But the palliative care was offered by the cancer support services, and they were very impressive. The Macmillan nurse visited us several times. She wasn't actually needed as a nurse at that stage, but she organised [things for us]. L10 wife, age 52, renal, CA(B)

Only one couple thought that there might be too much support, and that this could get in the way of managing to feel normal and carry on with life remaining.

Female carer: I think that the whole of the care system is excellent, but at times you feel as if you're being drawn into a situation of illness and counselling and doctors, and sometimes to try and keep any sort of normality is quite difficult - .

Male patient: Yes.

Carer: And you've almost got to struggle to do that. So I think it's nice to know that people are there if you want them, but you sometimes feel a little bit swamped, don't you?

Patient: Yes, you do. I'm sure, for example, some people quite like the total medical – what's the word I'm looking for - .

Carer: Yes, just the - .

Patient: Involvement and things. But on the other hand I think it can draw you in too much and you're going to become almost saturated by it. Whereas if you stand back a

little bit and try and keep it in perspective and in balance, I think it's probably better for somebody like myself anyway, you know. K2 age 64, Prostate, Lives with wife PT1

A few patients also identified various agencies without health services and Social Services who had helped them. These included: Welfare Rights; the British Legion; the Royal Air Force Association; and the Disablement Information Centre.

## Summary: key findings

This chapter has examined those themes in the patient and carer interview data that bear on their connections with health and social care services, focusing on: knowledge about services; experience of services and types of practitioner; the quality of relationship enjoyed with individual health professionals; evaluations of how trustworthy, reliable and 'safe' services are; and the perceived accessibility and availability of services. These dimensions of the relationship between patients/carers and services played an important part in shaping place of death preferences.

### Hospices

- Hospice experiences were overwhelmingly positive, contributing to a hospice being the main place of death preference for 20% and the place of death of equal preference with home for 22% of patients in the sample (see Chapter 4).
- Most patients in our sample (73%) had personal contact with one of the two hospices in the MB area, and were thus knowledgeable about hospice services. Contact with a hospice almost always engendered positive regard for it.
- Many patients and carers described how their pre-conception that a hospice was simply a dismal place that one entered to die was replaced, on acquaintance, with an understanding that the hospice was an extremely pleasant, caring, even cheerful, place that one could access for the treatment of one's symptoms and for support. Respondents noted that the 'true' nature of hospices was not widely understood.
- Particularly valued features of hospices were: the caring attitude of staff encountered, the fact that the staff gave patients and carers time and respect, the pleasant hospice ambience, and the feelings engendered of 'being safe'. There was a sense of trust in the integrity of hospice services and staff. Hospices were seen to offer a service that could be relied upon, especially in times of dire need.
- The support services offered by hospices to bereaved relatives were much appreciated by carers, even though these services were not always taken up.

- Very few problems with hospice services were reported. The distance from home to hospice was a difficulty for a few, and the fact that a bed might not be available when 'my time comes' was a concern for some.

### Community oriented services

- The quality of the relationship established with community based and primary care professionals played a critical role in shaping patients' sense of trust in the reliability and value of these services. This, in turn, shaped place of death preferences and outcomes. For example, a home based death was difficult to contemplate if one's experience of community/domiciliary practitioners was poor. A good quality relationship was one where patients and carers felt that individual service providers were reliable, responsive to need, available, understanding and caring; in short, that they would 'be there' in all senses when things 'took a turn for the worse'. Some GPs and all Specialist Palliative Care Nurses (SPCNs) were described as embodying these qualities.
- **SPCNs** were highly valued by patients and carers. Once an SPCN had introduced her/himself, patients and carers perceived them to be accessible and to offer a range of resources: information, organisational skills, linkage with other services, practical and financial advice. Their reported attitudinal qualities included: compassion, understanding, and caring.
- Patients and carers generally lacked knowledge about the way in which they had been referred to a SPCN, reflecting their more general lack of knowledge about service structures, options and systems. This lack of knowledge strongly suggests that patients who are not referred within the system to a specialist nurse are unlikely to know about the existence of the SPCN service, nor about how to access it.
- Most patients and carers had no knowledge of the **Marie Curie nursing service**. The few that used the service were extremely appreciative of it.
- Patients' experiences of **GP services** were very variable. Some GPs were closely involved in the care of the patient, but many were reported as merely prescription providers. Some GPs were much trusted and praised, but others were felt to be of little help. GPs were valued if they had time for patients, they expressed interest and concern, and were easily accessible. Less helpful GP attributes were perceived to be: an indifferent attitude, slow referral to specialist services, and inaccessibility. Mild criticisms were made by most patients and carers of out-of-hours arrangements, focusing on the problems raised in their encounter with a doctor unfamiliar with the details of their case. However, serious difficulties associated with the limited scope of assistance provided by an on-call doctor were reported by one carer.
- **District nursing services** had been experienced by almost half the patients in the sample (46%) by the time of interview. These nurses were described as undertaking practical

nursing tasks in the main, but also as providing important 'supportive' care in many cases. There were few criticisms of district nurses, and much praise. However, relationships between patients, carers and district nurses appear to have been more pragmatic than personal, certainly in comparison with the SPCN relationship, in part explained by the fact that several district nurses could be seen by a patient in the course of their illness.

- **Social Services:** Some patients and carers reported receiving help from Social Services and social workers. Most of these contacts were to secure equipment or welfare benefits, and respondents were generally satisfied with the help received. Only a few, who lived alone, made use of home care services, and these were generally gratefully received. A small number of patients had refused the offer of home care on the grounds that they 'could manage' at present. There was sometimes reluctance to have strangers dealing with personal needs and 'rummaging around in my home'. Health professionals, usually Macmillan or district nurses, were the main instigators of contact with Social Services. Assistance from health professionals with form filling for welfare benefit claims was valued greatly by patients. Amongst those who had not been involved with Social Services, knowledge about their role and what assistance might accrue was minimal.

## Hospitals

- Patients recounted both positive and negative hospital experiences associated with their diagnosis, treatment and illness management. Negative hospital experiences played a strong part in directing patients and carers away from considering a hospital as a place of death option, and towards either a hospice or home preference. Bereaved carers who had seen their loved-one die in hospital also had mixed evaluations of the end-care of life care received there, with aspects of this care being heavily criticised in three cases (of the 7 cases of hospital death).

## Nursing homes

- There was a great deal of reluctance among patients to consider nursing homes as an end-of-life option, though a few recognised that circumstances might force them to enter a nursing home as 'a last resort'. This tended to be the attitude even when individual nursing homes were known to provide good quality care. However, two patients interviewed in residential care were satisfied with their locations. A few younger patients noted that a nursing home would not be an option because homes did not, as a general rule, admit people under retirement age.

## Chapter 10

### Discussion, Conclusion and Recommendations

#### Introduction

This project set out to answer four research questions:

- Where do cancer patients die in the Morecambe Bay area (MBA) – at home, in hospice, in hospital, or elsewhere?
- Why do they die in these locations?
- What are patient and carer preferences for place of death in the MB area?
- Does the place of death match patient and carer preferences?

**Actual place of death patterns** have been identified through data collection and analysis as follows:

- Area and individual level statistical analysis of the location of 6,900 cancer deaths in the MBA (data from ONS mortality data files, 1993-2000).
- Analysis of semi-structured interviews (n=16) with health professionals and associated workers involved in the delivery of palliative services in the MBA, to establish the scope of specialist palliative care service provision in the area.
- Analysis of patient (n=41) and carer (n=18) interviews on the circumstances surrounding end of life care and actual place of death of a cohort of 41 terminally ill cancer patients located across the MBA.

**Patient and carer place of death preferences** have been identified through the analysis of the two interview data sets to:

- establish patients' preferences and preparations for end of life care in the context of illness management, social circumstances and informal care arrangements, and service use and evaluation.
- establish professionals' knowledge about, and perspectives on, patient and carer preferences, and to identify professionals' views about the 'ideal' place of death arrangements for cancer patients.

By these means we have generated and presented detailed findings that fulfil the project's original research objectives (see Chapter 1). In short, we have developed an understanding of: i) the nature of patient and carer preferences in the MBA, ii) the factors that shape these

preferences, and iii) the factors that influence the actual locations of patient deaths in the MB area.

This chapter brings together the key findings of the study, and considers these in the light of current knowledge (reviewed in Chapter 2) on patients' place of death preferences and on the factors that determine actual place of death. It also makes a number of recommendations for service providers in the MB area.

## Key findings

### (i) Actual place of death

- In the mid-1990s in England and Wales, place of death for cancer patients was as follows:
  - 55% died in hospital
  - 17% in hospice
  - 26% at home
  - 2% elsewhere.
  
- Of 6,900 cancer deaths in MB, 1993-2000:
  - 35% died in hospital
  - 33% in hospice
  - 22% at home
  - 10% in nursing/retirement homes or elsewhere.
  - The probability of dying at home is higher in the earlier part of the study period, suggesting a trend away from home deaths.
  
- In our interview sample of 41 patients, of those who had died by the end of the study (35):
  - 20.5% (7) died in hospital
  - 50% (17) in hospice
  - 23.5% (8) at home
  - 3% (1) in a nursing home
  - 3% (1) either at home or in hospice (not known which).

**Discussion:** The relative consistency of home deaths in the three sets of figures above is of note (23.5%, 22%, 26%). This suggests that the capacity of MBA community-based specialist palliative care services to support home deaths is broadly representative of the average capacity at national level.

The marked difference between MBA (as a whole) and national place of death patterns is found in the low proportion of patients who die in hospital (35% vs. 55%) and the high proportion

who die in hospice (33% vs. 17%). In combination, the average home death rate, the above average hospice death rate, and the below average hospital death rate in the MBA mean that MB cancer patients have a greater opportunity to die *in hospice rather than in hospital* than is the case nationally. This is associated with Morecambe Bay's unusually high number of hospice beds per capita, although this is skewed markedly in favour of the Lancaster locality (St John's Hospice).

**Recommendation 1: Service commissioners and providers should note that it is not generally the case that the MB hospices re-direct patients from home as a place of death to hospice, but that the re-direction is from hospital to hospice.**

The particularly high proportion of hospice deaths in our patient interview sample (50%, n=17) reflects the biases in the sample. All patients had contact with specialist palliative care nurses working in the community, giving this cohort a greater chance of some contact with hospice services (for example, for day care) than the average MB cancer patient. However, this connection with specialist nurses *also* gave these patients greater opportunity of accessing services supporting a home death, should that have been their preference. This suggests that our examination of the place of death preferences and actual place of death patterns in this cohort has been of particular utility in throwing light on the factors shaping both the desire for and the ceiling on deaths at home.

## **(ii) Preference for place of death**

- In Chapter 2 it was reported that recent UK studies on cancer patients' place of death preferences had found that:
  - Between 50% and 90% of patients would prefer to die at home.
  - Among the patients in the highly regarded study by Townsend et al (1990), this figure was 58% (reducing to 49% as death approached) together with:
    - 20% - hospice preference
    - 20% - hospital preference
  - Dunlop (1989) found patient preferences for place of death as follows:
    - 53% - home
    - 29% - hospice
    - 14% - hospital
    - 3% - nursing home.
  - Studies have found that a minority of patients switched their preference from a home death to one in another setting as death approached and new illness management difficulties arose.
- In our patient cohort, of those patients who expressed a preference for place of death (n=28) the preference pattern was as follows:

- 36% (10) - home
- 29% (8) - hospice
- 32% (9) - home *or* hospice
- 3% (1) - nursing home
- 0% - hospital
- Expressed another way, a home death was a *preferred or acceptable* option for 68% (n=19) of patients while a hospice death was a *preferred or acceptable* option for 61% (n=17) of patients.
- Of those patients who completed the interview series (17), 4 (23%) altered their preference in a later interview.

**Discussion:** It is now a conventional wisdom that most cancer patients would prefer to die at home, and this is reflected in the push towards the greater facilitation of deaths at home in current palliative care policies at national and local Cancer Network levels. Findings from our patient interviews support this: the greatest single preference was for a home death (36%). However, as a sole preference, this home preference is lower than would be expected from other studies. In contrast, the preference for a hospice death (29% as sole preference) is higher in our study than was found by Townsend et al (1990). What really differentiates our study, however, are the findings that an additional 32% of patients held an equal preference for a home *or* hospice death, and that no patient wished to die in hospital. *This means that preferences in our sample were overwhelmingly in favour of either a home or a hospice death.* Thus we would have to qualify any endorsement of a strong policy push towards home deaths by pointing to an almost equal preference for death in hospice.

The biases in the sample, summarised above, certainly play a role here. Seventy-three per cent of patients had personal contact with one of the two hospices in the MB area. Hospice experiences were overwhelmingly positive, contributing to a hospice being a place of death preference for many. If the sample had been strictly representative of the MB cancer population there would no doubt have been a small percentage of patients who would have expressed a preference for a hospital death. This would have included, for example, patients with particular tumour types, such as lymphomas, because such patients would have forged an especially close association with hospitals for treatment and palliation purposes. Nevertheless, it is reasonable to conclude that a larger and strictly representative sample would also have yielded place of death preferences that were strongly in favour of home or hospice (singly or in combination). The factors associated with these preference patterns are examined below.

**Recommendation 2: In the main, cancer patients in the MBA would prefer to die either at home or in hospice. Services should be in place to accommodate these preferences.**

### **(iii) Do preferences for place of death match outcomes?**

Among patients in our interview cohort who had died by the end of the study (35):

- 60% (n=6) of those whose sole preference was to die at home actually died at home.
- 100% (n=4) of those whose sole preference was to die in hospice actually died in hospice.
- 100% (n=9) of those whose preference was to die *either* at home *or* in hospice actually died at home or in hospice; but 7 of the 9 died in hospice.
- Although no patient had a preference to die in hospital, 7 (20%) did die there.
- Of deceased patients whose sole preference was to die at home, 50% (n=2) in the Barrow/Ulverston area died at home; 66% (n=2) in the Kendal area died at home; 60% (n=3) in the Lancaster area died at home.
- 21% (n=3) of deceased patients who lived alone died at home compared with 28% (n=5) of patients who lived with others. Thus living alone did not result inevitably in the death occurring in an institutional setting.

In interview, health professionals, particularly those in hospice settings, reported that:

- The demand for hospice beds often exceeds supply, even in the Lancaster area.

**Discussion:** Given the small numbers involved in our cohort of interviewed patients, caution is required in the interpretation of these findings. Nevertheless, a clear picture emerges: patients who wished to die at home were not always able to do so. This was true for all three localities in the MB area. In contrast, patients who wished to die in hospice were all able to do so. If a patient had an equal preference for a home or hospice death, their preference could be met in all cases, but these deaths were overwhelmingly accommodated in hospice rather than at home.

Despite not wanting to die in hospital, a fifth of patients did end their lives in one of the three hospitals in the MB area. The numbers involved in this sample are too small to examine inter-area variations in place of death locations within the MBA. However, our geo-epidemiological analysis of 6,900 cancer deaths found that patients living in the Barrow area were 84% *more* likely to die in hospital, while those in the Kendal district were 68% more likely to do so, than those living in the Lancaster district. Conversely, patients living *outside* the Lancaster area were between 36% and 51% *less* likely to die in a hospice than those living within the Lancaster area.

**Recommendation 3: If patients' place of death preferences are to be met, specialist and non-specialist palliative care services in all parts of the MB area will require development and reconfiguration such that patients are enabled to die at home in greater number, and are supported in avoiding a hospital death (unless that is their preference). This would begin to reverse the trend away from home deaths reported above (i).**

**Recommendation 4:** The high level of preference for a hospice death found in this study, together with the 100% match between preference and outcome for hospice deaths, indicates that the current level of hospice bed provision in the MB area should be sustained. Thus, the development of community based services to support a greater number of home deaths that is recommended above should not be at the expense of hospice beds.

**Recommendation 5:** The geographically skewed nature of hospice bed provision within the MB area is problematic, resulting in an increased chance of dying in hospital as one moves from Lancaster, through Kendal and westward to Barrow. Service commissioners and providers should examine the possibilities for equalising access to hospice beds across the MB area.

**(iv) Do place of death patterns in the MBA suggest social inequality in place of death opportunities?**

The geo-epidemiological analysis of 6,900 cancer deaths (1993-2000) in the MB area found that (controlling for other variables):

- Deprived electoral wards are significantly more likely to have cancer patients dying in hospital.
- Cancer patients are *more* likely to die at home if: they are male; they are relatively young; they have cancer of the respiratory system; and live in Barrow or South Lakeland.
- Cancer patients are *more* likely to die in hospital if: they live in more deprived wards; live in Barrow or South Lakeland; they are male; they are older people; they have cancer of the lymphatic system.
- Cancer patients are *more* likely to die in hospice if they are relatively young and live close to a hospice.
- There are proximity effects, with wards relatively close to a hospice *more* likely to have patients dying in a hospice. The same is true for hospital deaths.

*Discussion:* Our research did not find an association between the proportion of deaths at home and patients' socio-economic status (as measured by ward affluence/deprivation). This modifies the findings reported by researchers (Higginson et al 1999) who have found an inverse association between home deaths and deprivation, but without making adjustment for other variables (in particular, local variations in the supply of hospice services). We did find a

positive association between the proportion of deaths in hospital and deprivation, and an inverse relationship between the proportion of deaths in nursing homes and deprivation.

In common with other studies, we found that there are associations between gender and age and place of death. Men are more likely to die at home but gender has no effect on the likelihood of death in hospice. Women are more likely to die in nursing homes. Younger patients are more likely to die at home or in a hospice, while older cancer patients are more likely to die in hospital.

**Recommendation 6: Specialist palliative care service commissioners and providers will be pleased to know that home and hospice deaths are not differentially patterned by socio-economic status in the MB area. However, deaths in other settings do show such variations. These and other social variations (gender, age, proximity to services) in place of death that are in evidence should be addressed because some of them amount to health care inequalities in the face of the overwhelming patient preference for either a home or hospice death.**

#### **(v) Factors that influence *actual* place of death**

The analysis of data from our three data sources has produced a list of factors that influence the place of death of cancer patients in the MB area. These are presented in Table 24, with details provided for each factor according to the data source. These factors work singly and in combination to determine place of death outcomes. In headline form, the factors are as follows:

<b>Factors influencing actual place of death</b>
Service provision and usage, including proximity to services.
Changes in hospice services (towards day-care and higher patient throughput).
Symptom management.
Carer's capacity to care.
Patient's social circumstances.
Patient and carer attitudes to death and dying, and the strength of their place of death preference.
Patient gender.
Patient age.
Patient socio-economic status.
Tumour type.
The historical trend towards an increased proportion of patients with complex needs.

**Discussion:** The literature on place of cancer deaths (see Chapter 2) has identified many of the same factors as are listed above (that is: service provision, distance to services, carer availability and capacity, symptom management, gender, age, socio-economic status, tumour type, strength

of patient preference). The additional factors in our list are ‘changes in hospice services’ and ‘the historical trend towards an increased proportion of patients with complex needs’. Our study therefore confirms and extends knowledge of the factors that shape the place of death of cancer patients, and we have been able to engage in an examination of these factors at a level of detail rarely found in other studies. There is no reason to believe that any of the factors that operate in the MB area are exclusive to it, and thus our study contributes to the general understanding of the factors in play.

The most important influence on place of death in the MBA is the pattern of service provision. This factor is critical in placing a ceiling on the proportion of deaths that can be supported at home. The health professionals interviewed spoke at length about the type and scope of specialist palliative care services in their localities, and all suggested that service supply side factors were the key influence on place of death outcomes. While there are many common service ingredients across the MBA, there are also marked variations by locality, for example in: the number of palliative care beds and hospice capacity; the range of specialist staff involved in services; service funding levels; the availability of Marie Curie night-sitting services, 24-hour district nursing, and out-of-hours palliative care expertise. Some professionals had a sense of inequity in the distribution of resources across the Bay, with the Barrow end of the patch being the ‘poor relation’.

All professionals interviewed wished to see greater opportunity for home deaths if that was the patient and carer preference. However, none could see how significant progress could be made in this regard without increased resources being made available for specialist and non-specialist palliative care. The further development of community based palliative care services was seen by all to be important, though *not* at the expense of other services.

The specialist palliative care nurses (SPCNs), in particular, discussed the ways in which a lack of necessary palliative care services in the community often meant that ‘crisis’ situations arose for patients and carers that could not be coped with at home. This might lead to a hospice or hospital admission, followed by a death in these settings:

***Recommendation 7: Service commissioners and providers in the MB area should consider the ways in which community based palliative care services (specialist and non-specialist) can be further developed, but not at the expense of hospice provision. The community services in greatest need of development are: 24-hour district nursing services, an out-of-hours on-call specialist palliative care service, all-week Marie Curie night sitting services, more comprehensive social service support.***

The second most important influence on place of death in the MBA is the capacity of the main informal carer. This, of course, is linked to other factors, especially the patient’s social circumstances and symptom management. SPCNs and other front-line professionals reported having observed many scenarios in which a carer reached a point when s/he felt unable to cope at home with a patient’s illness - for example, with the patient’s pain or other symptoms, or with the patient’s emotional state. Carers could become exhausted through lack of sleep, or may no longer be able to manage the emotional strain of seeing a loved-one slipping away. The interviewed patients and carers confirmed these observations. Thus, for a number of reasons, carers often needed to call upon more comprehensive professional assistance, though they might leave this to the last ‘crisis’ moments, only giving up their struggle to shoulder the main care burden at home when all extant resources were used up. If professional assistance was not forthcoming, or did not allow for the full support of the patient *and carer* at home, patient care would usually be relocated to a hospice or hospital. In such situations, many patients and carers had to give up on any desire for the death to occur at home. This could leave the carer with regret or guilt in the aftermath of death.

**Recommendation 8: Service commissioners and providers in the MB area should consider the ways in which support for informal carers can be maximised so that deaths at home can be supported, if that is the patient and carer preference.**

**Recommendation 9: In developing services, commissioners and providers should take account of the full range of factors detailed in Table 24.**

**(vi) Factors that influence preference for place of death**

The analysis of data from two of our data sources (professionals’ interviews, patient and carer interviews) has produced a second list of factors associated with patient and carer *preference* for place of death in the MB area. These are presented in Table 25, with details provided for each factor according to the data source. In headline form, the factors are as follows:

<b>Factors associated with patient and carer preference for place of death</b>
Patient concern for the welfare of the carer/family.
Patient’s assessment of the carer’s capacity to care.
Patient’s fears of loss of dignity
Symptom management.
Patient’s social circumstances.
Patient and carer perceptions of the reliability of services, and the degree of ‘safety’ they offer.
Patient’s attitude to a hospice

Patient's knowledge and experience of hospitals.
Patient's knowledge and experience of community services.
Patient's attitude to nursing homes.
Patient's attitude to, and outlook on, death and dying, including religious faith.
Previous personal experience of death and dying.
Carer's attitudes and willingness to care.

**Discussion:** In Chapter 2, it was noted that the factors that influence cancer patient and carer preference for place of death are poorly understood, with only a few factors having been identified, as follows: symptom management, gender, having a religious faith, and previous personal experience of death and dying. As Higginson and Sen-Gupta (2000: 299) noted in their review of the literature on this topic:

No consistent conceptualisation of the factors that determine preferences for place of terminal care of patients with cancer emerged from the studies reviewed and this should be the focus for future work [...]

We would suggest that this study has contributed in a significant way to the consistent conceptualisation of these factors. A cursory glance at the list of factors in Table 25, and at the detail that accompanies their presentation, will reveal that they are not likely to relate exclusively to the MB setting, but have a more general relevance. Two important points can be made about these factors.

First, these are factors that have become apparent through a qualitative methodological engagement with patients, carers and health professionals. This has enabled the subtleties of place of death preference to become evident. We have found that preferences are not always clear cut, may sometimes be absent, are often 'either-or' (see (ii) above), and are frequently seen by their holders to be contingent upon future eventualities as yet unknown ('it depends on how bad things get...'). Thus preferences were rarely stated categorically by patients, but tended to take the form of a leaning in one direction, qualified by a commentary on their concerns about the well-being of others in their lives and by speculations about how things might change with events. This leads us to be somewhat sceptical about the apparent certainty of patients preferences for place of death as reported in other studies (see the review by Higginson and Sen-Gupta, 2000).

Second, in the context of an emerging policy mantra that 'cancer patients wish to die at home', our list of factors suggest strongly that patients sometimes have good reasons for not wanting to die at home. Principal among these are: patients' concerns for the well-being of carers and family; their beliefs that their carers are unable to shoulder the burden of care; their fears for a

loss of dignity when the self-care of the body ceases; their concerns about the management of distressing symptoms; and the favourable impression that is formed of hospices through day-care visits or in-patient episodes. When a home death is not perceived to be an option, patients almost invariably turned to the hospice as the favoured place of death.

There is clear evidence in this study that the changing nature of hospice services – the growth in day-care provision and the encouragement of in-patient stays of short duration that allow a patient to return home (resulting in increased patient throughput) – operates as a factor in generating patient preferences for end of life care in hospice settings. That is, because an increased proportion of the cancer patient population in the MB area come into direct contact with a hospice, and because contact with a hospice almost always generates a very high regard for it, the proportion of patients who wish to end their days in hospice grows.

***Recommendation 10: Specialist palliative care service commissioners and providers (local, national) should take account of all of the factors associated with patient place of death preferences documented here. With these in mind, and with utmost sensitivity, professionals working with patients should seek to identify and understand the preferences that both patients and carers hold, and should be alert to tracking any change in preference. In doing this, it should be recognised that patients take many considerations into account, and that preferences are formed in the light of patients' personal histories and current social relational contexts.***

#### **(vii) Other study findings and recommendations**

In the summary sections of Chapters 5 to 9, a number of other important findings are reported, and much additional detail is supplied to support the key findings presented above. In brief, our other findings and recommendations are as follows:

- Patients and carers generally lacked knowledge about the way in which they had been referred to a specialist palliative care nurse (SPCN), reflecting their more general lack of knowledge about service structures, systems and options. This suggests that patients who are not referred within the system to a specialist nurse are unlikely to know about the existence of the SPCN service, nor about how to access it.

***Recommendation 11: There should be greater (early) provision of information to patients and carers on the range of services available and on their means of access.***

- Patients' experiences of *GP services* were very variable. Some GPs were closely involved in the care of the patient, but many were reported as merely prescription providers. Some GPs were much trusted and praised, but others were felt to be of little help. GPs were valued if they had time for patients, they expressed interest and concern, and were easily accessible. Less helpful GP attributes were perceived to be: an indifferent attitude, slow referral to

specialist services, and inaccessibility. Mild criticisms were made by most patients and carers of out-of-hours service arrangements, focusing on the problems raised in their encounters with doctors unfamiliar with the details of their case. However, serious difficulties associated with the limited scope of assistance provided by an on-call doctor were reported by one carer.

***Recommendation 12: Increased opportunities and incentives for training in palliative care should be made available to GPs.***

***Recommendation 13: Out-of-hours services in the MB area should receive assistance in developing their palliative care capacity (especially: training of staff, availability of specialist drugs)***

- Bereaved carers who had seen their loved-one die in hospital had mixed evaluations of the end-of-life care received there, with aspects of this care being heavily criticised in three cases (of the 7 cases of hospital death).

***Recommendation 14: Hospital services should be assisted in improving the quality of end of life care.***

- Some patients want to obtain more detailed and explicit information about the likely course of development of their disease, about the symptoms that might occur, and about the meaning and significance of symptoms as indicators of the nearness of death. This knowledge, they feel, would help them 'to prepare'. However, patients are aware that these matters carry a high sensitivity value, and are appreciative of the fact that this can make it difficult for them to ask questions and for professionals to supply answers.

***Recommendation 15: Professionals in close contact with patients should be aware that many patients want, but are unlikely to ask for, more explicit and detailed information about the course of their disease, about the symptoms that are likely to occur, and about the signs that indicate that death is fast approaching. Professionals may need support/training in identifying and responding to this need.***

- Carers who deal with patients in whom cognitive deterioration is evident have pressing and particular support needs.

***Recommendation 16: Professionals should be responsive to the particular needs of a carer dealing with a patient with high levels of emotional distress and/or cognitive deterioration.***

- Our study has underlined the importance of different dimensions of the patient's social context.

***Recommendation 17:* In assessing the patient's need for formal health and social services, health and social care professionals should gain a full understanding of the contours and dynamics of the social relationships involved in the patient's social setting. The informal care resource has to be assessed (and re-assessed over time) so that it can be worked with to optimal effect. This would be of benefit to both patients and carers.**

- *Non-malignant conditions:* Most of the professionals interviewed noted that they dealt overwhelmingly with cancer patients (the specialist medical professionals interviewed occasionally dealt with patients with other conditions). All thought that palliative care services should be available to patients with non-malignant conditions, but noted that this could not be achieved within the constraints of existing services and resources. One respondent doubted, with regret, the fund-raising appeal of provision for conditions other than cancer.

***Recommendation 18:* Service commissioners and providers should give full consideration to extending specialist palliative care services so that patients with non-malignant conditions have an equal opportunity to access these excellent services.**

**Table 24: Factors associated with actual place of death, presented for the three study data sources**

Factors	Interview data: health professionals	Interview data: patients and carers	Geo-epidemiological data
<p><b>Service provision and usage, including proximity to services.</b></p>	<ul style="list-style-type: none"> <li>• The type and scope of provision of specialist palliative care services in the locality determines place of death options, especially:               <ul style="list-style-type: none"> <li>- Number of hospice and other palliative care beds.</li> <li>- The degree of development of specialist palliative care services directed at community/home settings, including specialist social work provision.</li> </ul> </li> <li>• The type and scope of provision of non-specialist palliative care services in the locality determines place of death options, especially:               <ul style="list-style-type: none"> <li>- District nursing coverage</li> <li>- GP training/skill in palliative care</li> <li>- Out-of-hours services</li> <li>- Marie Curie / night sitting services</li> <li>- Social services / social care support</li> </ul> </li> <li>• The timing of patient referral to the specialist palliative care team impacts on place of death options (e.g. late or ‘crisis’ referrals less likely to die at home).</li> <li>• The quality of collaboration between the primary health care team and specialist palliative care team has an influence on place of death options. A poor quality relationship means less chance of a home death.</li> <li>• The same is true for the quality of links that specialists have with out-of-hours service</li> </ul>	<ul style="list-style-type: none"> <li>• In situations of patient deterioration and emergency, the response of services is often to admit the patient to hospital, sometimes via A&amp;E</li> <li>• A hospice bed is not always available when required and this can result in a hospital admission.</li> </ul>	<ul style="list-style-type: none"> <li>• Distance to services. There are proximity effects influencing place of death: patients are more likely to die in a hospice or hospital if they live close to these services.</li> </ul>

	<p>providers.</p> <ul style="list-style-type: none"> <li>• The limited storage, use and knowledge of palliative care medicines by some GPs, especially out-of-hours staff works against the support of patients at home.</li> <li>• Limitations on the number of residential care/nursing home beds in a locality (i.e. limited intermediate care options) place restrictions on the number of patients who can be offered this place of care/death option. Limitations are related to Social Services policy, priorities and funding.</li> <li>• The speed with which patient information is passed from consultants to GPs in a locality (i.e. slow passage of information) may delay primary care involvement in palliative care, militating against home deaths.</li> <li>• The geographical distance between the patients' and/or carers' home and hospices/other services can be a factor in determining place of death (i.e. the greater the distance the less likely to die there).</li> </ul>		
<b>Changes in hospice services.</b>	<ul style="list-style-type: none"> <li>• In recent years, the opening up of hospices to greater numbers of patients through day-care services and policies of higher patient throughput has introduced greater numbers of patients to the hospice setting. A high proportion of these patients choose to end their lives in hospice. However, bed number limitations mean that not all can be accommodated.</li> </ul>		
<b>The historical trend towards an increased proportion of patients with complex</b>	<ul style="list-style-type: none"> <li>• The increased life expectancy of people with cancer in the palliative care phase has led to the growth in the number of patients with complex needs who are unlikely to be</li> </ul>		

<b>needs.</b>	managed at home in current service contexts.		
<b>Symptom management</b>	<ul style="list-style-type: none"> <li>The nature and severity of symptoms sometimes means that the patient cannot be supported at home under current service arrangements. This directs the patient to hospice or hospital, and the death is more likely to occur in these settings.</li> </ul>	<p>Carers' accounts indicate that symptom management crises occurred, often resulting in an emergency admission to hospital or hospice, usually followed by death soon after in that setting. Patients and carers relied on professional advice in these circumstances, though the feelings and abilities of the carer were relevant in decision making. Crises were marked by:</p> <ul style="list-style-type: none"> <li>Very sudden deterioration.</li> <li>Uncontrolled symptoms, e.g. pain.</li> <li>Distressing or frightening symptoms (to both patient and carer, e.g. cognitive deterioration).</li> <li>If the deterioration occurred away from home, then the patient is unlikely to return home.</li> <li>In some crises, another lay person or service (e.g. police) would intervene and influence events and thus the place of death.</li> </ul>	
<b>Carer's capacity to care</b>	<p>This depends on:</p> <ul style="list-style-type: none"> <li>Carer's physical and psychological/emotional health status, fitness.</li> <li>Carer's age.</li> <li>Intensity and duration of caring demands (degree of exhaustion of carer).</li> <li>Other demands on the carer – employment, children, other family members.</li> <li>Carer's attitude/outlook (e.g. willingness to provide care at home).</li> <li>Quality of relationship between patient and carer/family.</li> </ul>	<p>Patients and carers made an assessment of the carer's capacity to care in terms of:</p> <ul style="list-style-type: none"> <li>Carer's own health problems.</li> <li>Carer's emotional state.</li> <li>The level of support available to carers from other family members.</li> <li>The level of support available to carers from health and social services.</li> <li>The nature of the care work needed at the end of life – e.g. intimacy of care tasks, carer's ability to lift patient.</li> </ul>	
<b>Patient's social circumstances</b>	<p>The patient's social circumstances play an important role in determining their place of death options, especially:</p>	<p>Patients made an assessment of their social circumstances in considering their likely place of death, highlighting:</p>	

	<ul style="list-style-type: none"> <li>• Whether the patient lives alone or with others.</li> <li>• Socio-economic status/social class. Patients of lower socio-economic status often have family networks (carers) in the locality whereas those of higher socio-economic status may have moved away from family and friends to retire in the MB area.</li> <li>• Age and gender</li> <li>• Household composition – who lives in the household, and their relationship to one another</li> <li>• The quality of wider community relationships in which patients and carers are embedded .</li> <li>• Carers’ employment status.</li> <li>• Carers’ childcare or other caring responsibilities.</li> <li>• The nature/suitability of the patient’s living environment: space, stairs, location of bathroom/toilet, cleanliness etc.</li> </ul>	<ul style="list-style-type: none"> <li>• Whether a carer is present or not.</li> <li>• Whether they lived alone or with others, and their preference for living arrangements.</li> <li>• Whether fearful about being alone when their condition deteriorates.</li> </ul>	
<p><b>Patient and carer attitude and outlook to death and dying, and to place of death</b></p>	<p>Place of death may be influenced by:</p> <ul style="list-style-type: none"> <li>• Whether the patient is ‘facing up’ to their impending death (‘in denial’, non-acceptance of death).</li> <li>• Patients’ more general values and beliefs.</li> <li>• The strength and visibility (to service providers) of patient and carer preference/desire for a particular place of death.</li> </ul>	<p>Some patients expressed:</p> <ul style="list-style-type: none"> <li>• Their determination to die in a particular location.</li> <li>• Their desire not to die in particular locations.</li> </ul> <p>Some carers expressed:</p> <ul style="list-style-type: none"> <li>• A determination to keep the patient at home.</li> <li>• A preference for care to occur away from home.</li> <li>• Fears and distress about what would happen as the illness plated out.</li> </ul>	

<b>Patient gender</b>			<ul style="list-style-type: none"> <li>• Male patients are <i>more</i> likely than females to die at home.</li> <li>• Male patients are <i>more</i> likely than females to die in hospital</li> </ul>
<b>Patient age</b>			<ul style="list-style-type: none"> <li>• Young patients are <i>more</i> likely than older patients to die at home.</li> <li>• Young patients are <i>more</i> likely than older patients to die in hospital.</li> <li>• Young patients are <i>more</i> likely than older patients to die in hospice.</li> </ul>
<b>Patient socioeconomic status</b>			<ul style="list-style-type: none"> <li>• Deprived electoral wards are significantly more likely to have cancer patients dying in hospital.</li> <li>• Ward-level deprivation is a significant determinant of whether patients die in a nursing or retirement home, with less deprived wards more likely to have patients dying there.</li> <li>• Ward-level deprivation has no effect on the probability of dying either in a hospice or at home.</li> </ul>
<b>Tumour type</b>			<ul style="list-style-type: none"> <li>• Patients are <i>less</i> likely to die at home and <i>more</i> likely to die in hospital if they have cancer of the lymphatic system.</li> <li>• Patients are <i>more</i> likely to die at home if they have cancer of the respiratory system.</li> </ul>

**Table 25: Factors associated with preference for place of death, presented by the two data sources**

<b>Factors</b>	<b>Interview data: health professionals</b>	<b>Interview data: patients and carers</b>
<b>Patient concern for the welfare of the carer/family.</b>	<p>Patients sometimes prefer a hospice or hospital death because:</p> <ul style="list-style-type: none"> <li>• They do not want to be ‘a burden’ on loved ones.</li> <li>• They do not want the family (especially children) to have to live with a memory of the death occurring in their home setting.</li> </ul>	<p>Some patients expressed a preference for a hospice death because they:</p> <ul style="list-style-type: none"> <li>• Did not want to be a burden on family/friends, particularly on offspring who had other commitments.</li> <li>• Did not want to leave the ‘memory’ of their death in the house. This is also related to not leaving memories that were clouded by the patient’s distress and pain – so symptom management is also relevant here.</li> <li>• Did not wanting to ‘put them through it’, thus preferring end of life care to be managed by professionals.</li> </ul> <p>Some patients indicated their concern to ‘care for the carer’, and that this was a priority up to and beyond death, e.g. by putting their affairs in order.</p>
<b>Patients’ assessment of the carer’s capacity to care.</b>	<p>Patients take the following into account when talking about their care needs and place of death preferences:</p> <ul style="list-style-type: none"> <li>• The carer’s health status</li> <li>• Other demands on the carer – employment, family.</li> <li>• The nature and quality of their relationships with the carer/family.</li> </ul> <p>Any difficulties here direct patients towards the hospice, hospital or other institutional setting as their place of death preference.</p>	<p>Patients’ preferences for place of death took the following into account:</p> <ul style="list-style-type: none"> <li>• The main carer’s frailty or incapacitation through illness.</li> <li>• The emotional stability of the carer/s.</li> <li>• The caring skills of the carer. Some carers were noted as having particular ‘qualifications’ for caring, e.g. worked as nurses/care assistants.</li> <li>• The closeness of the emotional bond with the carer/s.</li> <li>• The carers’ other commitments (e.g. family/work).</li> </ul> <p>Any difficulties here direct patients towards the hospice as their place of death preference. Care by professionals may be favoured in situations where informal caring options are perceived to be problematic, undesirable or impossible.</p>
<b>Patients’ fears of loss of dignity</b>	<ul style="list-style-type: none"> <li>• When intimate care work is involved (e.g. dealing with incontinence), some patients prefer to be cared for by professionals than by relatives (especially if the carer is a son or grandchild).</li> </ul>	<p>Patients’ preferences for place of death took account of:</p> <ul style="list-style-type: none"> <li>• The appropriateness of particular carers undertaking intimate care tasks (e.g. toileting, bathing). For example, it might be thought ‘not right’ that a son would undertake certain ‘personal’ care tasks. These assumptions were heavily influenced by gender norms.</li> </ul>

		<ul style="list-style-type: none"> <li>Their concerns and worries about managing symptoms such as incontinence. These factors may direct a patient's preference towards professional rather than lay care arrangements at the end of life.</li> </ul>
<b>Symptom management.</b>		<ul style="list-style-type: none"> <li>Some patients expressed a difficulty in forming a place of death preference because there were uncertain about the progression of the disease and about what the signs of dying might be.</li> <li>Some patients expressed fear of potentially uncontrollable symptoms leading to loss of bodily control (e.g. incontinence, pain, mental deterioration). Their concern about this tended to be associated with place of death preferences that involved professional care (hospice).</li> <li>Some patients did not want carers to have to witness distressing symptoms – leading them to favour professional end of life care in hospice.</li> </ul>
<b>Patient's social circumstances.</b>		<p>Patients' place of death preferences took account of:</p> <ul style="list-style-type: none"> <li>The range and availability of 'supportive others' (family, friends) for final care, especially where the patient lived alone.</li> <li>The quality of relationships with people in the wider community – friends, neighbours.</li> <li>Fears of being alone and vulnerable.</li> <li>The type and location of facilities in the home that related to mobility and hygiene (bedroom, bathroom, toilet, kitchen etc).</li> </ul> <p>Any difficulties here direct patients towards the hospice as their place of death preference.</p>
<b>Patient and carer perceptions of the reliability of services, and the degree of 'safety' they offered.</b>		<p>Patients and carers valued services that that experienced as:</p> <ul style="list-style-type: none"> <li>Available and accessible</li> <li>Responsive to carers needs as well as patients'.</li> <li>Engendering feelings of reliability, 'trust' and 'safety', i.e. that known professionals and services would 'be there when you really needed it'.</li> </ul>
<b>Patient's attitude to the hospice</b>	<ul style="list-style-type: none"> <li>Some patients dislike or fear the 'death' connotations of hospices. This may be linked to not facing up to their impending death. A hospital may be preferred as the location of care because of its 'cure' and 'treatment' associations.</li> <li>Once patients visit a hospice, they almost always develop a very</li> </ul>	<ul style="list-style-type: none"> <li>Where a patient had no direct experience of a hospice, it tended to be viewed negatively.</li> <li>Where a patient had been a hospice in-patient or had attended day care, evaluations of the hospice tended to be overwhelmingly positive and to transcend general cultural views of hospices as grim 'places to die'. Only</li> </ul>

	positive regard for it. Negative pre-conceptions are usually dispelled. It may become the preferred place of death option.	in one case was a patient was put off the hospice by an admission experience.
<b>Patient's knowledge and experience of hospitals.</b>	<ul style="list-style-type: none"> <li>Most patients do not want to dies in hospital, but extensive contact with particular hospital services (e.g. lymphoma patients) may mean that they develop a preference for a hospital death.</li> </ul>	<ul style="list-style-type: none"> <li>Hospital experiences were usually off-putting and associated with a preference for death to occur elsewhere.</li> <li>Several patients stated a strong preference not to die in hospital</li> </ul>
<b>Patient's knowledge and experience of community services.</b>		<ul style="list-style-type: none"> <li>A preference for a home death was usually associated with a strong sense of trust in community-based professionals.</li> </ul> <p>A home death may not be seen to be an option because:</p> <ul style="list-style-type: none"> <li>Some patients and carers have anxieties that symptom relief may not be available to the patient at home e.g. when having to consult out-of-hours services, or because of the time taken for a professional to arrive.</li> <li>Some patients and carers lack knowledge about the availability of community service support.</li> </ul>
<b>Patient's attitude to nursing homes.</b>		<p>With one exception, nursing homes were not preferred options for place of death because:</p> <ul style="list-style-type: none"> <li>Generally, the image of nursing homes was poor, and knowledge of them limited.</li> <li>Several patients stated a strong dislike of nursing homes.</li> <li>Younger patients felt they would be out of place. Those that had made enquiries found that few homes took people under 65 years of age.</li> </ul>
<b>Patient attitude to, and outlook on, death and dying, including religious faith.</b>	<p>A patient's place of death preference:</p> <ul style="list-style-type: none"> <li>May not be formulated because the patient is not 'facing up' to their impending death, is 'in denial'.</li> <li>Is influenced by their general values and beliefs. These may pre-dispose them to a particular place of death option.</li> </ul>	<ul style="list-style-type: none"> <li>Some patients reported not wanting to think about dying. Some hoped they might die in their sleep, or were leaving it to chance. Thus, place of death preferences were unformed.</li> <li>Some patients were 'realistic' about their situation, were likely to have thought about place of death options, and to have formed a preference.</li> <li>Patients with a religious faith tended to be quite matter of fact about death, and not to be particularly concerned about place of death.</li> <li>Some patients were determination to maintain their identity and independent social functioning for as long as possible. In some cases, this was related to wanting to manage their own death and dying as much as possible, though there was usually a recognition that they may need to hand control over to others as death drew very close. Preferences could be for a home or hospice death.</li> </ul>
Previous personal		<ul style="list-style-type: none"> <li>Where patients and carers had faced death before in their lives they</li> </ul>

<p>experience of death and dying.</p>		<p>tended to be more matter of fact about death and to have no particular preference for place of death.</p> <ul style="list-style-type: none"> <li>• Experiences of others' deaths could colour place of death preferences depending on how 'good' or 'bad' the death had been.</li> </ul>
<p><b>Carer's attitudes and willingness to care.</b></p>		<ul style="list-style-type: none"> <li>• Some carers' expressed fears about being able to manage the care tasks and emotional challenges. This might be associated with a preference for the care and death to be managed in a hospice.</li> <li>• Some carers were concerned to 'put the patient first' – to go along with the patient's wishes for place of death even though their own preference differed.</li> <li>• The degree of a carer's determination to manage the patient at home played a role in determining the strength of a patient's attitude to a home death.</li> <li>• If carers felt unsupported by others (e.g. by family and/or service providers) they sometimes expressed a hospice place of death preference.</li> </ul>

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## APPENDIX 1 The research proposal (1998)

**Title:** Place of Death in Morecambe Bay Health Authority (MBHA): patterns and preferences for place of final care and death among terminally ill cancer patients and their carers.

### Objectives

The need for the proposed research has been identified by Morecambe Bay Health Authority, and has the support of key oncology clinicians in the MB NHS Acute Trust together with representatives of cancer user groups in the area (see 'Background'). *The immediate study objectives are:*

- 1) To gain an understanding of the unusual (compared with the national) profile of 'place of death' patterns for cancer patients in the MBHA area.
- 2) To describe and explain how decisions, events and circumstances interact to determine actual place of death for cancer patients in the MBHA area.
- 3) To identify the preferences of terminally ill cancer patients and their informal carers in the MBHA area regarding the place of palliative/final care and the place of death. *The longer term objectives are:*
- 4) To provide information which can assist in the further development of a palliative care strategy by MBHA, one which has support from service providers in a range of settings as well as lay service users. A key issue which the research would inform is whether to establish a specialist palliative care service in the community.
- 5) To contribute to health services research in the rapidly changing field of palliative care, a field in which leading scholars acknowledge a) that there are many unanswered questions about patient/carer preferences, and b) that average national patterns and levels of general and specialist palliative service provision and usage should not be mistaken for recommended levels for optimum care<sup>1 (p.202), 2, 3</sup>; thus there is no single 'ideal model of care'. The unusual configuration of services in MBHA, especially in the Lancaster locality (with its relatively high level of hospice beds per capita), offers the opportunity to provide valuable new insights for palliative care elsewhere.

### Background

#### *Key policy developments - national, regional, local*

The Government is pledged to work towards the effective implementation of the Policy Framework for Commissioning Cancer Services<sup>2</sup>, including a commitment to high quality palliative care services which are responsive to the individual needs and preferences of people with cancer, their families and carers.<sup>4</sup> This has initiated a process of designation, development, and accreditation of palliative care services.<sup>5</sup> In response to this the NW Region Palliative Care Group has embarked on a programme of accreditation of adult palliative care services within the region, including local self-assessments.<sup>6</sup> The self-assessment currently underway in the Morecambe Bay (MB) area has spawned this research proposal. MBHA has reviewed palliative care services in the district and considered the options for service development.<sup>7</sup> One of the issues which has emerged is the marked difference between the MBHA 'place of death' profile for cancer patients as compared with the national one. In addition, there are marked variations in the place of death of cancer patients across the district:<sup>8</sup>

- Nationally, 55% of cancer patients die in hospital, 17% in hospice, and 26% at home (1993 E&W).
- In MBHA: 34% of cancer deaths occur in hospital, 36% in hospice, and less than 20% at home.
- Of those dying of cancer, hospice deaths account for: 23% of deaths in Furness and South Lakes; 28% in Kendal, and 48% in Lancaster. Only 10% die at home in Morecambe, compared with 16% in Kendal, 19% in Lancaster, 29% in South Lakes, and 24% in Furness.

The relatively high proportion of hospice deaths among cancer patients in Lancaster (48%) and Kendal (28%) stands out in comparison with Furness and South Lakes (23%) which is nearer the national average (17%). The Report noted that 'The reasons for these differences need to be understood before any major service changes are planned.... These figures show that the number of patients dying at home is lower than national averages. This may be the result of patient preferences and may reflect the development of hospice services'.<sup>7</sup> The need for this research proposal was thus identified by MBHA.<sup>7, 8</sup>

#### *Knowledge about cancer patients' and family/carers' preferences regarding place of death*

Policies are replete with statements that services must reflect users' preferences and accommodate choice, but what is known about preferences with regard to place of final care and death, and how does this compare with actual place of death? In an authoritative paper, Higginson<sup>1</sup> reviews the research evidence on all aspects of palliative care noting that:

- studies<sup>9, 10</sup> estimate that 50-70% of cancer patients would prefer to be cared for or to die at home;
- a longitudinal study<sup>11</sup> suggested that as death approached cancer patients changed their preferences: hospital and home became less preferred and hospice more preferred, although even one week before death 50% still wished to be cared for at home;
- there is strong evidence that conventional care alone fails to meet the needs of many patients and families/carers (for relief of pain and other symptoms; practical, social and emotional needs pre- and post bereavement);

- Addington-Hall et al.<sup>12</sup> found that for both cancer and non-cancer deaths there had been continued problems of unrelieved pain and other symptoms and that relatives bore the brunt of caring. Despite preferences to be cared for/ to die at home, acute hospital admission in times of crisis was common.

A recent study<sup>13</sup> comparing cancer patients who did/did not die at home found that: 21% of patients died at home; 38% of all patients were reported by bereaved carers to have expressed a preference for place of death - 73% of whom wanted to die at home; of those who had expressed a preference for a home death, only 58% had achieved this. It was concluded that crucial to the achievement of a home death were: recognition of a preference for a home death, the motivation to 'stick it out' at home, and adequate community support to provide the practical means to fulfill the preference. Another recent study in Doncaster Health Authority found statistically significant evidence that place of death is associated with social class, highlighting issues of equity of access to services; the authors conclude that more research is needed into the distribution of preference for place of death among cancer patients.<sup>14</sup> There is other research evidence that the pattern of place of death also varies with age and ethnicity.<sup>3</sup> In summary, there is evidence that (i) the majority of cancer patients would prefer to die at home, (ii) only a small proportion of these have their preferences fulfilled, (iii) there are marked but largely unexplained variations in place of death associated with social class and other social variables - little is known about the social distribution of place of death preferences.<sup>15, 16, 17</sup> There is no research evidence on these matters in MBHA which currently has a place of death pattern at variance with national averages, associated with developed hospice provision in Lancaster.

### **Plan of investigation**

In this under-researched area our approach is twofold: (a) to *build on* existing research designs by repeating (but not exactly) two studies reported in the medical/palliative care literature,<sup>14,9</sup> (b) to develop these studies in new directions as appropriate. The fact that the MBHA area has an unusual and internally variable configuration of hospice and other palliative care services means that this approach will yield particularly interesting data but preserve some degree of comparability. There are three key elements in the study design: i) the epidemiological study of place of death data, ii) the sociological study of patient and carer preferences concerning place of final care and death, and iii) the epidemiological and sociological study of patterns of service development and the views and preferences of professionals and other stake-holders. The research team has considerable strengths in these disciplines.

#### Objective 1: To gain an understanding of the profile of place of death patterns for cancer patients in the MBHA area

##### *Methods:*

A preliminary assessment of place of death, by locality, has already been undertaken in MBHA,<sup>7</sup> but the report called for further research into the determinants of place of death. Our first objective will be to model place of death using data from the Public Health Mortality File.<sup>14</sup> We shall do this using data for three years (1995-1997), since the MBHA report looked only at 1996. From the MBHA report we would expect about 2400 cancer deaths over this period. We shall use logistic regression and other generalised linear models to determine some of the influences on place of death, using covariates that come from the mortality data themselves (age, gender, tumour type) and from ancillary sources (such as the Census and geodemographic indicators). This will allow us to investigate variations in equity of access to hospice services. This research will provide a useful backcloth to the exploration of patient preferences (Objectives 2 and 3 below).

#### Objective 1 (above) and Objective 2: To describe and explain how decisions, events and circumstances interact to determine actual place of death in MBHA

We would describe the development of palliative care services in the MB area paying attention to the differences in Lancaster, Kendal, South Lakes and Furness. This would involve a 'rapid appraisal' of service provision using readily available documentary evidence and new data generated through semi-structured interviews with selected key professionals, voluntary sector workers and community leaders. Individuals to be approached for interview would be identified through 'snowball' or 'reputational' sampling techniques, c. 20 in total. In addition to enabling us to gather data on service developments and patterns of provision the interviews with key service providers such as GPs and cancer support nursing staff would enable the preferences of local 'stake holders' to be voiced. Service providers' explanations for current place of final care/death patterns in MB, and what they think would constitute and 'ideal' situation for patients and carers, will complement the study's other foci on patient and carer preferences.

#### Objective 2 (above) and Objective 3: To identify the preferences of terminally ill cancer patients and their family/carers in MBHA regarding the place of palliative/final care and the place of death

##### *Methods:*

We would conduct a very similar prospective study to that undertaken by Townsend et al,<sup>9</sup> reported in the BMJ in 1990. However, we would go beyond that study by giving much more weight to the qualitative data so generated - exploring the meanings patients and carers attach to their experiences. Protocols and systems would be set up by one of the applicants (Professor McIlmurray and his staff) so that the research team was routinely informed of patients diagnosed as having cancer, and those whom consultants thought likely to live for less than one year in the MB area. Among those thought likely to live for less than one year, a stratified (by area of residence) random sample will be selected (over 12 months) with a view of obtaining an achieved sample of 50 cancer patients across

the MBHA area. Interestingly, Townsend et al found that only a small proportion of their sample did not know their diagnosis or prognosis. An interviewer who has experience in interviewing the dying and bereaved (either the project researcher or a trained cancer support nurse already in contact with the patient) would approach those sampled at the stage when those in charge of their medical care estimated that the patient had about 2 months to live - travelling to the patients for interview. Following Townsend et al, patients would be interviewed at around fortnightly intervals. A semi-structured questionnaire incorporating some widely used measures (e.g. EORTC scales - QLQ-C30) would be used with carefully and sensitively crafted questions covering the following key areas: quality of life, levels of pain and other symptoms, what patients feel about current care arrangements, whether patients have plans for their future care. The aim would be to track care places/patterns and the reasons for any changes (e.g. for hospital admission), and to determine preferences for place of final care (a) given the existing situation, and (b) if circumstances were instituted to allow the choice.<sup>9(p.416)</sup> Carers would be interviewed for their assessment of the patient's care circumstances twice: whilst the patient was alive and three months after the patient's death.

#### Objectives 4 and 5

These longer term objectives would be met through the project's dissemination plans. In addition, two members of the research team (Mansfield, McIlmurray) would address these objectives being centrally involved in strategic decision-making concerning palliative care and other cancer services in the MB area.

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## APPENDIX 2 Documentary Evidence

- Barnett, D. (no date) Chaplaincy at St John's Hospice. <http://www.sjhospice.org.uk/chap.htm>
- Holdcroft, P. (1984) The role of the health visitor in oncology. *Health Visitor* 57: 103-104
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### Issues of the magazines:

*Rapport* (Published by CancerCare) February 1986- Winter 1995.

*Keeping in touch* (Published by St. John's Hospice) October 1987 - Winter 1995.

*Rapport Keeping in Touch: The magazine for cancer support and palliative care in North Lancashire and South Cumbria*. (Published by St. John's Hospice and CancerCare) 1995 – ongoing.

### Websites:

<http://www.sjhospice.org> (includes information about St. John's, Lancaster, CancerCare, Lancaster and St. Mary's, Ulverston)

<http://www.hospiceinformation.co.uk> (national information)

<http://www.hospice-history.org.uk/suba.htm> (HHP)

<http://www.hospice-spc-council.org.uk> (national information)

## APPENDIX 3 Description of the HHP

### **The Hospice Histories Project**

Founded in 1995 by Professor David Clark

Team members:

Dr Clare Humphreys (Research Associate)

Michael Wright (PhD student)

Margaret Jane (Secretary)

Anthony Greenwood (Support Manager)

Hospices and the palliative care movement to which they gave rise have helped to transform ideas and practice relating to the care of seriously ill and dying people and those close to them.

The work of hospice and palliative care is still developing rapidly and we take the view that understanding the past can lead to a better awareness of current issues and dilemmas. We characterise our approach to our subject matter as that of a 'critical friend'.

We also believe that it is important to capture now the voices and stories of the modern hospice founders.

There is a danger that important hospice records may be lost to posterity and so our project is seeking to safeguard these by drawing attention to sound archival procedures

Aims:

- Undertake and foster academic study in the history of hospices, palliative care and related fields
- Catalogue & help safeguard archival records relevant to hospice & related developments in Britain & Ireland
- Establish a hospice and palliative care digital archive

## APPENDIX 4 The HHP interview schedule

### Oral History Interviews

### Guidance on interviewing

“The rich store of social and historical experience held in the memories of people of all walks of life IS history. It is, or should be, recorded and used in a wide range of educational and cultural forms.”

(Trevor Lummis, 1987)

The purposes of the interview are

- (1) To obtain a public record of the person’s contribution to hospice and palliative care
- (2) To place this contribution in the wider context of the person’s life story

Interviews usually begin with the person’s early origins, followed by education, family life, professional training (if any), subsequent career/employment, and in particular involvement in palliative care. The interviewee should dictate what is said – for example, they may say more or less about early origins.

Try to avoid question and answer format, encourage a narrative or story.

Avoid superfluous questions or interjections – try to give non-verbal responses (nodding, smiling, shaking head) rather than verbal reactions (“Oh really!”, “Wow!!”, etc).

Take “off the record” comments in one of two ways:

Switch off recorder, but make a confidential note afterwards of what was said.

Tell interviewee that this passage will be removed from final CD ROM recording and transcript and flag the file accordingly.



## APPENDIX 5 The POD interview schedule

### Interview Schedule for professionals

NB as appropriate to occupational group

Section 1. - For participants not taking part in the HHP

#### Professional practice

Tell me about your contact with patients and carers in the terminal phase.

How many do you see?

What service do you provide?

What are your aims with them?

Are there any groups/types of people you don't see who might benefit from your services?

Change – past and upcoming?

Section 2. - For all participants

#### Place of death and final care

What do you know about where people die?

Any data sets?

Where do you think people want to die?

Do you think they have their preferences met?

Are there any gaps in the service?

What factors do you think affect where they die?

What do you think would be the ideal configuration of services?



## Patterns and preferences

October 2000-September 2002

### CRITERIA SHEET

**Please refer all patients who fit these criteria:**

- ◆ Aged 18 or over
- ◆ Diagnosed with cancer of any type
- ◆ Likely to die within a year
- ◆ Not receiving any treatment aimed at cure
- ◆ They may or may not be receiving palliative treatment
- ◆ They may or may not be receiving palliative services

**Please fill in as much of the referral form as you can.**

#### TERMS IN THE REFERRAL SHEET

**Tumour type** – please provide a general description.

(e.g lung, lymphoma, breast)

**Stage in the cancer journey** – please give any specific information about the illness or treatment here.

(e.g. palliative, receiving palliative radiotherapy/chemotherapy, terminal care, metastasised cancer)

**Any comments** – please make any comments about the illness or the patient's circumstances, which you feel may be relevant.

(e.g. living in a nursing home, lives with son/daughter, has young children, has aggressive dog, currently in hospital/hospice)

#### IMPORTANT NOTES

- ◆ We will contact you again before we approach any patients you refer.
- ◆ Even if you think the person should not be interviewed, please still refer them. You need not put their name and address, but we would like you to complete the rest of the form.

If you have any queries, or need more forms or envelopes, please contact Dr Sara Morris – Phone: 01524 594126

## APPENDIX 7 Patient and carer information sheet

### *The care preferences project*

#### Information sheet

We are conducting a research study in order to find out from people who are coping with serious illness about their preferred care arrangements. We are particularly interested in what kind of extra help people need and would like when faced with serious illness, what help is offered and the kind of help that is most useful. We also want to look at people's preferences for where their care takes place.

In order to find out what people want and need we are asking you to participate in a short series of interviews with a researcher. The interviews will be arranged to suit your convenience. The researcher will come to you and the interviews will be tape recorded with your permission. If you agree to take part you will be asked some very general questions, so that you have the opportunity to tell us what is important for you in your own particular circumstances.

All the information you give us will be held in strictest confidence and will not be passed on to anyone else in a form which can lead to the identification of individuals. Participating in the study will not affect your medical treatment in any way. Tape recorded interviews will be stored securely and destroyed at the end of the project.

We would like you to take part, but if, for any reason, you do not want to, you are completely free to refuse. Likewise, if you have initially agreed, and then wish to withdraw, you may do so without any problem. In neither case will we ask for any explanation, and there will be absolutely no adverse consequences for you.

This study is being conducted by researchers at Lancaster University with the support of medical and other staff at your NHS Trust and local Health Authority. It is being funded by the NHS and the findings will ultimately be used to improve the range and nature of support services on offer to patients and carers. The study will take two years in all, so please do not expect any immediate changes in services. The research to be carried out has been approved by the local Research Ethics Committee appointed by the Health Authority.

If you have any questions about the study, you can contact either:

	Sara Morris (Project Researcher)	Tel: 01524 594126
or	Carol Thomas (Project Leader)	Tel: 01524 594092

## *The care preferences project*

We have asked doctors and nurses to distribute this information sheet to people who are likely to be able to help us with our research project.

We hope you can take a few moments to read it.

We need to point out that **not everyone** who receives this information sheet will be approached by our researcher.

If you are happy to be approached for your help – **do nothing**.

We **may or may not** contact you.

If we do, we will explain more about the project and ask you if you are still willing.

$\alpha$

If you do not want to be approached at all, please fill in the form at the bottom of the page and send it to us at this address:

Dr. Sara Morris,  
Department of Applied Social Science,  
Cartmel College,  
Lancaster University,  
Lancaster, LA1 4YL

Alternatively, you may phone us at 01524 594126.

There is usually someone to take your call during office hours, and an answer phone takes messages at all other times.

**Please do not contact me about this project**

Name:

Address:

Date:

**APPENDIX 8 Patient and carer informed consent form**

**Patient and carer consent form**

*The patient/carer should complete the whole of this sheet.  
Circle yes/no as appropriate:*

Have you received and read the information sheet?	Yes	No
Have you had the opportunity to ask questions and discuss the study?	Yes	No
Have you received satisfactory answers to all of your questions?	Yes	No
Have you received enough information about the study?	Yes	No
Do you understand that you are free to refuse to participate in this study at any time?	Yes	No

**I am willing to participate in this study**

Patient/carer signature:.....Date.....

Name (BLOCK CAPITALS).....

Witness signature:.....Date:.....

Name (BLOCK CAPITALS).....

**THE INFORMATION SHEET MUST ACCOMPANY THIS FORM**

## APPENDIX 9 Demographic data sheet

### ABOUT YOUR CIRCUMSTANCES

1. Are you:  Male  Female
2. How old are you?
3. Are you:  Single  Married  Living with a partner  Divorced/separated  
 Widowed
4. Do any of the following usually live in your household with you? *Please ✓ all that apply*  
 Wife/husband/partner  Child(ren)  Parent(s)  Other relative(s)  
 Friend(s)  I live alone  Other
5. Which best describes your accommodation?  
 Owner-occupier(s) (owning the property outright or buying the property through a mortgage or loan)  
 Renting from a private landlord or Housing Association  Renting from the Council  
 Living in temporary accommodation  Other
6. What is your postcode?
7. Do you, or anyone in your household, own or have regular use of a car or a van?  
 Yes  No
8. Which of the following **best** describes your **usual** situation?  
 I am in full-time paid work  I am in part-time paid work.  I am retired  
 I look after the home and family full-time  I am unemployed  I am in full-time or part-time education (school/college/university)
- If you are in paid work, what is your job? \_\_\_\_\_
9. Do you consider yourself to be?  
 White  Black-Caribbean  Black- African  Black-Other  
 Indian  Pakistani  Bangladeshi  Chinese  
 Any other ethnic group (*please describe*) \_\_\_\_\_
10. What country were you born in? \_\_\_\_\_
11. Is English your first language?  Yes  No
12. Do you have a religious faith?  Yes  No  
 If YES, what is your faith? \_\_\_\_\_
13. Do you have any caring responsibilities for others (e.g. children)?  Yes  No  
 If yes, what is your relationship to them? \_\_\_\_\_  
 Ages of any children \_\_\_\_\_

## APPENDIX 10 Illness details form

### ILLNESS DETAILS

1. What is the name of your current illness?

\_\_\_\_\_

2. When was this illness diagnosed by doctors? *Please give the date as near as you can.*

Date:   /   /      
          day                  month                                  year

3. Apart from this current illness, do you have any other long-standing illness or disability?

No

Yes If YES, *please could you say what:*

\_\_\_\_\_

4. Have you had any hospital treatment recently (within last three months)?

No

Yes If YES, *please could you say what:*

chemotherapy

radiotherapy

surgery

other

5. Are you taking any medication regularly?

No

Yes If YES, *please could you say what:*

\_\_\_\_\_

6. What is your GP's name?

\_\_\_\_\_

TODAY'S DATE:

/   /

PATIENT IDENTIFICATION:

Name:

Address:

## APPENDIX 11 Present care interview schedule

### Present care

- ◆ Do you need any extra help because of your illness? (e.g. practical, emotional, spiritual, information, psychological, equipment, financial)
- ◆ If so, please tell me about your care arrangements.

#### Friends and family

- Who is helping you?
- Who is your main carer?
- Who else might help you if you needed it?
- Who would you call on first for help apart from your main carer?
- Are you able to talk freely about your illness with the person who is your main carer?
- Are you able to talk freely about your illness with anyone else?

#### Professional care

- Which healthcare professionals are helping you? (health/social services)
- Do you know how they heard of you?
- Who would you contact first if you had a problem?
- How often do you have contact with them?
- Is there anything you would like from them that they haven't provided?
- ◆ Do you have any particular comments about your current care arrangements?
  - Are you happy with them?
  - Do you get enough help?
  - Place of care?
- ◆ Do you foresee any problems with your care arrangements?

## **APPENDIX 12 The Palliative Care Outcome Scale (POS)**

Not included due to copyright.

### **Outline**

Over the past three days ...

- Pain
- Other symptoms
- Anxiety
- Family/friends anxiety
- Information provision
- Sharing feelings
- Worthwhile life
- Feeling good about self
- Wasted time relating to health care
- Practical matters

Main problems in the last three days.

Reference: Higginson, I (1998) The Palliative Outcome Scale. King's College, London

## APPENDIX 13 Future Care schedule

### CHANGES

Have there been any changes in your care arrangements since we last saw you?

### SERVICE CHECKLIST

Health and social services

1. What have you had?
2. What have you been offered and by whom?
3. Have you asked for anything?
4. What do you think, or know, each of these has to offer someone in your situation?

Hospital (acute and community)  
Hospice  
Community (GP, district nursing etc.)  
Private hospital  
Nursing home  
Social Services (home help, finances etc.)

- ◆ If you met someone in a similar situation to yourself,
  - are there any services you would recommend as helpful?
  - what would you say was particularly helpful about them?

### FUTURE CARE

- ◆ Do you have any plans for your future care?
- ◆ How would you like to see your care arrangements change if your illness gets worse?
- ◆ What do you imagine would make things easier and more comfortable for you?
- ◆ If your illness gets worse, where would you like to be?
- ◆ Would you like, for example to go to a hospital, be at home, go to a friend/family, go to hospice, go to a nursing home, stay where you are now?
- ◆ What do you imagine your future care will be like?
  - In reality
  - In an ideal world
- ◆ Do you think there might be any difficulties in getting the kind of care arrangements you would prefer?

## APPENDIX 14 Tracking interviews

### Short tracking schedule

- ◆ Has anything happened since we last saw you?
- ◆ Has anything changed?
  - With regard to your illness
  - With regard to your care arrangements
- ◆ Are you happy with your care arrangements?
  - Do you have enough help?
  - Is the place in which you are receiving you care the right place for you?
- ◆ Do you foresee any problems with your care arrangements?

## APPENDIX 15 Illness Details Form for carers

### ILLNESS DETAILS

1. What was your relationship to [the patient]? E.g. wife, son etc.

\_\_\_\_\_

2. When did [the patient] die? Please give the date as near as you can.

Date:   /   /      
          day          month          year

3. Where did [the patient] die?

At home       In the hospice       In the hospital       In a nursing home

Somewhere else

If somewhere else, where?

\_\_\_\_\_

4. Did [the patient] ever say that there was a place where he/she would prefer to die?

No       Yes

If, yes, where was that?

\_\_\_\_\_

5. On balance, do you feel that where he/she died was the right place for him/her or not?

No       Yes       Not sure

6. Were you able to talk freely about the illness with [the patient]?

No       Yes, a little       Yes, a lot

7. Have you been able to talk freely about the illness or bereavement with anyone?

No       Yes, a little       Yes, a lot

If so, who?

\_\_\_\_\_

8. Did anyone amongst your family or friends taking care of you in ways which are over and above what they would normally do for you during [the patient]'s illness?

Yes, someone cared for me in this way       No

9. Is anyone amongst your family or friends taking care of you in ways which are over and above what they would normally do for you at this time?

Yes, someone is caring for me in this way       No

If so, who?

\_\_\_\_\_

**TODAY'S DATE:**

## APPENDIX 16 The General Health Questionnaire (GHQ)

We would like to know how your health has been in general **OVER THE PAST FEW WEEKS**. We want to know about present and recent complaints, not those you had in the past. Please answer **ALL THE QUESTIONS** in this section by ringing the answer which most nearly applies to you.

### HAVE YOU RECENTLY (over the past few weeks)

- |  |                    |                         |                        |                      |
|--|--------------------|-------------------------|------------------------|----------------------|
| 1. been able to concentrate on whatever you're doing?    | BETTER THAN USUAL  | SAME AS USUAL           | LESS THAN USUAL        | MUCH LESS THAN USUAL |
| 2. lost much sleep over worry?                           | NOT AT ALL         | NO MORE THAN USUAL      | RATHER MORE THAN USUAL | MUCH MORE THAN USUAL |
| 3. felt you were playing a useful part in things?        | MORE SO THAN USUAL | SAME AS USUAL           | LESS USEFUL THAN USUAL | MUCH LESS THAN USUAL |
| 4. felt capable about making decisions about things?     | MORE SO THAN USUAL | SAME AS USUAL           | LESS SO THAN USUAL     | MUCH LESS CAPABLE    |
| 5. felt constantly under strain?                         | NOT AT ALL         | NO MORE THAN USUAL      | RATHER MORE THAN USUAL | MUCH MORE THAN USUAL |
| 6. felt you couldn't overcome your difficulties?         | NOT AT ALL         | NO MORE THAN USUAL      | RATHER MORE THAN USUAL | MUCH MORE THAN USUAL |
| 7. been able to enjoy your normal day to day activities? | MORE SO THAN USUAL | SAME AS USUAL           | LESS SO THAN USUAL     | MUCH LESS THAN USUAL |
| 8. been able to face up to your problems?                | MORE SO THAN USUAL | SAME AS USUAL           | LESS ABLE THAN USUAL   | MUCH LESS ABLE       |
| 9. been feeling unhappy or depressed?                    | NOT AT ALL         | NO MORE THAN USUAL      | RATHER MORE THAN USUAL | MUCH MORE THAN USUAL |
| 10. been losing confidence in yourself?                  | NOT AT ALL         | NO MORE THAN USUAL      | RATHER MORE THAN USUAL | MUCH MORE THAN USUAL |
| 11. been thinking of yourself as a worthless person?     | NOT AT ALL         | NO MORE THAN USUAL      | RATHER MORE THAN USUAL | MUCH MORE THAN USUAL |
| 12. been feeling reasonably happy all things considered? | MORE SO THAN USUAL | ABOUT THE SAME AS USUAL | LESS SO THAN USUAL     | MUCH LESS THAN USUAL |

IDENTIFIER:

Patient Name:

Carer Name:

Date:

Reference: Goldberg D., Bridges K., Duncan-Jones P., Grayson D. (1988) Detecting anxiety and depression in general medical settings. *British Medical Journal* **297**, 897-899.

## APPENDIX 17 Letter to bereaved carers

[Address]

[date]

Dear

We are very sorry to hear of your loss, and send our condolences.

We hope this is not too difficult a time to ask for your help in completing the research study in which [patient's name] [and yourself] very kindly took part. One of the study's aims is to find out the kind of preferences for help and support that **carers** have in the process of looking after someone who is seriously ill with cancer, and whether these preferences were met.

We are writing to ask if we might contact you about the possibility of an interview. As with the previous interviews, we ask about your experience of dealing with the demands of the illness, and whether you received the help you wanted from the health services or other people in your life. This conversation is recorded and used to help us with our research. Confidentiality and anonymity are assured, and interviews are arranged at your convenience.

It is entirely up to you whether you take part or not. If you would rather not take part, please fill in the attached form and return it in the pre-paid envelope (no stamp needed). Alternatively, you can phone me on: 01524 594126. I am also very happy to answer any questions you may have about this study.

If I do not hear from you by within a fortnight, I will phone you to see if you are willing to help.

We hope that this letter has not stirred up too many painful memories. Please do not hesitate to get in touch if you have any concerns. We would be very grateful if you felt able to participate.

Yours sincerely

Dr. Sara Morris  
Department of Applied Social Science  
Lancaster University

If you do not wish to be contacted, please fill in this form and return it in the pre-paid envelope

Please do not contact me.

**NAME** \_\_\_\_\_

**ADDRESS** \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

## APPENDIX 18 Bereaved Carers schedule

### Bereaved Carers

When did the patient die? \_\_\_\_\_

Where did the patient die? \_\_\_\_\_

Was the patient admitted to any institution in the month before death? \_\_\_\_\_

Dates/places \_\_\_\_\_

ID \_\_\_\_\_

Date of interview \_\_\_\_\_

### 1. The end of the illness

- *View of care arrangements towards the end*

sample question: Tell me something about the progress of [patient's name]'s illness towards the end. Did they stay at home, or were they admitted to the hospital or hospice at any point?

- *Use of health and social services*

sample question: Did you have any particular help from the health and social services in dealing with the illness towards the end?

- *Medication*

sample question: What kind of help did [patient's name] have with any pain or symptoms towards the end of their illness, such as medicines and pills?

- *Activities of daily living and mobility*

sample question: Were there any particular aspects of [patient's name]'s daily care toward the end that you needed help with?

- *Care in the home*

sample question: Was there someone (not health personnel) who helped you care for [patient's name] at home towards the end of the illness?

- *Availability of care*

sample question: If you needed help, who did you call on? Who did you turn to first?

### 2. Final situation

- *Final care*

sample questions: Did [patient's name] say what kind of care they wanted at the end of their illness? Were these preferences met?

- *Location*

sample questions: Did [patient's name] say where they would like to be cared for at the end of their illness? Where did you want them to be cared for at the end of their illness?

### 3. Bereavement care

Have you had any help with coping with your bereavement? If so, from whom?

**APPENDIX 19 Place of Care Form**

<b>NAME</b>	<b>ADDRESS</b>	<b>DATE OF DEATH</b>	<b>PLACE OF DEATH</b>	<b>ADMISSIONS TO HOSPICE (dates)</b>	<b>ATTENDED DAY CARE AT HOSPICE (yes/no)</b>