**MAINTAINING INTEGRITY IN THE FACE OF DEATH**

The Views and Experiences of People Affected by Lung Cancer in Discussing Preferences and Wishes for End of Life Care

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# ABSTRACT

This thesis explores the views and experiences of people with lung cancer, and family members, of discussing preferences and wishes for end of life treatment and care. It presents an interpretive analysis based on the application of a constructivist grounded theory approach. Study participants included: eighteen men and seven women with lung cancer and nineteen family members. Participants were mainly from lower socio-economic groups living in the north of England. Single, joint and group interviews were used to gather data. Interview transcripts were analysed using a constant comparative method and conceptual models were drawn to aid the development of the theoretical interpretation.

The study found that preferences and wishes for future care and treatment were not the main concern of people with cancer; rather, any concerns for the future were about the social aspects of death. Participants talked about their experiences of facing death whilst striving to live in the present. Planning for one's own dying and eventual death was not something that people with lung cancer reported having discussed, except when, out of concern for their families, practical arrangements needed to be made following death. The disclosure of a poor prognosis had a huge emotional effect on participants, who ascribed a variety of meanings to this news. Participants' reported that clinicians usually focused on their disease; they did not recall being offered any 'options' or 'choices' for future care. They commented that their preferences and wishes for future treatment and care were influenced by their clinician, spouse, other family members and their knowledge of others affected by cancer.

The theory 'maintaining integrity in the face of death' is proposed. This theory purports that patients with advanced lung cancer and their families focus on acting and talking as 'normal' to help them balance living in the present whilst facing death. This thesis makes several

contributions to knowledge. First, it provides the views of people from an underrepresented group of cancer patients from lower socioeconomic classes who are rarely included in research. Secondly, it shows how people facing the end of their life place little importance on choice. They focus instead on living in the present and carrying on as normal, which challenges current UK policy that seeks to promote individual patient choice at the end of life through advance care planning. The study findings suggest that policy makers and health and social care professionals need to develop ways of helping people prepare for a 'social' rather than a physical or 'medicalised' death: a focus on developing advance care planning that provides information to support people's practical needs at the end of life, delivered as a family intervention, thereby helping people living with lung cancer to maintain their integrity in the face of death.

# ACKNOWLEDGMENTS

I wish dedicate this thesis to the people affected by cancer who participated in this study. Their willingness to invite me into their homes and talk to me about their experiences has been a privilege, without which this thesis would not have been possible.

I would like to thank Macmillan Cancer Support who funded my research fellowship, which allowed me to undertake this PhD. I am indebted to my two academic supervisors Professor Jane Seymour and Professor Sheila Payne whose patience and expert guidance have helped shape my thinking and enabled me to complete this thesis.

In addition, this study would also not have been possible without the support of the lung cancer nurse specialists at both study sites. I would also like to thank the research advisory group who helped guide each step of the research process. I particularly want to thank Mrs Betty Jackson and Nicky Godfrey for their contribution.

I would like to thank my friends Luce, Linda, Jo, Ev and my father, who have encouraged me along the way and offered me a listening ear. Finally, I would like to thank my husband Gordon and my son Isaac, who initially encouraged me to start this work and have tirelessly supported and championed my efforts. Their enduring patience and support, sometimes at personal cost, has enabled me to complete this work.

# PREFACE

The purpose of this thesis is to explore the views and experiences of people affected by lung cancer about discussing preferences and wishes for end of life care and treatment.

This preface aims to introduce who I am and will provide a description of the genesis of this thesis and the 'lens' (Creswell and Miller, 2000) or 'voice' (Guba and Lincoln, 2005) I use in developing it. A lens is described by Creswell and Miller (2000) as a determinant of validity used to illuminate to the reader the researcher's 'worldview' that inherently influences the study or the choice of methodological approach (Creswell, 2007). Clough and Nutbrown (2002), describe the researcher's 'voice' as the values, knowledge, ethics and morals that influence or motivate the researcher's choice of research questions and methodology. In addition, Guba and Lincoln (2005) suggest that expressing one's 'voice' enables the location of a researcher's standpoint within a text. My lens or voice is influenced by professional and personal values and experiences that together have shaped this research inquiry.

This thesis has developed from a professional interest in how people will respond to the introduction of advance care planning in the UK. Having worked and studied as a district nurse in western Canada in the 1990s I became aware of the concept of advance care planning and advance directives, which offered people the opportunity to influence their future health care decisions, should they become incapacitated in the future. I was also aware of the apprehension felt by my Canadian colleagues about getting involved in supporting people in discussions about their future. This appeared to come from a concern related to some people's increasing demands and expectations about their care and treatment. In addition, health care managers' guidance to staff was not to influence the writing of advance directives for fear of litigation. Colleagues described difficulties in initiating discussions, especially when some people expressed a wish to explore alternative therapies that challenged the medical model of

treatment. Nevertheless, I viewed advance care planning as supporting a person's individual right to autonomy over their lives.

This professional background led me to become interested in advance care planning (ACP) at a time when it was beginning to receive interest in the UK, and before its formal introduction under the Mental Capacity Act (Department of Constitutional Affairs, 2005). As a palliative care nurse specialist working in the UK, I was interested in how people living with advance disease could be supported by ACP, and how it might benefit them. I received a grant from the North Trent Cancer Network Social and Primary Care Oncology Research Group to conduct a small pilot study aimed at developing and testing an ACP intervention used by a small team of lung cancer nurses in the north of England (Horne et al., 2006). The study (which will be discussed in more detail in the following chapter) resulted in the collation of a variety of views of people with lung cancer, their families and the lung cancer nurses who used the intervention. The diversity of reactions to ACP resulted in further questions about whether ACP is culturally acceptable to people living in the UK. I questioned whether discussions about people's wishes and preferences for the future were already occurring in health and social care practice, but were perhaps not identified by health professionals within the concept of advance care planning.

In addition to my professional background I have had personal experience of initiating a discussion with my own mother (diagnosed with motor neurone disease) in the presence of my father about her future wishes regarding artificial feeding. This conversation had not been initiated by a health professional. As a nurse I was aware of the future decisions they might need to make about treatment and care; I therefore initiated a discussion that resulted in my mother expressing her wishes to her general practitioner (GP), who then followed these wishes when she later developed aspiration pneumonia and subsequently died.

I am also a mother who has written a joint will with my husband (for the purposes of future guardianship of our son in the event of death) and I have told my husband about some of my

wishes about my future care. As a mother, wife, sister, nurse, friend and a Christian, I recognise that these roles and relationships have influenced the development of this thesis.

As this thesis developed, both my professional and personal views were further shaped by the participants I met in this study. My position has changed from that described above, as I have been influenced by the views of those I studied. From listening to people's views about their lives, I have sought to understand the meanings their experiences had for them within their social contexts and to interpret their views and experiences as authentically as possible. Nevertheless, I recognise I cannot exclude the possibility that my lens or voice may have influenced the resulting theoretical interpretation. As well as offering further explanation of my earlier assumptions and the reflective account that follows, this short introduction will help the reader to interrogate for themselves the credibility of the theoretical interpretation.

Throughout this thesis I write using the 'first person'. This fits with my chosen methodological approach, which recognises the role of the researcher in constructing the theoretical interpretation.

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# OPERATIONAL DEFINITIONS

End of life care

> "*Helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support*" (Department of Health, 2007, p.11)

Living will and advance directive

In England and Wales the term 'living will' and 'advance directive' have been replaced with the term 'advance decisions to refuse treatment' in keeping with the Mental Capacity Act (Department of Constitutional Affairs, 2005).

Advance decision to refuse treatment

An advance decision to refuse treatment is defined by the NHS (2009) as:

> "*An advance decision to refuse treatment (previously known as a living will or advance directive) is a decision you can make to refuse a specific medical treatment in whatever circumstances you specify. This can include the choice to refuse treatment even if doing so might put your life at risk.*" (p.3)

The NHS End of Life Care Programme (Department of Health NHS End of Life Care Programme, 2008) add that advance decisions to refuse treatment: "*will only come into effect when the individual has lost capacity*" (p.8).

## Advance statements

The General Medical Council (2010) define an advance statement as:

> *"…a patient's views about how they would or would not wish to be treated if they become unable to make or communicate decisions for themselves. This can be a general statement about, for example, wishes regarding place of residence, religious and cultural beliefs, and other personal values and s well as about medical treatment and care*" (p.85)

## Lasting power of attorney

The Department of Health (2008) defines Lasting Power of Attorney as:

> "*A Lasting Power of Attorney (LPA) is a new statutory form of power of attorney created by the Mental Capacity Act (2005). Anyone who has the capacity to do so may choose a person (an 'attorney') to take decisions on their behalf if they subsequently lose capacity"* (p.3)

# CHAPTER 1 : BACKGROUND AND LITERATURE REVIEW

## Introduction

This chapter contains the background to the main concepts and context of this study on lung cancer patients' experiences of discussing end of life care. It will provide an overview of the incidence, prevalence and mortality of lung cancer. I will then introduce advance care planning as a possible opportunity for supporting discussions about preferences and wishes for end of life care and link this to some of the issues of modern dying, in particular to 'open awareness' of dying, and to a 'good death'. The second part of this chapter provides a review of the international literature on advance care planning and lung cancer patients' experiences. This then leads to posing the research questions that direct this study.

## Background

### Lung cancer incidence, prevalence and mortality

Lung cancer is the most common cancer in the world, affecting approximately 39,000 new people per year in the UK (Cancer Research UK, 2010b), with a higher incidence in men than women (Cancer Research UK, 2010). Lung cancer is a disease often diagnosed too late to enable treatment with curative intent (McWilliams et al., 2009) and affects people in deprived areas two and a half times more than those living in non-deprived areas (Cancer Research UK, 2010b). Therefore, for the majority of these patients there is little hope of cure. Living with lung cancer has gradually begun to be associated with longer survival rates, with a one year survival rate for people in England and Wales, rising from 13-15 % for those diagnosed in 1971-75 to 27-30% for those diagnosed in 2004-2006 (Cancer Research UK, 2010a). However, 5 year survival rates have only marginally increased (Zee and Eisen, 2008; Naidu and Rajesh, 2008; Office for National Statistics, 2010) and people from deprived wards have a higher mortality rate than those from non-deprived wards (Coleman et al., 2004). The increased one year survival rate is

due to developments in treatment (Zee and Eisen, 2008), earlier diagnosis (Read et al., 2006) and the cessation of smoking following early diagnosis (Parsons et al., 2010). Dying trajectories are longer and less certain, making it more difficult to predict or anticipate death. However, many people with lung cancer are still hopeful of an extended life, although they live with uncertainty about the course of their illness. This creates opportunities for advance care planning.

## Advance care planning

The Department of Health (2008, p.4) defines advance care planning (ACP) as:

"*a voluntary process of discussion about future care between an individual and their care providers, irrespective of discipline. If the individual wishes, their family and friends may be included. It is recommended that with the individual's agreement this discussion is documented, regularly reviewed, and communicated to key persons involved in their care.*"

The Department of Health (2008) suggests that ACP usually takes place when an individual's condition is expected to deteriorate in the future, and is used to communicate wishes and decisions should they lose capacity or are unable to communicate their wishes to others. There are several concepts and outcomes linked to ACP, which have been represented in figure 1.1.

Figure 1.1. Conceptual framework demonstrating possible relationships between ACP and related outcomes (Horne et al., 2009)

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                      ┌─────────────────────────────┐
                      │   Advance care planning     │
                      └─────────────────────────────┘
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| **Instructional directives**: advance directives; living wills; advance decisions to refuse treatment. | **Proxy decision-making**: lasting power of attorney, enduring power of attorney, public guardian. | **Documented or verbal preferences for care**: statements of wishes, values, history. |

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                      ┌─────────────────────────────┐
                      │      Implementation         │
                      └─────────────────────────────┘
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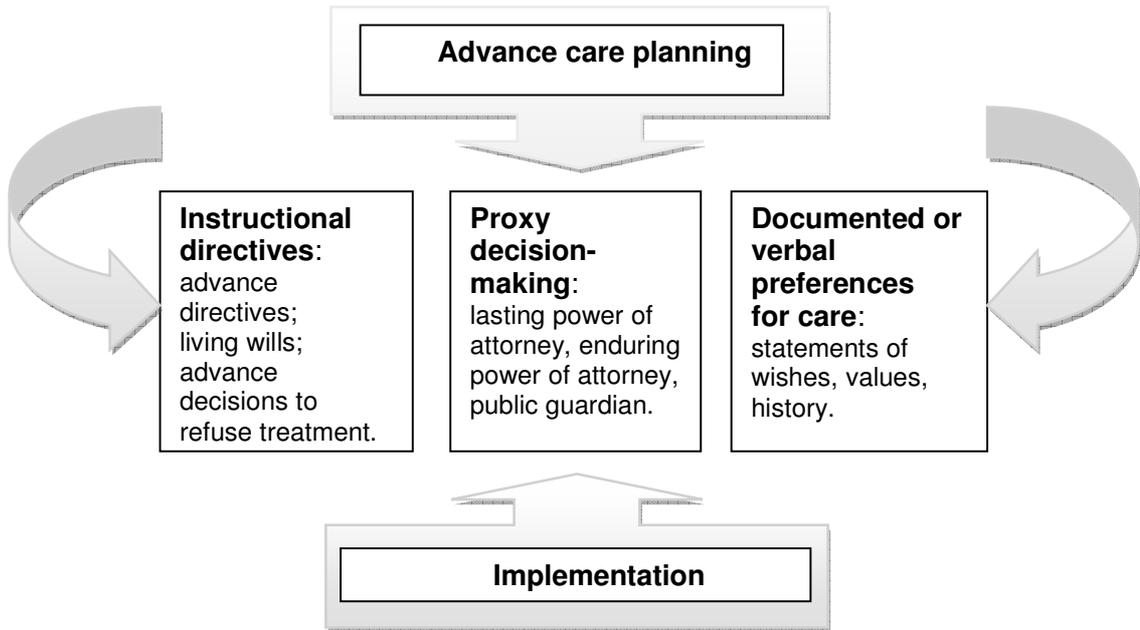
ACP is linked to a move towards 'open awareness' (Glaser and Strauss, 1966) or 'truth telling' in death and dying, which has become a trend in palliative care and promoted as helpful in facilitating a 'good death' (Sandman, 2005; Seymour and Horne, 2010). However, there are difficulties in determining what constitutes a 'good death' for individuals who have many different needs. There are also differing competing notions of a 'good death', which have been influenced by the development of medical technologies and several key court cases where patients or their families have advocated for withdrawal of treatment or requested assistance in hastening death. The many public and political debates supporting the desire to provide a 'good death' have brought the issue of autonomy in decision-making at the end of life to the forefront in the UK.

End of life care policy and the legal framework for ACP in the UK.

Advance care planning has gained interest in recent years perhaps aided by pressure groups such as Age UK, who have argued that older adults should be provided with opportunities to make 'choices' about their end of life care (Seymour et al., 2005b). The notion that it is important for patients to have a role in decisions about their care and treatment is a relatively new concept within health care, which began to emerge following the consumerism movement in North America of the 1970s. This social movement was followed by the development of the American Hospital Association Patient's Bill of Rights (Annas, 1973), which significantly sought to change the perception of the doctor-patient relationship to one of professional-client, enabling people to have a more active role in decision making about their care and treatment.

In Britain, the Citizens' Charter published in 1991 (House of Commons Public Administration Select Committee, 2008) was an attempt by the government to introduce rights for people in relation to information and explanations about public services, including rights to medical treatment and care within a specific time frame and rights to have complaints investigated promptly. However, options for providers of treatment and care and the quality of that care was not a feature (Stocking, 1991).

In the UK, the National Health Service (NHS) launched an end of life care initiative (Department of Health, 2003) to support improved quality of patient care for people with a variety of life limiting illnesses across all care settings. An important aspect of this initiative, which was added to through further policy (Department of Health, 2008; Department of Health, 2009), was seeking ways of ensuring that patients' views are heard, informing them of their options and asking them about their preferences and wishes for end of life care. The NHS has sought to promote the use of tools such as the Gold Standards Framework, Preferred Place of Care (PPC) and the Liverpool Care Pathway under the umbrella of advance care planning. However, apart from research related to the Liverpool Care Pathway (Murphy et al., 2004; Ellershaw and Ward,

2003), there is little research evidence to support the use of these tools, and until recently a definition of advance care planning in England (Department of Health End of Life Care Programme, 2007) was not available.

In the UK, the Mental Capacity Act (2005) has offered for the first time legislation that provides the opportunity to record a potentially legally binding advance decision to refuse medical treatment or to appoint a lasting power of attorney. It thereby supports the rights of people to influence their future care and treatment in the event they become incapacitated. Although this legislation now exists, and NHS policy supports the use of advance care planning, health professionals may not yet have an understanding of how to open up discussions with patients regarding their future. Nor do we have evidence that health professionals have the knowledge and skills to enable patients to make decisions for the future (Horne et al., 2006; Seymour et al., 2010) or to provide support in documenting these advance wishes or decisions. This context makes it essential to examine the role of health professionals in promoting patients' awareness of their options for care and treatment, including discussion and documentation of any preferences and choices for end of life care.

## Theoretical framework

The theories that initially influenced this study were those developed by Glaser and Strauss (1966) and Kubler Ross (1970). Glaser and Strauss (1966) proposed a theory of 'awareness of dying' that included four awareness contexts. Firstly, a context they named 'closed awareness' was proposed to be a state whereby staff are aware the patient is dying but the patient is unaware of their dying. The second awareness context is 'suspicion awareness' which is described as a patient suspecting he or she is dying and seeking clues from staff to refute or confirm their suspicions. Third, 'mutual pretence' is perceived as a context where patients and staff are both aware of the patient dying, but pretend otherwise. Lastly, 'open awareness' is proposed as a context whereby the patient and staff both know that the patient is dying and are able to talk about it together. Interpretations of this theory, as a means for understanding social

interaction surrounding modern dying and as an argument in health care policy and practice support the disclosure of information or 'truth-telling' to patients about their approaching death (Field, 1996), thus breaking what has been called the 'silent conspiracy' of death (Armstrong, 1987).

Kubler-Ross's (1970) theory on the psychological stages of dying suggests that patients move through five different stages prior to death, whilst also maintaining hope. She described these as 'denial and isolation', 'anger', 'bargaining', 'depression' and 'acceptance'. Kubler-Ross (1970) suggests that people can 'master' fear of dying through working towards an attitude of accepting death. Kubler-Ross, who was a psychiatrist, offered a theoretical interpretation of accounts of peoples' views about dying that has influenced other clinicians to view a 'good death' as encouraging patients to move towards acceptance of their demise.

These were the predominant theories influencing health care professionals in both the UK and North America from the 1970's onwards. In the literature review that follows, the authors of the empirical studies do not make explicit their theoretical assumptions. However, references to: supporting preparation for a 'good' or 'natural' death, to the disclosure of prognoses so people can plan for the future and the development of methods to involve people in decision-making about their treatment and care, suggests the above theories have underpinned their studies.

Although not aware of the influence of these theories on my own thinking at the outset of the study on which this thesis is based, I became aware of their influence as I challenged my own assumptions through reviewing the literature and, latterly, in seeking to position the new theory that later developed from this study's findings.

## Summary

There are inherent difficulties in engaging patients in ACP and a lack of research about how patients express individual preferences and wishes for the future or even if they want to. Patients may have other priorities at the end of life or prefer to leave decision making about care and treatment to others (Drought and Koenig, 2002). Moreover, preferences and wishes are contextual, influenced by many factors, including the societal and political contexts in which end of life care is organized, accessed and delivered. Whether resources are available to provide options in end of life care is also debatable (Munday et al., 2007).

Little is known about the perspectives of patients with lung cancer about end of life care and whether they have preferences for care and treatment and what, if any, benefits planning for their end of life care may have for them and their families. Advance care planning (ACP) may be one potential method of enabling patient choice for those with lung cancer, which has not yet been adequately explored or developed in the UK.

## Literature review

### Introduction

In this next section I will present a review of the literature which seeks to explore issues related to advance care planning (ACP). I will highlight the findings and discuss the current debates about the potential use of ACP as a complex intervention for use in palliative care and with people affected by lung cancer.  The purpose of the review is to appraise the research conducted in this area and identify any potential gaps in the literature.

### Design and Method

The method I used for the review of the literature was to initially conduct a broad search using terms related to ACP.  The keywords used were: "advance care planning"; "advance

statements"; "cancer"; "end-of-life" and "palliative care". This search resulted in over 700 relevant articles and produced a variety of different topics related to ACP which made it difficult to decide which articles were relevant to my proposed research question. I made a decision not to look at evidence relating solely to advance directives (as defined in the operational definitions) because of the vast amount of literature available. However, where I discuss documentation related to ACP, this may include advance directives where it is relevant to the discussion.

I then decided to adopt the principles of a systematic review developed by Hawker et al (2002) to enable a more focussed search of the literature. The use of a Cochrane Collaboration approach to systematic reviews was not adopted because it restricts the researcher to include only studies conducting clinical trials or intervention studies. The benefit of using Hawker et al's (2002) review method is that it recognises the contribution of evidence from studies using qualitative and other methods as well as randomised controlled trials. Hawker et al (2002) developed inclusion and exclusion criteria with specific search terms to guide the literature search. They also used techniques such as a set of predetermined criteria to screen abstracts for relevance and to organise extraction of data, and a set of questions to aid analysis. I developed the following specific aims and objectives to guide the review.

*Aims and Objectives*

Aim

To review and critically appraise the literature about **ACP** between the years 1970 – 2010 in relation to **patients' experiences**, **target population**, **discussion** about **end of life care** and **interventions**.

Objectives

1) To report on how **ACP** is described in the literature in relation to the **target population**, **discussions** about **end of life** and the development of an **intervention**.

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2) To identify and review literature on **patients' experiences** of **ACP** in a **palliative care** context with a focus on **end of life.**

3) To identify and review literature on the **experience** of **patients** with **lung cancer** towards the end of life.

I wanted to review how ACP had developed over time and with what groups of patients. I also wanted to consider what research had been conducted to explore patients' experiences of planning for their end of life care and treatment and compare how that may have influenced the development of ACP. Group search terms were taken from the three objectives stated above. Three separate searches were completed:

- Group One: advance care planning, discussion, intervention, end of life, target population.
- Group Two: advance care planning, patient experience, palliative care, end of life.
- Group Three: lung cancer, patient experience, palliative.

I decided to search the term 'target population' using the following life-limiting disease groups: cancer, heart failure, respiratory disease, renal failure, HIV/AIDS, Alzheimer's and dementia. I used these disease groups because, having done a broader initial search, I was aware of which patient groups were included in the majority of papers.

Inclusion and exclusion criteria

Only articles published in English were included in the search because translation costs were not included in the grant for this study. Databases included were CINAHL; Medline; PsychINFO; EMBASE; BNI; SOSCI. Searching was conducted from 1970 onwards depending on the databases available and the same databases were used for each group. 1970 was

chosen as a starting point as issues around the introduction of ACP did not appear in the literature until the late 1970s. Hand searching was used to follow up references.

I screened abstracts from retrieved articles for relevance and excluded literature that focussed only on advance directives, cardiopulmonary resuscitation or ones that did not include patients with life-threatening illnesses. In the group two search, I included only literature that described the development of an advance care planning intervention. In group three I included literature about living with lung cancer because of the dearth of literature on patients with lung cancer at the end of life. After I collated the abstracts they were then screened for a 'fit' with the aim and objectives of the review. Many of the abstracts were duplicates from the broader search. I then requested full papers of abstracts which were relevant to the aims and objectives of the review to read and assess their scientific rigour using the following criteria:

- o  assessed for relevance to the objectives of the review
- o  assessment of scientific rigour of the study

To analyse and synthesize the data retrieved I interrogated the full papers using the following questions.

Figure 1.2 Questions posed to interrogate the literature (using the stated objectives)

1. What are the experiences of patients who have life threatening disease of discussing and planning for their end-of-life care?
2. How are patients' experiences of ACP explored in the literature?
3. What are the target populations (using identified disease types) which have been explored in the literature in relation to ACP?
4. How are end-of-life discussions initiated with those who have life-threatening illnesses?
5. How are ACP interventions described in the literature?
6. How have ACP interventions been developed?
7. What are the components of the ACP interventions and how is the intervention

conducted?

8. What are the intended and actual outcomes of the ACP interventions described within the literature?

9. What are the reported end-of-life experiences of patients living with lung cancer?

This process enabled the issues about ACP to be more easily identified. Themes and issues were identified by reading the texts several times and looking for similarities and differences within the findings from the relevant papers. The literature review process is now described. The literature search results are shown in table 1.1

Table 1.1 Literature review process

| Group 1 Search terms | Group 2 Search terms | Group 3 Search terms |
|---|---|---|
| ↓ | ↓ | ↓ |
| 665 hits | 751 hits | 1082 hits |
| ↓ | ↓ | ↓ |
| 630 – after duplicates removed | 711 – after duplicates removed | 1078 – after duplicates removed |
| ↓ | ↓ | ↓ |
| Abstracts screened for relevance n =630 | Abstracts screened for relevance n =711 | Abstracts screened for relevance n =1078 |
| ↓ | ↓ | ↓ |
| Full papers requested n = 51 | Full papers requested n = 44 | Full papers requested n = 14 |
| ↓ | ↓ | ↓ |
| Papers reviewed n = 16 | Papers reviewed n = 15 | Papers reviewed n = 10 |

## Findings

The numbers of hits for each group of search terms are listed in table 1.0. Two PhD theses were requested and screened for relevance. Sixteen papers were found to be relevant from group one, fifteen papers were relevant from group two, with five papers being relevant to group one and two objectives (Briggs et al., 2004; Martin et al., 1999; Singer et al., 1998). In group three ten papers were relevant. Table 1.2 outlines a brief critique of the key scientific components of each paper included in the review.

Table 1.2 Scientific review of included papers

| Author | Date | Journal | Article title | Aims | Study design | Participants | Reported main findings | Critique |
|--------|------|---------|---------------|------|--------------|--------------|------------------------|----------|
| Briggs, L. *USA* | 2003 | Innovations in End-of-life Care | Shifting the Focus of Advance Care Planning: Using an In-depth Interview to Build and Strengthen Relationships. | To describe the rationale for developing patient-centered ACP interview | Case study | N/A | ACP is 'hard work' for facilitator, intimacy can be established between ACP facilitator and patient, patients are afraid to talk to loved ones and 'listening' is the intervention. | ACP rationale viewed from perspective of ACP facilitator. Comparing patient experiences with facilitators could have enhanced findings |
| Lynn, J. & Goldstein, N. *USA* | 2003 | Annals of Internal Medicine | Advance Care Planning for Fatal Chronic Illness: Avoiding Commonplace Errors and Unwarranted Suffering | To describe a case of a nursing home patient who received mechanical ventilation despite a DNR. | Case study | N/A | Failure to plan and communicate patients' documented preferences can result in 'suffering'. The need to develop strategies to support patients and families with decision-making and ensure communication of documented decisions is paramount. | Case study based on critical incident approach drawing on negative effects of not planning ahead. Including views of staff or family members may have enhanced learning from this approach. |
| Briggs, L. Kirchhoff, K. et al *USA* | 2004 | Journal of Professional Nursing | Patient-centered advance care planning in special patient populations: a pilot study | To assess feasibility of a patient-centered ACP approach with patient/ family member. | Prospective experimental design. | 27 surrogate pairs (patient and family member). | Greater congruence with statement of treatment preferences and less conflict in decisions between patients and their surrogates in experimental group. | One setting, small sample. No data about whether decisions were realised at end of life or patients' experiences of the interview |

| Author | Date | Journal | Article title | Aims | Study design | Participants | Reported main findings | Critique |
|---|---|---|---|---|---|---|---|---|
| Hines, S. Glover, J, et al *USA* | 1999 | Annals of Internal Medicine | Dialysis Patients' Preferences for Family-based Advance Care Planning | To examine haemodialysis patients' preferences for involving physicians and family members in ACP | Prospective quantitative interview study | 400 haemodialysis patients | Patients more likely to report comfort discussing end of life issues with family than completing an Advance directive. Patients more likely to discuss specific treatment preferences with family/surrogates than doctor. | No report on development, testing and validity of questionnaire used. |
| Singer, P. Martin, D. et al *Canada* | 1998 | Archives of Internal Medicine | Reconceptualising Advance care Planning from the Patient's Perspective | To examine traditional assumptions by exploring ACP from patients' perspective | Prospective qualitative interview study | 48 people receiving haemodialysis from a previous sample of people who had requested a copy of their chosen AD form and viewed educational videos | Themes: 1) preparing for death, 2) about relationships and not being a burden 3) social process 4) involved loved ones. Only 29% of the sample had completed an AD form, but patients felt they had done ACP as loved ones knew their wishes. 69% had talked to family about wishes. Patients cited Health professionals too busy to talk too and topic too personal. | Patient's views may have been affected by previous involvement in ACP intervention study by same authors. Generalisations cannot be made to other populations due to sampling. |

| Author | Date | Journal | Article title | Aims | Study design | Participants | Reported main findings | Critique |
|---|---|---|---|---|---|---|---|---|
| Martin, D. Thiel, E. et al *Canada* | 1999 | Archives of Internal Medicine | A New Model of Advance Care Planning: Observations From People With HIV | To develop a conceptual model of ACP by examining perspectives of individuals engaged in it. | Prospective qualitative interview study | 140 people with HIV from a previous study sample for people who had been recruited to an RCT trialling a disease specific AD form | Themes: 1) preparing for death/facing death  2) achieving a sense of control 3) strengthening relationships | People's views may have been affected by enrolment in prior RCT by same authors. Generalisations and proposed recommendations should be treated with caution due to sampling. |
| Drought, T. & Koenig, B. *USA* | 2002 | The Gerontologist | "Choice" in End-of-Life Decision-Making: Researching Fact of Fiction | To critique the normative power of autonomy based bioethical practices related to patient choice and receiving excellent palliative care | Review and a description of longitudinal qualitative ethnographic interview study. | 88 patients, and family members, health professionals of sampled patients. | From review: Choice model of ethics is fundamentally illusive and flawed. Prognostic information rarely used in clinical practice. Existence of preferences are assumed but not validated. From study findings: doctors had not discussed end of life choices with patients despite prognosis < 6 months. Patients did not perceive choice. Some felt abandoned when doctors asked them to choose. Decisions appear to evolve without any element of choice. | Excellent bioethical discussion but research analysis and findings poorly reported in terms of development of themes and little use of patients' words. |

| Author | Date | Journal | Article title | Aims | Study design | Participants | Reported main findings | Critique |
|--------|------|---------|---------------|------|--------------|--------------|------------------------|----------|
| Steinhauser, K. & Christakis, N. *USA* | 2001 | Journal of Pain and Symptom Management | Preparing for the End of Life: Preferences of Patients, Families, Physicians, and Other Care Providers' | To expand the taxonomy of preparation in relation to end of life care by examining patients', families' and health professionals' preferences. | Mixed methods using focus groups and cross-sectional national survey | 12 focus groups (6 people in each) including patients, multi-professionals and bereaved carers. 24 interviews. Stratified random sample of health professionals, seriously ill people and bereaved carers | Qualitative findings themes: pain & symptom management, preparation for death, completion, contributing to others, affirmation of whole person. Survey findings: agreement between all in relation to being prepared for end of life and knowing family is prepared. | Method of data collection and sample were appropriate. However, qualitative findings illustrated with only health professionals quotes, and difficult to determine differences/similarities between patients and others. |
| Curtis, J. & Patrick, D. *USA* | 1997 | Journal of General Medicine | Barriers to Communication about end-of-life care in AIDS patients | To identify barriers and facilitators to communication about end of life medical care for patients with AIDS and their physicians | Prospective qualitative focus group study | 47 AIDS patients in 6 focus groups, 19 physicians - 3 focus groups | Treatment preferences are in flux, living will a barrier making discussion unnecessary. Some patients felt discussing EOL would cause harm. Patients feel need to protect doctors from perceived uncomfortable discussions. Some felt should wait for doctor to initiate discussion. | Questionable ethical sensitivity of study as patients/physicians were not informed the focus group would discuss end of life issues. Distinct population of younger adults, therefore questionable transferability to other ages/disease groups. |

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| Author | Date | Journal | Article title | Aims | Study design | Participants | Reported main findings | Critique |
|---|---|---|---|---|---|---|---|---|
| McSkimming, S. et al, *USA* | 1999 | Supportive Care of the Dying: A Coalition for Compassionate Care | The Experience of Life-Threatening Illness: Patients' and Their Loved Ones' Perspectives | To understand the experience of life-threatening illness in the health care system through testimony of those who have lived it. | Ethnographic focus group study using semi-structured guide | 33 focus groups including 77 patients (mixed aetiologies), 70 family members, 81 bereaved carers. | Patients reported as not afraid of dying - but doctor is. Need to talk about dying, what to expect, fear of losing capacity. Reported doctors ignored or discouraged their questions. Wish for patient/family to be approached as 'unit'. Health care professionals not initiating ACP. | Part of a larger study of life-threatening illness. Population from catholic health care organisations may have influenced views. Participants were invited to feed back on emerging themes. Findings reported clearly. |
| Morrison, R. et al *USA* | 2003 | Journal of American Geriatrics Society | The Effect of a Social Work Intervention to Enhance Advance Care Planning Documentation in the Nursing Home | To assess effect of multi-component ACP intervention directed at nursing home social workers | Experimental study: one intervention group and one control group. | 139 long term care residents | Intervention group residents more likely to have care and treatment congruent with preferences but for CPR. | No theoretical framework or hypotheses. Questionable effect of researcher on the intervention. Also 16 residents in the intervention group compared to 8 in control group already had documented preferences on admission |
| Ratner, E. et al *USA* | 2001 | Journal of American Geriatrics Society | Death at Home Following a Targeted Advance-Care Planning Process at Home: The Kitchen Table Discussion | To determine whether home care patients preferences to die at home can be honored through an ACP process | Longitudinal intervention study although reported as quality improvement project using case series | 84 older adults receiving home care services | 99% patients offered discussion about end of life care, 69% died between 6-20montsh. 64% stated preferred place of care. 70% died at home, 61% enrolled in hospice home care, 47% patients died within 30 days of ACP. | No reporting of ethical review and no consent. Poor explanation of methods, no control group. Limited ability to generalise findings. |

| Author | Date | Journal | Article title | Aims | Study design | Participants | Reported main findings | Critique |
|---|---|---|---|---|---|---|---|---|
| Hammes, B. & Rooney, B. *USA* | 1998 | Archives of Internal Medicine | Death and End-of-life Planning in One Midwestern Community | To define the prevalence and type of end of life planning and relationship between plans and decisions in local health care organisations | Retrospective study to evaluate a community wide advance directive education program | 540 deceased adults records/death certificates. Survey of doctors and bereaved carers | 85% patients had AD, 353 had POA, 98% forgone treatment. Preferences typically recorded one year prior to death. | Methods matched aim. No indication of whether patients end of life experience improved or impact on carers. |
| Englehardt, J. et al, *USA* | 2006 | American Journal of Managed Care | Effects of a Program of Coordinated Care if Advanced Illness on Patients, Surrogates and Health Care Costs: A Randomized Control Trial | To evaluate a new program of coordinated care (including ACP) | RCT using one experimental group and a 'usual care' control group | 275 patients (advanced illness inc. cancer patients) and 143 surrogates | Increased patient satisfaction, increased family involvement, AD's completed earlier with experimental group than usual care group. No effect on mortality. No difference in cost. | ACP was just one component of a complex intervention. Findings did not report on outcomes of patient preferences. |
| Happ, M. et al, *USA* | 2002 | Journal of American Geriatrics Society | Advance Care Planning and End-of-life Care for Hospitalized Nursing Home Residents | To describe ACP and other components of end of life care for nursing home residents who experienced hospitalization during the last 6 months of life | Secondary data analysis from a larger RCT | 43 deceased older adults who lived in one nursing home | ACP discussion initiated on admission with 1/3 rd of residents participating. Discussions focused on CPR. ACP reviewed only when changes in physical or cognitive decline. 'Do Not Resusitate' order did not always transfer across to hospital setting | Limitations are that secondary data used for this study obtained from a larger study testing nurse intervention to maintain restraints free hospital care. Small sample. Analysis based on written patient nursing home record, field note documents from larger study. |

| Author | Date | Journal | Article title | Aims | Study design | Participants | Reported main findings | Critique |
|---|---|---|---|---|---|---|---|---|
| The SUPPORT principal investigators, USA | 1995 | Journal of American Medical Association | A Controlled Trial to Improve Care for Seriously ill Hospitalized Patients | To improve end of life decision making and reduce the frequency of mechanically supported, painful and prolonged dying process | Large RCT 2 phased trial : Phase 1) prospective observational study, Phase 2) intervention testing. | Phase 1: 4301and their doctors pts, Phase 2: 4804 patients and their doctors | Phase 1: median age 65, 31% pts preferred CPR withheld, 49% of these did not have DNR form, for those with DNR's these written within 2 days of death. Mean number of days in ICU was 8. Phase 2 findings: intervention failed | The intervention included prognostic information to doctors, nurse- led discussion with patient and if wished an interview with physician/surrogate decision-maker.  Limitations: Intervention developed based on needs of doctor - not patient. Nurse free to shape role, but with doctor's permission. |
| Perry, E. et al *USA* | 2005 | American Journal of Kidney Disease | Peer Mentoring: A Culturally Sensitive Approach to End-of-Life Planning for Long-Term Dialysis Patients | To explore the impact of peer mentoring on end of life decision making | RCT using 2 experimental groups and control group. | 203 patients with end stage renal disease (white and African American): Group 1: 93; Group 2: 85; Group 3: 83 and 17 peers for group 1. | Use of peer mentors in African American population enhanced AD completion over other information only and control groups but not in white population. | Complex and structured intervention using volunteer peers. Transferability to lung cancer patients and UK populations questionable due to short trajectory of lung cancer/cultural differences. |
| Shorr, A. et al *USA* | 2000 | Journal of Pain and Symptom Management | Regulatory and Educational Initiatives Fail to Promote Discussions Regarding End-of-Life Care | To determine if hospital-based regulations and educational interventions could encourage physicians to discuss end of life issues with their patients | Observational cohort quantitative study | Two hospital based patient cohorts with prognosis < 3 years : 1) 184 patients 2) 121 patients | Combined interventions of physician education and hospital policy failed to promote end of life discussions between doctors and their patients | Focus on DNR completion rather than patient centered areas for discussion. Findings did not provide insight into why interventions failed. |

| Author | Date | Journal | Article title | Aims | Study design | Participants | Reported main findings | Critique |
|--------|------|---------|---------------|------|--------------|--------------|------------------------|----------|
| Song et al *USA* | 2009 | Research in Nursing and Health | RCT of SPIRIT: An effective approach to preparing African American dialysis patients and families for end of life | To determine the feasibility and acceptability of SPIRIT with ESRD | RCT: intervention group was one hour interview with trained facilitator. Control group was 'usual care'. Used interviews to gain dyad views | 58 patients and chosen surrogate decision-maker dyads | Quality of communication improved and dyad congruence about goals of care improved in intervention group. Surrogate decision-making confidence improved over time in both groups. Opportunity to share emotions/beliefs valued by dyads. | Small sample for RCT and only one person delivered intervention. Intervention described well so could be duplicated. |
| Heyman and Gutheil *USA* | 2010 | Health and Social Work | Older Latino's attitudes toward and comfort with end of life planning | To determine which of two one to one education interventions would influence Latino elders' attitudes toward and comfort with end of life planning compared to the control group receiving standard care. | Quantitative post-test only control group design. 2 intervention groups and 1 control group. | 84 Latino elders receiving care from a home care agency | Group A (an intervention group) statistically different to control group in attitudes towards and comfort with end of life planning. Group B (had additional topics for discussion) no significant difference to control group. | Lack of pre-test. Interview to test influence of interventions only 2 weeks post intervention 79 elders refused to take part - some due to discomfort with topic. |
| Levy et al *USA* | 2008 | Journal of Palliative Medicine | Improving end of life outcomes in nursing homes by targeting residents at high risk of mortality, for palliative care: program description and evaluation | To evaluate a new complex program of (including ACP). Included training in nursing home life- sustaining options for treatment to seek resident preferences. | Quantitative study using case notes review pre and post complex intervention. Used descriptive statistics. | 72 case notes. 27 pre-implement-ation of intervention and 45 post-implement-ation | Rise in AD completion from 12% pre-intervention to 100% post intervention. Less nursing home resident deaths in hospital but no difference in length of stay. No difference in hospice programme referrals but increase in palliative care consultations. | Small sample for design. Evaluation relating to ACP was on AD completion and effect on hospitalisation rather than patient reported outcomes. |

| Author | Date | Journal | Article title | Aims | Study design | Participants | Reported main findings | Critique |
|---|---|---|---|---|---|---|---|---|
| El-Jawahri et al *USA* | 2010 | Journal of Clinical Oncology | Use of video to facilitate end-of-life discussions with patients with cancer: A RCT. | To determine whether the use of a goals of care video to supplement verbal description cancer improve end of life decision making for patients with cancer, | RCT with one control group and one intervention group. | 50 patients with malignant glioma: 27 control group and 23 intervention group | Significant difference in number of patients choosing comfort care over life prolonging care or basic medical care and in number of patients declining CPR in intervention group. 82.6% patients very comfortable watching the video and most found it very helpful. | Small sample for an RCT. Sample mainly white and well educated from a hospital clinic setting. No data about outcomes of care, stability of decisions, inclusion of family member/s or patient experience. |
| Hill et al *UK* | 2003 | European Journal of Cancer Care | Do Newly Diagnosed Lung Cancer Patients Feel their Concerns are Being Met? | To explore concerns of lung cancer patients and enquire whether concerns experienced by patients had been considered by the care team | Quantitative study using face to face administered questionnaire | 80 newly diagnosed lung cancer patients | Patients identified at least two worrying concerns with less than 30% of patients reporting health care professionals had appropriately discussed these. 'Illness itself' and concerns about family in the future were most highly rated. Care team reportedly focused on physical concerns. | Only a few patients completed whole questionnaire. Researchers removed 'dying' from list of concerns about 'future' but did not explain rationale. |
| Hughes and Arber *UK* | 2008 | International Journal of Palliative Nursing | The Lived Experience of Patients with Pleural Mesotheiloma | To explore the lived experience of patients diagnosed with pleural mesotheiloma | Qualitative phenonmenological interview study | 5 lung cancer patients (4 men, 1 woman) | Patients reported: not being able to work, loss of identify and frustration/distress at dependence on others. Desire to do normal activities, social isolation, 'looking well' and difficulty talking about cancer reported. | Limitations: small study in community setting. Useful insight into issues important to patients with mesotheiloma |

| Author | Date | Journal | Article title | Aims | Study design | Participants | Reported main findings | Critique |
|---|---|---|---|---|---|---|---|---|
| Murray et al *UK* | 2004 | Palliative Medicine | Exploring the spiritual needs of people dying of lung cancer or heart failure | To explore if patients with life threatening illness and their informal carers experience significant spiritual needs, how they vary over time and how they perceive they may be helped and supported in addressing needs. | Qualitative longitudinal interview study | 20 lung cancer patients and 20 end-stage cardiac patients | Spiritual issues important, unmet need. Fear, distress and uncertainty experienced. Devastation and shock following diagnosis. Hope and despair intermingled. Reported loss of control. Fostering hope/positive thinking viewed as supportive. | Part of a larger study comparing needs of people dying from lung cancer and heart failure. Longitudinal interviews only possible with small number of the sample. |
| Sjolander and Bertero *Sweden* | 2008 | Nursing and Health Sciences | The significance of social supports and social networks among newly diagnosed lung cancer patients in Sweden | To understand the impact of social support and social networks from different people's points of view | Qualitative interview study using constant comparative method for analysis | 10 lung cancer patients (8 men/2 women) aged 47-88 years | Core category 'receiving confirmation as a person' with 4 subcategories of: 'good relationships within a social network', 'conversation enables support', 'confidence in the situation' and 'to manage by oneself'' | Theoretical interpretation appeared to 'fit' with findings. Small study with newly diagnosed patients. Would be useful to repeat with people closer to death. |
| Yardley et al *UK* | 2001 | Palliative Medicine | Receiving a diagnosis of lung cancer: patients' interpretations, perceptions and perspectives | To document patients' views in the delivery of diagnosis of lung cancer, their attitudes to methods used and their ideas for improvement. | Qualitative phenomenological approach - interview study | 13 patients with lung cancer (9 men/4 women) aged 58-72 years. | Themes: communication, family and communication issues, reactions to diagnosis, treatment and prognosis, patients' suggestions for improvement | Recruitment by researcher in clinic. Interpretation described briefly with words removed from patient quotes. |

| Author | Date | Journal | Article title | Aims | Study design | Participants | Reported main findings | Critique |
|---|---|---|---|---|---|---|---|---|
| Hughes et al *USA* | 2008 | American Journal of Hospice and Palliative Care | Confronting death: perceptions of a good death in adults with lung cancer | To examine perceptions of a 'good death' in patients with lung cancer | Cross-sectional survey administered through interview. SPSS used for descriptive statistics | 100 people with lung cancer (47 women/53 men) | Patients reported 'good death' was 'while sleeping', 'pain-free', 'peaceful passing' and 'dying quickly'. Marital status associated with more frequent mention of a peaceful death. Religious affiliated with less likely to mention 'dying while asleep'. | Survey design inhibited exploration of meanings into patient reports. 60% sample were members of a church. |
| Broberger et al *Sweden* | 2007 | Quality of Life Research | Spontaneous reports of most distressing concerns in patients with inoperable lung cancer | To examine what patients with inoperable lung cancer spontaneously report as most distressing and how their concerns change over time. To examine how these reports compare with the use of the EORTC-QL-C30+LC13 questionnaire for content and intensity | Quantitative study using face to face administered questionnaires | 46 patients who had identified distressing concerns from a larger study of 400 | 94 concerns identified. Main reported concerns were bodily distress, living with lung cancer and Iatrogenic distress. Over time patients appeared to minimise deterioration of health. EORTC instrument did not pick up 40 of reported concerns. | Small sample inhibited ability to determine statistical significance. Little description about actual concerns. Study focused on comparing use of different instruments. |

| Author | Date | Journal | Article title | Aims | Study design | Participants | Reported main findings | Critique |
|---|---|---|---|---|---|---|---|---|
| Krishnasamy et al UK | 2007 | Support Care Cancer | Patients and carer experience of care provision after a diagnosis of lung cancer in Scotland | To explore patient and carer experience of care provision following diagnosis of lung cancer | Qualitative longitudinal interview study using thematic analysis | 23 patients, 15 carers. | Domains of need identified: pathway to confirmation of diagnosis, communication of diagnosis, treatment and prognosis, provision of coordinated family orientated care, support away from acute services. Reported change of needs shifted over time | Reported gate-keeping by clinician for patients deemed 'too ill to take part'. 128 patients out of 239 declined to take part and from 60 recruited only 23 completed all 3 interviews. Findings not illustrated with patient/carer own words. |
| McCarthy et al. *UK* | 2009 | International Journal of Palliative Nursing | Living with a diagnosis of non-small cell lung cancer: patients lived experiences | To explore patients' experiences of living with non-small cell lung cancer | Interpretive phenomenological interview study | 6 people with lung cancer | Four themes reported: 'maintaining life', 'the enemy within', 'staying on the train', 'I'm still me' | Small purposive sample. Limitation was patients nurse specialist was the researcher. Participants were all receiving chemotherapy. Findings supported by patient quotes. |
| Murray et al *UK* | 2002 | BMJ | Dying of Lung Cancer or Cardiac Failure: prospective qualitative interview study of patients and their carers in the community | To compare issues facing patients with lung cancer and end stage cardiac failure and to gauge whether services meet their needs | Longitudinal serial-interview study | 20 lung cancer patients and 20 end-stage cardiac patients | Patients with lung cancer reported struggle to maintain normal life, sense of wanting to know/don't want to know dying. Worried about family coping. Prospect of death persistent threat. Appreciated honesty but some colluded to avoid talking about dying. | Focus on comparing experience between patients with 2 different diseases, therefore depth of insight limited. |

| Author | Date | Journal | Article title | Aims | Study design | Participants | Reported main findings | Critique |
|---|---|---|---|---|---|---|---|---|
| Nilsson et al *USA* | 2008 | Cancer | Mental health, treatment preferences, advance care planning, location, and quality of death in advanced care patients with dependent children | To test the hypothesis that patients with advanced cancer with dependent children will be more anxious and less likely to engage in ACP initiatives than those without dependent children. | Results of baseline interview using questionnaire - part of a larger longitudinal study: National Institute of Health Coping with Cancer. | 668 patients (152 had advanced lung cancer), 343 spouses | Patients less likely to have ACP initiatives (living will, DNR, proxy decision-maker) and more likely to opt for life extending treatment than those without dependent children. Patients with dependent children more worried than those without dependent children and half as likely to be peaceful. No differences in discussions with clinician about end of life care. | Limited by design (descriptive statistics and comparative tests) to explore why patients with dependent children more worried and less likely to engage in ACP. Authors conclude patients with dependent children require more psychosocial support and lack guidance on how to raise issues about ACP with their family. |
| Sawicki et al *USA* | 2008 | Journal of Palliative Medicine | Advance Care Planning in Adults with Cystic Fibrosis | To assess the experience with ACP reported by adults with Cystic Fibrosis. To assess reported communication between these adults and their families/clinicians | Cross sectional survey design | 234 young adults with cystic fibrosis, mean age 34 with less than 5 years to live | 12% had talked to clinicians about ACP and 28% clinicians had asked about ACP. 30% reported having identified a proxy decision maker or had a living will. Only having a clinician initiate ACP discussion and person having specific wishes about future were significantly associated with reporting completed ACP/AD document. | Study mainly young adults. Study did not explore the impact on patient experience of clinically initiated ACP discussion or patient benefits/outcomes of ACP. |

| Author | Date | Journal | Article title | Aims | Study design | Participants | Reported main findings | Critique |
|---|---|---|---|---|---|---|---|---|
| Kataoka-Yahiro et al. *USA* | 2010 | International Journal of Palliative Nursing | Advance care planning among Asian Americans and Native Hawaiians receiving haemodialysis | To explore the attitudes of Asian Americans and native Hawaiians to death and dying, ACP and completion of ACP. | Cross-sectional design using questionnaire | 50 patients with stage 4-5 chronic kidney disease receiving dialysis (aged 30-82 years old). | Preferred initiating ACP with family/friends rather than physicians. 94% comfortable talking about death. 'Worse death' viewed as physical dependence on family/friends, inability to communicate with family/friends in addition to pain. | Limited by sample size to generalise. Design limited ability to find out reasons or meaning of patients' reports. |
| Davison and Simpson *Canada* | 2006 | BMJ | Hope and advance care planning in patients with end stage renal disease: qualitative interview study | To explore participants experience through discussions about prognosis, end of life care and hope | Qualitative study using semi-structured interviews with thematic analysis | 23 interviews with 19 patients with end stage renal disease. | Nature of hope was individual, complex, shaped by values. Role of hope in ACP is central in determining future goals. Role of family - give greatest meaning and sustain hope through connected relationships. | Did not define 'hope' or 'ACP'. Lack of demographics re-education, or socioeconomic status. Assumption by authors that hope important for ACP. |

*Introduction*

The following sections describe and critique the research methods reported in the papers included in the literature review (table 1.2). This is followed by the findings from the review.

## Research Methods used

The research designs used varied between thirteen qualitative interview or focus group studies, one mixed method and ten randomised controlled trials to test post-test interventions, which included three pre and post intervention trials. Seven studies employed cross-sectional designs and six others longitudinal design. Two case studies were also included.

## Critique of the appropriateness of methods used

A variety of methods were used to research advance care planning in differing patient populations. The methods for exploring the experiences of patients, families and staff appeared to generate some insight into the different definitions and meanings of advance care planning. Some studies (Singer et al., 1998; Martin et al., 1999; Drought and Koenig, 2002; Davison and Simpson, 2006) reported on the individual views of patients or their family members, although the choice of design of other papers reporting patients' experiences (Kataoka-Yahiro et al., 2010; Sawicki et al., 2008; Nilsson et al., 2009) prohibited in-depth descriptions. Most papers reported post intervention trials or an evaluation of a program of care. For the most part there was little discussion of the rationale for developing these interventions. Few studies considered whether advance care planning facilitated 'better' outcomes for patients' end of life care or chose designs suitable for considering the longitudinal effects of an ACP intervention to determine whether ACP was able to improve end of life care and treatment. The methods employed for exploring

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patients' experiences of living with lung cancer were for the most part qualitative interview studies, and they generated descriptions of concerns, effects of receiving a diagnosis and experiences of physical, spiritual or emotional distress. None of these studies explored the discussion of preferences or wishes about future care or treatment, although one study specifically surveyed people's views of the components of a 'good death'.

Findings identified from the three sets of data will be presented separately under the following three main themes:

1) ACP interventions, which includes how ACP is described, developed and initiated with patients who have a life-threatening disease, and an analysis of the reported actual and intended outcomes of ACP.

2) Patients' experiences of discussing and planning for end of life care including, methods used to explore patients' experiences.

3) Patients' experiences of living with lung cancer at the end of life.

Each of these themes will be discussed in turn.

*ACP interventions*

Sixteen papers that reported on studies describing ACP as an intervention were included from group one search terms. The main findings are tabulated on the following pages (Table 1.3 - 1.5)

Table 1.3 Summary findings from literature review of ACP interventions

| Authors | Year | ACP initiated by: | | | | | Who participates in ACP: | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | doctor | Nurse | social worker | peer | other skilled facilitator | Patient | family member or surrogate decision maker | doctor | peer | facilitator | stand alone intervention | part of another intervention |
| Morrison et al | 2003 | | | ✓ | | | ✓ | ✓ | | | ✓ | ✓ | |
| Briggs | 2003 | | | | | ✓ | ✓ | ✓ | | | ✓ | ✓ | |
| Ratner et al | 2001 | | | ✓ | | | ✓ | ✓ | | | ✓ | ✓ | |
| Hammes & Rooney | 1998 | | | | | ✓ | | | | | | ✓ | |
| Briggs et al | 2004 | | | | | ✓ | ✓ | ✓ | | | ✓ | ✓ | |
| Englehardt et al | 2006 | | ✓ | ✓ | | | ✓ | ✓ | | | ✓ | | |
| Happ et al | 2002 | | | ✓ | | | ✓ | ✓ | | | ✓ | | |
| SUPPORT | 1995 | | ✓ | | | | ✓ | | | | ✓ | ✓ | |
| Martin et al | 1999 | | | | | | | | | | | | |
| Perry et al | 2005 | | | | ✓ | | ✓ | | | ✓ | | ✓ | |
| Shorr et al | 2000 | ✓ | | | | | ✓ | | ✓ | | | ✓ | |
| Singer et al | 1998 | | | | | | | | | | | | |
| Levy et al | 2008 | | ✓ | ✓ | | | ✓ | | | | ✓ | | ✓ |
| Song et al | 2009 | | ✓ | | | | ✓ | ✓ | | | ✓ | ✓ | |
| Heyman and Guthiel | 2010 | | | ✓ | | | ✓ | | | | ✓ | ✓ | |
| El-Jawarhri | 2010 | | | | | ✓ | ✓ | | | | ✓ | ✓ | |

Table 1.4 Reported outcomes from literature review on ACP Interventions

| Authors | Reported Outcomes | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Assessment | Assessment of capacity to decide | Documentation | | Identity of power of attorney or substitute decision maker | Interview | Use of discussion guide or worksheet | Patient or family education | Congruence between care received & stated preferences | | Reduced technologies to unnecessarily prolong life | |
| | | | Advance directive | Medical notes | | | | | intended | actual | intended | actual |
| Morrison et al | ✓ | ✓ | ✓ | ✓ | ✓ | | | | ✓ | ✓ | | |
| Briggs | ✓ | | | ✓ | | ✓ | | ✓ | | | | |
| Ratner et al | ✓ | ✓ | ✓ | ✓ | | ✓ | ✓ | | ✓ | ✓ | | |
| Hammes & Rooney | | | | ✓ | | | | ✓ | ✓ | ✓ | | |
| Briggs et al | | ✓ | | | ✓ | ✓ | ✓ | ✓ | | | | |
| Englehardt et al | | ✓ | ✓ | | | ✓ | ✓ | ✓ | | | | |
| Happ et al | ✓ | | | ✓ | | | | | | | | |
| SUPPORT | | | | | | ✓ | | | | | ✓ | ✗ |
| Martin et al | | | ✓ | | | | | ✓ | | | | |
| Perry et al | | | ✓ | | | ✓ | ✓ | ✓ | | | | |
| Shorr et al | ✓ | | ✓ | | | | | | | | | |
| Singer et al | | | ✓ | | | | | ✓ | | | | |
| Levy et al | ✓ | | ✓ | | ✓ | ✓ | ✓ | | | | | |
| Song et al | ✓ | | | | ✓ | ✓ | | | | | | |
| Heyman and Guthiel | | | | | | ✓ | ✓ | ✓ | | | | |
| El-Jawarhri | ✓ | | | | | | ✓ | ✓ | | | | |

Table 1.5 Reported components of ACP interventions and outcomes

| Authors | Reported outcomes | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Improved symptom management | | Reduce decisional conflict/increase in congruence between patient and family and/or doctor | | Improved communication between patient, family, health professionals | | Patient/family satisfaction, comfort or acceptance in discussing EOL care | | Completion of advance directive or documented EOL discussion | | Promote readiness for death | |
| | intended | actual | intended | actual | intended | Actual | intended | actual | intended | actual | intended | actual |
| Morrison et al | | | | | | | | | ✓ | ✓ | | |
| Briggs | | | | | | | | | | | | |
| Ratner et al | | | | | | | ✓ | ✓ | | | | |
| Hammes & Rooney | | | | | | | | | ✓ | ✓ | | |
| Briggs et al | | | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | | | | |
| Englehardt et al | | | | | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Happ et al | | | | | | | | | | | | |
| SUPPORT | ✓ | ✗ | ✓ | ✗ | | | | | ✓ | ✗ | | |
| Martin et al | | | | | | | | | | | | |
| Perry et al | | | | | | | ✓ | ✓ | ✓ | ✗ | | |
| Shorr et al | | | | | ✓ | ✗ | | | ✓ | ✗ | | |
| Singer et al | | | | | | | | | | | | |
| Levy et al | | | | | | | | | ✓ | ✓ | | |
| Song et al | | | ✓ | ✗ | ✓ | ✓ | ✓ | ✓ | | | | |
| Heyman and Guthiel | | | | | | | ✓ | ✓ | | | | |
| El-Jawarhri | | | | | | | ✓ | ✓ | | | | |

Some studies reported on trials that developed or tested an ACP intervention (SUPPORT Principal Investigators 1995; Hammes and Rooney, 1998; Singer et al., 1998; Martin et al., 1999; Ratner et al., 2001; Happ et al., 2002; Briggs et al., 2004; Morrison et al., 2005; Heyman and Gutheil, 2010; Song et al., 2009; El-Jawahri et al., 2010). Other papers presented a case study using an intervention (Briggs, 2003), and another paper presented an intervention aimed at coordination of care that included ACP as part of the intervention (Engelhardt et al., 2006; Levy et al., 2008). All papers originated from North America and studied a variety of patient groups with advanced chronic diseases.

*Target populations*

The majority of studies that developed and tested ACP interventions targeted mixed populations of patients with chronic life-threatening diseases (Briggs, 2003; Briggs et al, 2004; Norlander, 2000; Ratner et al, 2001; Happ et al, 2002; Hammes and Rooney, 1998; Englehardt , 2006; SUPPORT, 1995; Shorr et al, 2000) in the USA or Canada. Three papers reported on research with a sample of patients with a single disease type (Song et al., 2009; Perry et al., 2005; El-Jawahri et al., 2010). Five studies included cancer patients within their sample (SUPPORT, 1995; Hammes and Rooney, 1998; Shorr et al, 2000; Ratner et al, 2001; Englehardt, 2006). One study included in this review reported the development of an ACP intervention for cancer patients alone (El-Jawahri et al., 2010). The lack of specific interventions for cancer patient populations arguably reflects the provision of North American hospice and palliative care services for all patients with life-threatening illnesses. Apart from El-Jawahri et al (2010), few papers featured patients with cancer other than within a mixed patient sample (Hammes and Rooney, 1998; Ratner et al., 2001; Happ et al., 2002), which included patients with other chronic or other life-threatening diseases. Arguably it may not be appropriate for ACP to be developed as a disease specific intervention, with most studies targeting mixed

populations; however, the assumption that ACP may benefit patients who have cancer is as yet undetermined.

The interventions reviewed were tested in community settings, which were predominately in patients' homes (Heyman and Gutheil, 2010; Ratner et al., 2001), in institutional settings (Shorr et al, 2000; SUPPORT, 1995; Briggs et al, 2004; Morrison et al, 2005; Levy et al, 2008; El-Jawahri et al, 2010), or in mixed settings (Hammes & Rooney, 1998; Englehardt et al, 2006).

*How are ACP interventions described in the literature?*

Fifteen papers included in this review described ACP in relation to the development of an intervention(Ratner et al., 2001; Larson and Tobin, 2000; Morrison et al., 2005; Briggs, 2003; Briggs et al., 2004; Happ et al., 2002; Hammes and Rooney, 1998; Engelhardt et al., 2006; El-Jawahri et al., 2010; Heyman and Gutheil, 2010; Song et al., 2009) and one paper described ACP as part of a program of care (Levy *et al.*, 2008). ACP interventions were described using a variety of terms such as an 'educational intervention' (Briggs, 2003), a 'framework' (Larson and Tobin, 2000), an 'interview' (Briggs et al, 2004), an 'intervention of counselling' (Morrison et al., 2005), or a 'process of discussion' (Hammes & Rooney, 1998) to initiate end of life discussions or conversations. These discussions were reported as a series of ongoing conversations (Ratner et al., 2001; Larson and Tobin, 2000; Engelhardt et al., 2006) that build relationships to enhance understanding between those engaged in discussion (Song et al., 2009; Briggs, 2003) and improve end of life decision making (El-Jawahri et al., 2010) or that enable patients to prepare for death or dying (Singer et al., 1998). Briggs (2003) proposed that 'listening' is the intervention, thus suggesting an emphasis on a patient-led discussion. What is included in ACP discussions will be discussed further when the specific components of ACP are considered.

The descriptions of ACP interventions appear to be linked to or include some form of 'assessment' of the patient's understanding about their condition, prognosis and decision-making capacity (Happ et al., 2002; Ratner et al., 2001; Morrison et al., 2005; Levy et al., 2008;

Song et al., 2009; El-Jawahri et al., 2010). Some form of documentation of patients' treatment or care preferences were reported as a component of ACP interventions which may or may not include completion of an advance directive (Happ et al., 2002; Singer et al., 1998; Ratner et al., 2001; Morrison et al., 2005; Martin et al., 1999; Levy et al., 2008) and identification of a durable power of attorney or surrogate decision-maker (Happ et al., 2002; Song et al., 2009). ACP interventions are reported in the literature in such a way as to suggest they are a 'special' event or series of events as opposed to being part of normal everyday care.

For the most part, the description of ACP as an 'intervention' does not feature in the literature until the later 1990s after a number of trials sought unsuccessfully to establish improved completion rates of advance directives (Singer et al., 1998; SUPPORT Principal Investigators 1995). The previous use of ACP to describe a discussion or completion of an advance directive (Singer et al., 1998) is not unproblematic as it can lead to confusion, suggesting ACP is defined as an intervention focussed on documentation of preferences for future care and treatment for legal purposes only. Later descriptions of ACP interventions (Briggs, 2003; Morrison et al., 2005; Martin et al., 1999; Ratner et al., 2001; Larson and Tobin, 2000), focus on initiating and conducting a series of in-depth discussions with patients and their families with the emphasis on improving end of life experiences. Prendergast (2001) accredits Hammes and Rooney (1998, figure 1.3) with changing the focus of how ACP is defined.

Figure 1.3 Hammes and Rooney (1998) 'Death and end of life planning in one mid-western community'.

*Background*

This is the first published study reporting on the implementation of an advance care planning intervention in the USA.

*Design*

This study aimed to evaluate the impact of a complex advance care planning intervention that had been delivered community-wide. The authors aimed to determine for a specific population the prevalence of ACP and the relationship between ACP and the health care decisions made in local health organisations. The ACP intervention was named '*Respecting Your Choices'* and included a community patient education programme, training of 120 local non-physician ACP educators, access to these educators in all health care organisations, common policies and practices in the use of ACP documents and documented decisions within patients' medical notes. The study design was a retrospective review of 540 deceased patients' medical notes and death certificates to collect data relating to ACP and any advance decisions made. They also surveyed physicians and interviewed proxies of the deceased.

*Findings*

Findings reported in this paper were that 437 (81%) patients had advance decisions recorded in their medical notes, 353 (77%) had identified a power of attorney, 528 (98%) patients who had requested refusal of treatment had their decision upheld. Patient preferences were recorded one year or more before death, with 20% recorded within months of death. These preferences included forgoing care or treatment related to resuscitation, feeding tubes, ventilation, antibiotics, intravenous fluids and hospitalisations. Congruency between preferences for non-hospitalisation and actual care received were lower compared to other advance decisions. The authors attributed this to families' wishes overriding patients' preferences.

*Summary*

This 'seminal' study has since resulted in the further development of the '*Respecting your Choices*' ACP intervention, including disease-specific versions in the USA and more recently in Australia.

Prendergast (2001) suggested that prior to Hammes and Rooney's (1998) study ACP had been focused on a medical model with advance directives as an end point. However, through the successful use of an educational intervention Hammes and Rooney (1998) were able to make recommendations for a change in practice focussing on facilitating discussions with patients about their values and preferences for end of life care, as well as documented advance refusals for life- prolonging treatments.

ACP has been described elsewhere in the literature as having certain functions. As described previously, one of these functions is to facilitate patients' discussions about future preferences for care and treatment (Song et al., 2009; Heyman and Gutheil, 2010; Engelhardt et al., 2006; Briggs, 2003) in the event they become incapacitated. More recently, advance care planning interventions have been described as having a prevention function (Engelhardt et al., 2006; Maxfield et al., 2003), since they can help patients and their families who need to make decisions at a time of serious illness, plan ahead for these eventualities. This description of advance care planning adds to the debate on whether patients can or want to make decisions for the future. It also suggests that the future is predictable, which may not be the case for patients with complex disease processes who live in potentially complex social and medical contexts and within the financial constraints of the current national health service.

## *Development of ACP interventions*

Only five papers described how an ACP intervention had been developed (Briggs, 2003; Briggs et al., 2004; Ratner et al., 2001; SUPPORT Principal Investigators 1995; El-Jawahri et al., 2010) and provided some rationale for the use of an ACP intervention. Three of these five studies designed an ACP intervention to improve communication with patients and their families about end of life issues (Briggs, 2003; Briggs et al., 2004; Ratner et al., 2001) and in response to government policy; however, only Briggs (2003) and Briggs et al (2004) provided detailed theoretical explanations of how and why they developed the ACP intervention in a particular way.

Some of the papers give insight into what influenced the authors to develop an ACP intervention. In the USA, the SUPPORT (1995) intervention is described in figure 1.4

Figure 1.4 The Support Principal Investigators (1995) 'A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients'.

*Background*

This is one of the earliest reported USA studies describing an ACP intervention. This study was conducted during a time when federal bodies were discussing people's rights to self determine their own future in relation to medical care and forego life-prolonging treatment and care.

*Design*

This four-year study aimed to improve end of life decision making and reduce the number of people supported by intensive technologies which prolonged the dying process. The design included two phases. Phase one was an observational study of 4301 patients that explored the process of decision-making and analysed patient outcomes within medical institutions and collected data between 1989 and 1991 prior to the Patient Self-Determination Act. Phase two was a controlled trial conducted between 1992 and 1994 after the Act came into force. This phase tested an intervention using a sample of 4804 patients and their physicians. The intervention was designed to increase communication and understanding of prognoses and preferences which the authors suggested would result in earlier treatment decisions and reduce the use of intensive care beds as well as "undesirable states before death" (p.1592). The intervention arm included prognostic information availability to physicians, nurse led discussion and information provision with the approval of the physician to elicit patient preferences, and could include an interview between physician and their surrogate decision maker.

*Findings*

Phase one: 960 (31%) patients preferred no cardiopulmonary resuscitation, and of these 49% did not have a 'do not resuscitate' (DNR) order, and only 47% of physicians accurately reported this preference. 79% of the 1150 people who died within the sample died with a DNR, and 46% of these orders were written in the last 2 days of life. More than a $1/3^{rd}$ (38%) of deceased patients were reported as having spent 10 days in intensive care prior to death. Surrogates of 50% of patients reported moderate to severe pain in the last 3 days of life.

Phase two: The prevalence and timing of DNR orders was the same in both the intervention and control groups. There was no difference in intensive care bed days between groups. Reported pain increased in the intervention group compared to the control and there was no change in hospital resources between groups. There was no difference in the number of patients or surrogates reporting a discussion about preferences. 59% of physicians of the 2652 patients in the intervention group reported receiving the prognostic report and 34% acknowledged receipt of a preference report from the nurse. Only 15% of physicians reported discussing specific information with patients or families.

*Summary*

The early findings from phase one of this study may have influenced the legal process in the USA, pushing the self-determination bill through the federal processes. The SUPPORT intervention failed to deliver the intended outcomes for patients and in that respect also failed to implement the premise of the Act which was to enable people to determine their own future.

The authors collaborated in the design of the intervention with the participating physicians who suggested they needed more reliable information about patients' prognoses and assistance in having more effective conversations with patients. This led to an intervention perhaps developed to support the wishes of physicians for accurate prognostic information rather than one which focussed on the needs of patients and their families for a more 'natural' death. Unfortunately the intervention failed to make any significant changes to patients' outcomes, which will be discussed later in this chapter.

Ratner et al's (2001) intervention involved social workers initiating a series of discussions with seriously ill patients in their homes and completion of an advance directive if the patient wished. Patients were also informed about hospice care and financial and community resources, and a documented advance care plan was then shared with the patients' GP and home care nurse. Ratner et al (2001) cite the development of their ACP intervention as deriving from a model of communicative ethics that consists of an ethical framework which views communication as more than the transfer of information or a questioning interview. Their model sought to achieve mutual understanding and reasoning between patients and their health professionals. Ratner et al (2001) developed the intervention to be facilitated by health professionals (nurses or social workers) and targeted it at seriously ill patients living at home, with the aim of promoting hospice care at home.

Briggs (2003) described the rationale for the development of a patient-centred focus to an ACP intervention as a response to a need to fill gaps in the current ACP programme. Figure 1.5 describes Briggs' (2003) study.

Figure 1.5 Briggs (2003) 'Shifting the focus of advance care planning: using an in-depth interview to build and strengthen relationships'

*Background*

The author of this case study (about a patient with end stage renal disease) was a nurse who worked with the researchers who designed the '*Respecting Choices'* ACP intervention *(Gundersan Lutherhan, 2007)*. Briggs reported a desire to address ethical issues surrounding decision making for patients having complex surgery with high mortality rates. Briggs collaborated with a team of researchers to use an interview approach.

*Design*

The aim of the intervention was to implement "meaningful conversations with people who are at risk of serious complications" (p1) to improve end of life care. A patient education theoretical framework was used and an interactive decision-making model incorporated the facilitative skills from the '*Respecting Choices*' programme. The intervention involved the ACP facilitator having an understanding of the specific disease process and progress as well as the different treatment modalities available together with the benefits and burdens of each. Communication skills were used to assist the person to describe their illness beliefs and assess the limitations or consequences of these beliefs. New or 'replacement' information was offered to influence or modify people's beliefs and to help them understand their future options for care and treatment. In addition, the facilitator explored and listened to people's concerns. This intervention was piloted and reported in Briggs et al (2004).

*Findings*

Briggs reported that this intervention was 'hard work' as it required excellent communication skills and confidence to build rapport with the person. She also reported that it was possible to be intimate with the patient even though she was a stranger to them. In addition, she reported that patients were sometimes afraid to talk to their families. Briggs concluded that 'listening' was the intervention.

*Summary*

This study and a later paper (Briggs et al, 2004) reporting the use of this intervention with a sample of patients with heart failure and end stage renal disease provide evidence of ACP as a means of focussing on the discussion with patients about their future preferences for care and treatment to improve their care, rather than a focus on reducing technologies to prolong life or save institutional resources.

Briggs (2003) also sought to further develop ACP to improve outcomes for patients from different populations and settings. This suggests there may be a need for different levels of intervention in ACP, with the need for more complex and detailed discussions with some

patients compared to others, and with higher levels of skill required by those facilitating ACP with some patient populations in comparison to others.

Another published study (Engelhardt et al., 2006) reported the development of an intervention that incorporated advance care planning as an integrated part of a set of six elements of a complex programme of care. This programme of care aimed at increasing patient satisfaction and consistency of care with patients' preferences. It is difficult to determine within this complex intervention the components of ACP, but it illustrates the central aim of ACP to improve end of life care and patient satisfaction. On the other hand, Levy et al (2008) also developed ACP as part of a wider programme of end of life care and aimed to increase documentation of advance decisions and reduce hospitalisations for people in nursing homes. Levy et al (2008) reported a significant increase in documented advance decisions, but did not achieve a reduction in the use of hospital resources. Whether ACP should be a stand-alone intervention or incorporated into other interventions seeking to improve end-of-life care is not yet known.

*Components of ACP interventions.*

In this section I will discuss how ACP has been initiated, who takes on this role and the components of the interventions as described within the literature. Six papers suggested that the key people involved in initiating ACP as an intervention were either social workers (Ratner et al., 2001; Morrison et al., 2005; Happ et al., 2002; Heyman and Gutheil, 2010) or combinations of social workers and nurses as 'care-coordinators' or facilitators (Engelhardt et al., 2006; Levy et al., 2008; Song et al., 2009). Some papers did not specify individual's profession, only stating that they were an experienced or 'skilled facilitator' (Briggs et al, 2004) or non-physician educator (Hammes and Rooney, 1998). Interestingly, one paper (Perry et al., 2005) included a description of the use of peers with renal disease initiating ACP with patients. Only one paper reported using physicians to initiate ACP (Shorr et al., 2000). Various techniques were used by the professionals to facilitate the ACP process, with professionals taking on different tasks such

as coordinating discussions (SUPPORT Principal Investigators 1995) initiating discussions (Morrison et al., 2005; Engelhardt et al., 2006; Ratner et al., 2001; Hammes and Rooney, 1998; Briggs, 2003; Briggs et al., 2004; SUPPORT Principal Investigators 1995; Shorr et al., 2000; Happ et al., 2002), showing a video (El-Jawahri et al., 2010) or referring to other facilitators for a discussion (Ratner et al., 2001; Perry et al., 2005). There appears to be little clarity about which professions are 'best' at ACP or which professionals patients prefer to take on the facilitation role. Some patients were reported to prefer discussing issues about end of life care with their families rather than their physician (which will be discussed further under the next theme), but whether patients would have the same view about nurses and social workers is not yet known.

Initiation of ACP appears to occur as part of an initial assessment of a health care institution or nursing home (Morrison et al., 2005; Briggs, 2003; Ratner et al., 2001; Happ et al., 2002; Shorr et al., 2000), which included in some papers an assessment of patients' capacity to make decisions (Engelhardt et al., 2006; Briggs et al., 2004; Morrison et al., 2005), including their preferences for decision-making (Ratner et al., 2001; Briggs et al., 2004).

Nine papers described an ACP intervention initiated through a research protocol. In these latter studies patients were usually contacted to take part in one interview or a set of interviews involving sometimes as many as eight patient contacts - in the form of face to face interviews or telephone conversations (Perry et al., 2005; Engelhardt et al., 2006). The purpose of the interviews was to discuss preferences for care (Briggs, 2003; Briggs et al., 2004; Ratner et al., 2001; SUPPORT Principal Investigators 1995; Engelhardt et al., 2006; Song et al., 2009). Some other papers describe a less directive approach where patients were given a form, survey or educational materials about advance directives for them to initiate ACP if they wished. Opportunities were given to patients to gain further information from trained facilitators to help in decision making (Martin et al., 1999; Singer et al., 1998; Shorr et al., 2000).

Some authors reported that they made use of discussion guides or an interview schedule to help structure conversations about end of life issues (Perry et al., 2005; Briggs et al., 2004; Song et al., 2009; Heyman and Gutheil, 2010) and they sometimes used these in combination with worksheets (Engelhardt et al., 2006; Perry et al., 2005). Some worksheets were used to focus the discussion on potential disease-specific scenarios (Briggs et al, 2004). The findings from this review suggest that interviews were used to discuss a variety of end of life issues such as: information sharing about patients' understanding of their medical condition and prognosis (Briggs, 2003; Briggs et al., 2004; SUPPORT Principal Investigators 1995; Ratner et al., 2001; Song et al., 2009), exploring misconceptions or misunderstandings (Briggs, 2003; Briggs et al., 2004; Engelhardt et al., 2006; Song et al., 2009), ascertaining what goals patients have for the future (Ratner et al., 2001; Perry et al., 2005; Morrison et al., 2005), eliciting patient preferences for future care and treatment (SUPPORT Principal Investigators 1995; Ratner et al., 2001; Briggs, 2003; Briggs et al., 2004; Morrison et al., 2005; Levy et al., 2008; El-Jawahri et al., 2010) and determining a patient's choice of substitute decision-maker (Briggs et al., 2004; Morrison et al., 2005; Song et al., 2009).

Other authors reported that they made use of educational videos instead of discussions to provide patients with information to enable them to write their own advance directives (Martin et al., 1999; Singer et al., 1998; El-Jawahri et al., 2010). Patient and family education about ACP appears to be a key component of most ACP interventions (Briggs, 2003; Briggs et al., 2004; Singer et al., 1998; Hammes and Rooney, 1998; Martin et al., 1999; Perry et al., 2005; Engelhardt et al., 2006). The focus of education appears to be on informing patients and their families about their legal rights to make an advance directive and appoint a proxy decision-maker and how to complete advance directive forms regarding their preferences and decisions for future care and treatment. Some ACP interventions are based on educational models such as the "Respecting Choices" Program (Hammes and Rooney, 1998; Briggs, 2003; Briggs et al., 2004) or patient centred ACP (Song et al., 2009). Various educational programmes to train personnel in facilitating ACP are also available to support implementation of ACP interventions

(Shorr et al., 2000; Ratner et al., 2001; Briggs et al., 2004; Perry et al., 2005; Morrison et al., 2005; Engelhardt et al., 2006). These educational initiatives for staff range from informal lectures with or without role-play to accredited continuing professional development courses.

Documentation was also found to be a key component of ACP in all reviewed papers. This took the form of a formal advance directive document completed by the patient (Martin et al., 1999; Singer et al., 1998; Shorr et al., 2000; Ratner et al., 2001; Perry et al., 2005; Engelhardt et al., 2006) or documentation by a health professional in the patient's medical notes regarding the patient's oral or written preferences for care (Hammes and Rooney, 1998; Happ et al., 2002; Briggs, 2003; Morrison et al., 2005; Levy et al., 2008). Some studies report patient documentation in the form of both an advance directive and health professionals' documentation of the ACP within patients' medical notes (Ratner et al, 2001, Morrison et al, 2005). Sharing of documentation of the ACP with other members of the patient's health care team was only reported in one paper (Morrison et al, 2005).

The development of policies within health care organisations (Hammes and Rooney, 1998; Shorr et al., 2000; Happ et al., 2002) suggests a systems based approach to ACP as a mechanism for ensuring organisations adhere to national policy, but it also could be viewed as an attempt to change health professionals' practice or behaviour. It was reported in one paper that policies appeared to contribute towards a positive outcome of the result of the ACP intervention (Hammes and Rooney, 1998) where whole communities were educated about ACP. The two other studies describing organisational policies did not report effective implementation of the ACP intervention (Happ et al., 2002; Shorr et al., 2000).

The findings from interrogating the literature suggest that there are various means of 'framing' ACP. In some studies ACP has been framed around the opportunity for patients to make decisions for the future in the event of incapacity (Briggs, 2003; Briggs et al., 2004) and to support consistency of care with patients' wishes for the future (Ratner et al., 2001; Engelhardt

et al., 2006). By contrast, others are 'apologetic' about the need to conduct ACP due to the legal requirements on all health organisations within the USA (Ratner et al, 2001). This finding suggests there are different approaches to ACP interventions which may have influenced the reported 'success' or otherwise of ACP in different study populations.

The success of an intervention in these studies was evaluated in the majority of papers either by evidence of the initiation of an advance care planning discussion or by completion of documented preferences (Ratner et al., 2001; Morrison et al., 2005; Shorr et al., 2000), an advance directive or a do not resuscitate order (Singer et al., 1998; Engelhardt et al., 2006; Hammes and Rooney, 1998; SUPPORT Principal Investigators 1995; Perry et al., 2005; Shorr et al., 2000; Levy et al., 2008). Other measurements of success included documented power of attorney (Hammes and Rooney, 1998), a reduction in the number of intensive care bed days, reported decrease in pain (Hammes and Rooney, 1998; SUPPORT Principal Investigators 1995), a reduction in the use of antibiotics, artificial hydration, hospitalisation (Hammes and Rooney, 1998; Morrison et al., 2005) or reduction of the financial cost (Englehardt et al, 2006). Little emphasis was placed on patients' own reports of the benefits of ACP to them and their families. However, Englehardt et al (2006) considered patients' or family members' satisfaction with participation in advance care planning discussions (Song et al., 2009), and other studies measured comfort with discussions (Perry et al., 2005; Heyman and Gutheil, 2010) and reported success in terms of patients' acceptance of ACP discussions (Song et al., 2009; Ratner et al., 2001) or satisfaction with the decision-making  process (Briggs et al., 2004).

*Actual and intended outcomes of ACP*

Fourteen papers described outcomes from the ACP interventions, and although the intended outcomes were not made explicit they did provide descriptions of the study aims. In analysing the evidence relating to ACP intervention outcomes it appears that only a few authors developed the intervention for the purpose of increasing the congruence of patients' stated preferences with the actual medical decisions made at the patients' end of life (Morrison et al., 2005; SUPPORT

Principal Investigators 1995; Hammes and Rooney, 1998; Ratner et al., 2001). The resulting

outcomes for patients in three of these studies were reported as positive (Ratner et al., 2001;

Morrison et al., 2005; Hammes and Rooney, 1998), with 98% congruence between the medical

care patients received and their previously stated preferences (Hammes & Rooney, 1998). Only

5% received medical treatment which conflicted with expressed preferences compared to 18% in

the control group (Morrison et al, 2005), and all patients who preferred to die at home were able

to achieve this (Ratner et al, 2001).

The SUPPORT study (1995) and the study reported by Shorr et al (2000) relied on

physicians to discuss and document decisions about foregoing life prolonging treatment. Both

studies failed to achieve this. The SUPPORT study used trained nurses to carry out an ACP

intervention; however, it appears that the physicians failed to use the documented ACP

discussions to influence the medical decisions they made on patient treatment and care, and this

resulted in treatment that was incongruent with the previously stated wishes of patients. In

considering the design of the intervention the investigators sought physicians' views about what

would enable them to discuss patients' preferences for care but they did not report whether

patient and family views were sought. The resulting intervention was designed to support

physicians in decision-making by providing nurse-led discussions and documentation for

physicians to use if they wished, rather than facilitating patients' ability to make their own

decisions or providing opportunity for joint decision making between physicians and patients.

Similarly, Shorr et al (2005) tried to control physicians' behaviour by designing an

intervention that sought to put organisational systems in place to educate, guide and remind

physicians to initiate conversations about end of life issues. The intervention failed to influence

physician behaviour, resulting in patients' preferences not being elicited.

The SUPPORT (1995) study failed to achieve its intended outcome as described earlier

(figure 1.3) and only 15% of physicians used the reports of patients' preferences provided by the

intervention nurses as a basis of discussion of end of life issues with their patients. This may be related to a lack of training or a change in the behaviour of physicians. Alternatively, there may have been limited time to engage in discussions with patients. Also, only 42% of patients in the study reported they wanted to have a discussion with their physician about their prognosis.

Other reports of studies' intended aims or outcomes included the improvement of communication about end of life care between patients, their families and health professionals(Shorr et al., 2000; Briggs, 2003; Engelhardt et al., 2006; Song et al., 2009) improved satisfaction or 'comfort' with discussions about end of life issues (Shorr et al., 2000; Briggs, 2003; Briggs et al., 2004; Perry et al., 2005; Engelhardt et al., 2006; Song et al., 2009; El-Jawahri et al., 2010; Heyman and Gutheil, 2010) and promotion of readiness for the end of life (Engelhardt et al., 2006).

An increase in the congruence between decision-making and the strengthening of relationships between patients, their families and health professionals was found in some studies (Morrison et al., 2005; Briggs et al., 2004; Song et al., 2009), and improved satisfaction with communication related to ACP is reported by Briggs et al (2004), Engelhardt et al (2006) and Song et al (2009). Increased comfort in discussing end of life care was reported in other studies (Perry et al, 2005; Song et al, 2005; Heyman and Gutheil, 2010). For Perry et al (2005), this outcome was dependant on the patients' ethnicity. Briggs et al (2004) suggest there is reduced decisional conflict amongst patients and their families as a result of the use of an ACP intervention, but in another study this was not apparent, nor did it change over time (Song et al, 2009). There was evidence to suggest an increased understanding and satisfaction in families who have been involved in the process (Briggs et al., 2004; Engelhardt et al., 2006; Song et al., 2009). Three of the reviewed studies (Engelhardt et al., 2006; Hammes and Rooney, 1998; Perry et al., 2005) reported an increase in patient completion of advance directives, an outcome which was not explicitly sought.

Morrison et al (2003) reported the presence of social workers at team meetings and their 'checking-in' on ward meetings, which, although not described as a component of the ACP intervention, may indeed have influenced the effect of the intervention and achievement of the intended outcomes. Englehardt et al (2006) used care coordinators to initiate ACP discussions with patients and their families, and these coordinators also had ongoing relationships with the providers of care for these patients. Ratner et al (2001) used social workers employed by a home health care agency to initiate ACP with patients referred by district nurses. It was reported that the social workers made referrals to hospice care if this was the patient's wish after ACP discussion had taken place, but no other reference was made to the questions of whether an ongoing relationship with the patient would affect outcomes. Other studies do not report ongoing relationships with the patients and their family.

Interestingly, the SUPPORT study (1995) and the study reported by Shorr et al (2000) which failed to achieve their intended outcomes, both relied on physicians: other studies used non-physicians to discuss decisions about end of life care with their patients and to document these in the medical records.

*Patient experiences of discussing and planning for end of life care*

A number of studies reported surveys of patients' preferences for end of life care (Haddad and Brown, 1994 ; Sahm et al., 2005; Fried et al., 2002; Alpert and Emanuel, 1998; Silverstein et al., 1991; Hawkins et al., 2005; Heyland, 2003) when they were early in the course of their illness such as at diagnosis or had a life expectancy of greater than 2 years. Some studies described an analysis of documentary evidence to report about the frequency of ACP discussions with patients and their outcomes (SUPPORT Principal Investigators 1995; Bradley et al., 2001).  Some retrospective studies have explored family members' views about deceased patients' end of life experiences, including their own perceptions of advance care planning or advance directives (Happ et al., 2002; Hammes and Rooney, 1998; Ganzini et al., 2002;

Klinkenberg et al., 2004). Two papers reported on the exploration of people's experiences of communication about end of life issues and the proposed use of ACP (Sampson et al., 2008; Selman et al., 2007). Few studies have explored the prospective experiences of patients towards the end of life.

Fifteen articles specifically sought patients' views about their experiences of discussing and planning for their end of life care. The main findings from these fifteen papers are represented in the following table.

Table 1.6 Literature review findings of patient experiences of ACP in palliative care settings

| Authors | Year | Patients | Family members | Health care providers | Preparation for death | Improving communication | Achieving a sense of control | Involving family and friends |
|---|---|---|---|---|---|---|---|---|
| Briggs | 2003 | ✓ | ✓ |  |  | ✓ |  | ✓ |
| Lynn & Goldstein | 2003 | ✓ |  |  |  |  |  |  |
| Briggs et al | 2004 | ✓ | ✓ |  |  | ✓ |  |  |
| Holley et al | 1999 | ✓ |  |  |  |  |  | ✓ |
| Singer & Martin | 1998 | ✓ |  |  | ✓ |  | ✓ | ✓ |
| Martin et al | 1999 | ✓ |  |  | ✓ | ✓ | ✓ | ✓ |
| Drought & Koenig | 2002 | ✓ | ✓ | ✓ |  | ✓-ve |  |  |
| Steinhauser & Christakis | 2001 | ✓ | ✓ | ✓ | ✓ |  | ✓ | ✓ |
| Curtis and Patrick | 1997 | ✓ |  | ✓ |  | ✓ |  |  |
| McSkimming et al | 1999 | ✓ | ✓ |  |  | ✓-ve |  | ✓ |
| Song et al | 2009 | ✓ | ✓ | ✓ |  | ✓ |  |  |
| Davison & Simpson | 2006 | ✓ | ✓ | ✓ |  |  |  | ✓ |
| Sawicki et al | 2008 | ✓ | ✓ | ✓ |  |  |  |  |
| Nilsson et al | 2008 | ✓ |  |  |  |  |  |  |
| Kataoka-Yahiro et al | 2010 | ✓ |  |  |  |  |  | ✓ |

Some of these studies also included an exploration of the views of family members or health care providers. Two of these papers were case studies of individual patients (Lynn and Goldstein, 2003; Briggs, 2003) conducted to explore the experiences of patients with chronic diseases. Two papers used an experimental design to test out an ACP intervention and described a group of patients (with chronic diseases) experiences of this intervention (Briggs et al., 2004; Song et al., 2009). One paper used a survey design to examine preferences for involving others in ACP (Holley et al., 1999), and three others used a similar design to explore patients' attitudes towards ACP (Kataoka-Yahiro et al., 2010; Nilsson et al., 2009; Sawicki et al., 2008). Of the remaining papers, three used semi-structured face to face interviews (Singer et al., 1998; Martin et al., 1999; Drought and Koenig, 2002; Davison and Simpson, 2006) and three used focus groups (Steinhauser et al., 2001; Curtis and Patrick, 1997; McSkimming et al., 1999) to explore patients' views about engaging in ACP discussions.

None of the papers reported any discussion of cancer patients' experiences with ACP in the UK. Several papers that reported studies originating in the USA about patients' experiences included cancer patients within their samples (Drought and Koenig, 2002; McSkimming et al., 1999; Steinhauser et al., 2001; Nilsson et al., 2009).

It appears that the provision of knowledge of patients' experiences of ACP within the literature is quite recent; however, four themes appear to emerge from the data. I will now discuss these themes to outline the current knowledge and the main gaps in the literature.

## Preparation for death

One of the issues related to patients' experiences of discussing and planning for end of life care is preparation for death. Two USA based papers and one UK paper identified that patients' experiences of ACP helped them to face or prepare for death and dying (Martin et al, 1999; Singer et al, 1998). Patients felt that discussions about their end of life care were enabling or 'forcing' them to think about death, talk to their families and loved ones and learn to cope with

the prospect of dying. The recognition that discussing death and dying is a difficult task is reported by both patients and health professionals alike (Briggs, 2003), with some patients waiting for doctors to initiate the conversation (Curtis and Patrick, 1997).

Improving communication

In considering the difficulties associated with discussing death and dying, there appears to be conflicting data regarding the outcomes of such discussions as perceived by patients. Some patients reported improved quality of communication with health professionals when engaged in ACP discussions (Song et al., 2009; Briggs et al., 2004). Others however, found that physicians were 'too busy' to conduct such discussions, that they actively discouraged or ignored their questions (McSkimming et al., 1999) or did not ask about ACP (Sawicki et al., 2008). Some patients were reported to have felt the need to protect their physicians from the perceived discomfort of such conversations. Patients also reported that, when there was earlier documentation of their preferences (from earlier in their disease trajectory), this negated the physicians' need to open up discussion about end of life care (Curtis and Patrick, 1997).

An increased awareness of end of life wishes amongst patients and their families is reported (Song et al., 2009; Briggs, 2003).  Patients have suggested that documenting future preferences would relieve the burden on their families (Steinhauser et al., 2001), and patients felt documentation of their wishes would increase family members' willingness to carry out their wishes, although in other studies patients' stated wishes were not always carried out by their families (Lynn and Goldstein, 2003). Conversely, patients with advanced cancer who had dependent children were reported as being less likely to engage in ACP (Nilsson et al 2008).This is an issue which will be explored later.

One of the benefits cited by patients of discussing and planning their end of life care appears to be their enhanced understanding of their condition, prognosis and choices for care

(Briggs, 2003). Patients also reported benefits from the opportunities to explore and express their preferences for future care with others (Song et al., 2009; Martin et al., 1999), which they might not otherwise have had or chosen to open up in conversation themselves. However, Drought and Koenig's study (2002) suggests that some patients do not want to confront or admit to the likelihood of their dying as a result of being asked about decisions for the future, or, as Nilsson et al (2008) reported they may opt for life prolonging treatments to protect their dependent children. This suggests the need for sensitivity in developing future interventions to facilitate patient discussions about preferences for future care and treatment.

### Achieving a sense of control

Three papers reported the finding that patients achieved a sense of 'control' from having an ACP discussion, and documenting their wishes protected their autonomy and gave them perceived control over their future (Steinhauser et al., 2001; Martin et al., 1999; Singer et al., 1998). ACP discussions and subsequent documentation can provide a 'framework' for patients to make decisions for the future in the event they become incapacitated. In a study conducted by Drought and Koenig (2002) it is reported that patients wanted to feel they had a say in what happened to them in the future and some control over their situation, although interestingly the findings also suggested that patients perceived a lack of choice at key decision points in their care; options were seen as simply 'falling into place'.

This sense of control was also linked to patients' desire to relieve their loved ones of the burden of future decision-making (Martin et al, 1999), to preserve oneself rather than be controlled by medical effectiveness of the disease (Davison and Simpson, 2006), and to make preparations for family members' needs after death (Drought and Koenig, 2002), and this was often the motivation for making preparations (Steinhauser et al., 2001).

Involving family/friends

One of the key themes reported in the literature about the experiences of patients in having ACP discussions about end of life care is the strengthening of their relationships and their desire to involve or not involve family and friends in these conversations. In a study exploring the role of hope in ACP for nineteen patients with end stage renal disease, Davison and Simpson (2006) reported that patients considered that staying connected to their families enhanced and sustained hope. However, it appears that some patients found it difficult to bring up the topic of end of life care with their families (Briggs, 2003), sometimes because family members struggled to talk about such things, but when they were assisted to do this they reported reaping the benefits of an increased awareness of each other's thoughts, feelings and preferences (Briggs, 2003) and a sense of relieving the burden of decision-making otherwise placed on their families (Singer et al., 1998; Martin et al., 1999; Steinhauser et al., 2001; Briggs, 2003). In contrast, some patients preferred not to involve family and friends in considering end of life preferences as they regarded this as a 'personal thing' (Singer et al, 1998), but on balance they preferred to discuss end of life issues with family members in preference to their physician (Hines et al., 1999; Singer et al., 1998; Kataoka-Yahiro et al., 2010) wishing for them and their family to be approached as a 'unit' (McSkimming et al., 1999).

*Patients' experiences of living with lung cancer towards the end of life*

I will now present the findings from a review of research about patients' experiences of living with lung cancer (group 3 search terms). Ten papers were included in this review: two reported studies conducted in Sweden, seven originated in the United Kingdom and one in the USA (Table 1.2). There was one survey (Hughes et al., 2008) relating to people's views about a 'good death' and one comparative study gaining the views of people dying from lung cancer and cardiac failure (Murray et al., 2002). The remaining eight studies have been included because they report aspects of patients' experiences in relation to end of life care, such as their lived experience, distressing concerns, spiritual issues and social support. The following table (Table 1. 7) presents the main themes found in the relevant papers.

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Table 1.7 Summary of findings from literature review of patients' experiences of living with lung cancer

| Authors | Year | Reported themes | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | Concern for family, protecting others or being a burden | Concern about the future | Social isolation | Concerns about illness itself | Physical effects | Psychological effects of diagnosis | Striving for normality | Wishes about a 'good death' |
| Yardley et al | 2001 | ✓ | | | | | ✓ | | |
| Sjolander & Bertero | 2008 | ✓ | | | | | | | |
| McCarthy & Dowling | 2009 | ✓ | ✓ | | | ✓ | | ✓ | |
| Murray et al | 2002 | ✓ | ✓ | | | ✓ | | ✓ | |
| Murray et al | 2004 | ✓ | ✓ | | | | ✓ | | |
| Broberger et al | 2007 | ✓ | ✓ | ✓ | ✓ | ✓ | | | |
| Krishnasmay et al | 2007 | ✓ | | ✓ | | | | | |
| Hughes et al | 2008 | ✓ | | | | | | | ✓ |
| Hughes and Arber | 2008 | ✓ | | ✓ | | ✓ | | ✓ | |

Concerns for family, being a burden on them and protecting others

One of the key themes found in all ten papers reporting the experiences of people living with lung cancer was the concern people with lung cancer felt for their families.  In an interview study with thirteen patients in the UK, Yardley and Davis (2001) reported that some did not want to inform their families about their diagnosis for fear of worrying them. Another paper described patients' accounts of the trauma they experienced when disclosing their diagnosis to their family (Krishnasamy et al., 2007). People expressed a wish not to be a burden (Sjolander and Bertero, 2008; McCarthy and Dowling, 2009; Hill et al., 2003) and a fear of becoming dependent on family members (Murray et al., 2002; Broberger et al., 2007), and this was reported as sometimes causing frustration, distress and anger (Hughes and Arber, 2008). Conversely, Hughes et al (2008) in a survey of a 100 lung cancer patients' definitions of a 'good death', reported that only 12 of the 96 participants made comments concerning families. Nevertheless, people living with lung cancer reportedly wanted to protect family members from emotional distress (Hill et al., 2003), which sometimes included putting on a 'brave face' (McCarthy and Dowling, 2009; Murray et al., 2004).


Concerns about the future

Five papers reported people's concerns about the future (Hill et al., 2003; Murray et al., 2002; Murray et al., 2004; Broberger et al., 2007; McCarthy and Dowling, 2009). Using a face to face administered questionnaire, Hill et al (2003) explored the concerns of 80 newly diagnosed patients with lung cancer in the UK. They reported that people had concerns about the future relating to the illness itself and that less than one third of these people were given the opportunity to discuss their concerns with their health care team. One possible limitation of the study reported by Hill et al (2003) is the design: they revised the 'concerns checklist' used to collect data, removing 'dying' from the list of possible concerns.  Broberger et al (2007) also used a questionnaire to examine potentially distressing concerns of people with lung cancer in Sweden. They reported patients' uncertainty and worry about what would

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happen in the future. Fear of deteriorating and the persistent threat of death were reported in two further studies (McCarthy and Dowling, 2009; Murray et al., 2002). In a phenomenological interview study which included six patients with lung cancer, McCarthy and Dowling (2009) found that people described their struggles to remain 'still me'. The interpretation of this finding was that patients were fearful of the future and worried about how they would die.

Murray et al (2002), in a paper exploring the spiritual needs of 20 people dying from lung cancer (as part of a much larger study exploring the experience of people dying from lung cancer or heart failure), reported findings that suggest that people think about how long they have got to live, but keep these thoughts to themselves and hope to get back to their 'old self'.

Physical effects

Four papers reported on the physical effects patients experienced when living with lung cancer (McCarthy and Dowling, 2009; Murray et al., 2002; Broberger et al., 2007; Hughes and Arber, 2008). The physical effects included: fatigue (McCarthy and Dowling, 2009; Broberger et al, 2007), altered body image (McCarthy and Dowling, 2009), pain and dyspnoea (Broberger et al, 2007) and the troublesome side effects of receiving chemotherapy or radiotherapy treatment (Murray et al, 2002).

Hughes and Arber (2008), in a UK study using in-depth interviews with five people with lung cancer known to a specialist palliative care service, reported on how physical effects influenced people's ability to work, and this was considered to result in loss of identity.

## Striving for normality

The fourth most common theme found in this review related to the ways in which people strive for normality. This was a finding in three papers (McCarthy and Dowling, 2009; Murray et al., 2002; Hughes and Arber, 2008). People strived to maintain a normal life or lead an ordinary life (Murray et al, 2002; McCarthy and Dowling, 2009) and desired to do 'normal activities' such as working, gardening or driving (Hughes and Arber, 2008, McCarthy and Dowling, 2009). These studies gave only brief details of their findings, making it difficult to tease out what meaning people made of their experiences.

## Social isolation

Three of the ten papers discussed the social isolation experienced by people living with lung cancer (Krishnasamy et al., 2007; Broberger et al., 2007; Hughes and Arber, 2008). In one instance, in a study by Hughes and Arber (2008), this related to difficulties in talking to others about having cancer. In addition, looking 'well' compared to other people with heart failure was viewed as a barrier to initiating discussions. Krishnasamy et al (2007) interviewed 23 patients following a diagnosis of lung cancer and 15 carers in Ireland. They reported that deterioration in function led to feelings of social isolation among patients.

## Psychological effects of the diagnosis and wishes for a 'good death'

The remaining findings from this review relate to the effects that a diagnosis of lung cancer has on patients. Some of these patients were given a prognosis at the same time they received the diagnosis (Yardley and Davis, 2001; Murray et al., 2004). The psychological effects of receiving a diagnosis of inoperable lung cancer were reported as shock and devastation; the general attitude in response to the disclosure was 'hoping for the best', but 'fearing the worst'.

Finally, Hughes et al (2008) survey study explored the attributes of a 'good death' as perceived by people with lung cancer. Being asleep and being pain-free were the most frequently reported desirable attributes of a 'good death'. A limitation of this study was its quantitative design, which sought to report descriptive statistics on people's statements about a 'good death' and did not explore the meanings people attributed to these statements.

## Discussion

The following discussion is a synthesis of the findings from all three group searches. Figure 1.6 shows the key findings from this review.

Figure 1.6 The key elements of ACP.
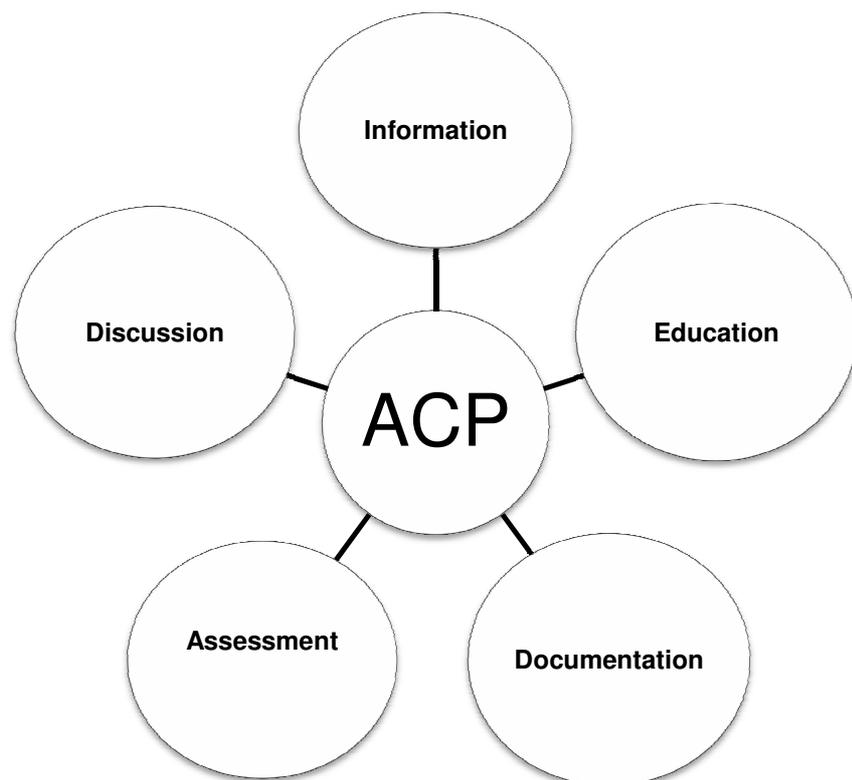
*Interpretations of ACP*

In analysing how ACP is described in the literature, it appears there are a number of ways that ACP is construed. These range from a simple checklist which prompts patients or their physicians to consider future preferences for treatment to a series of individualised face-to-face patient discussions initiated by highly skilled and trained facilitators and aimed at eliciting patients' wishes for end of life treatment and care. This makes it problematic in interpreting the meanings ACP has for patients and their families from across the various studies reviewed.

ACP interventions have been developed using different theoretical frameworks, for example an ethical framework to enhance patient autonomy, or a health economic framework seeking to reduce intensive care bed days. Later frameworks have had a variety of aims and interpretations. Furthermore, the principles and assumptions underpinning ACP in the literature also varied and have not been explicitly stated in most of the studies described in this review. It is therefore difficult to determine the influence of the authors' assumptions on the outcomes of the studies.

The main components of ACP from the findings of this review appear to include some form of patient and family education about ACP, specific documentation, an interview, and possibly some form of structured assessment which may or may not include health or social care assessment of patients' capacity to make decisions and their decision-making styles. Only 2 studies (Briggs, 2003; Engelhardt et al., 2006) tested all of these components.

*ACP involves provision of information/education*

A variety of methods and rationales were used to provide information or education to patients and their families as part of ACP. The rationale for the provision of information comes from a background of national policy and legislation in the USA, whereby all health care organisations must inform patients of their rights to make an advance directive, allowing

them to refuse medical treatment such as technologies to sustain life. Information about services for end of life care such as hospice care was also made available.

Sheaff (2005) suggests that patient information or education combined with an interview is superior to patient information on its own. None of the studies reported having considered this in relation to designing and developing ACP intervention studies. The study by Singer et al (1998) made use of educational videos in preparing patients for ACP and reported some negative patient responses when an attempt was made to discuss the content of the video with family members. Perhaps less of a negative response would have been forthcoming if health professionals had been available to mediate a discussion or interview with the patient and his family. However, no conclusions can be drawn from combining these two components from the findings in this review.

*ACP involves discussion*

The findings from this review broadly suggest that ACP in patients with serious illnesses involves an interaction or series of interactions with a person, and sometimes with their family, aimed at enabling dialogue and discussions about end of life issues. The core content of these discussions may or may not be recorded by health professionals in planning for that person's future care. The review suggests that where health professionals are involved in the discussion there may be some benefits for patients in respect of enhancing their understanding about their condition and prognosis, and having an opportunity to discuss end of life issues and preferences with others. However, there is a gap in the literature about the experiences of patients when discussing and planning for their end of life care; this is also evident in research about people living with lung cancer. There was evidence of the concerns about the future reported by people living with lung cancer, particularly in relation to their families, but there was no evidence of how these concerns were addressed by health and social care professionals. This lack of evidence about how patients' concerns are addressed seems paradoxical in the light of the significant number of papers describing health

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professionals' experiences of discussing death and dying with patients in a palliative care context.

It appears that there are a few studies which provide evidence to support the notion that patients appreciate the opportunity to discuss preparing for their death when an ACP discussion is initiated. An issue to take into consideration is whether ACP 'forces' people, who would otherwise prefer to avoid it, to think about or discuss their mortality. Some evidence suggests that people strive for 'normality', which may pose difficulties in initiating ACP. Some authors advocate 'forceful' interventions (Larson and Tobin, 2000; SUPPORT Principal Investigators 1995) and strongly recommend that end of life conversations should be a routine part of health care provision. However, there are assumptions here that open discussions about dying are helpful to patients and that they enable patients to prepare for a 'good death', neither of which assumption is supported by evidence.

From an ethical standpoint, using ACP discussions to 'force' a change in behaviour in patients and their families needs careful consideration. Such a course of action may expose health care organisations to accusations of coercing people into discussing and taking responsibility for planning their own care, treatment and end of life care management. An intervention designed to 'force' discussions about end of life issues could be potentially harmful to some patients who choose to deny death in order to live as normal a life as possible (Zimmermann, 2006; Larson and Tobin, 2000).

A possible alternative perspective on ACP is that it has the potential to serve as a useful instrument to enable people to talk about death and their own mortality by providing opportunities for a discussion within a 'supportive' context. Another view could be, as some patients have suggested within one of the reported studies (Singer et al, 1998), that making decisions and planning for death is a matter of 'trust', with patients relying on their family or health care professionals to make the 'right' decision for them when they become

incapacitated. Maltby and Fins (2004) also hint at the element of trust when patients ask their families to act as proxy decision-makers for them at the end of life. People living with lung cancer had concerns for their families and did not want to be a burden, which may suggest that ACP has a role in supporting discussion about these concerns and may help the person to put plans in place to protect their families from the burden of decision-making. Alternatively, a desire to protect family members from emotional distress may deter people from engaging in ACP, particularly where family members are present.

Larson and Tobin (2000) suggest that patients must ultimately make the decisions that determine their own future, perhaps suggesting that there is a legal framework underpinning ACP. However, as discussed earlier this may not be ethically appropriate in this country or acceptable within current health care practice, which to date has tended to be paternalistic in nature. Patients may not wish to choose to be autonomous and instead wish to devolve decision-making to other people such as family members, friends or health professionals. This highlights a potential dichotomy within current health care policy that seeks to empower patients to state their preferences and make their own decisions about their future, whilst not recognising that patients may not wish to discuss or make decisions in advance.

*ACP as documentation*

The studies reviewed described documentation of patients' preferences completed by the patient on their own or with the help of health professionals. However, the findings in this review suggest that patients' experiences of ACP are more than just documentation and that the development of ACP in North America has evolved from a document driven process, that on its own did not result in care delivered in concordance with patients' wishes, to an ongoing process of preparing patients for death with support from their families (Prendergast, 2001).

Findings from this review suggest that patients and their families in the UK may benefit from being assisted to discuss their preferences for future care; this challenges health care professionals to seek ways of achieving this. The lack of discussion about patients' concerns about the future highlighted in one study (Hill et al, 2003) provides some evidence of the potential benefits of ACP. The stability of patients' expressed or written preferences also needs consideration in relation to developing ACP. Patients may decide on a course of action that is documented, but then they may change their mind, preferring another option at a later date.

*Who does Advance care planning?*

Few studies reported whether patients choose to initiate advance care planning by discussing their wishes or writing these down, with or without the involvement of their families. Some patients reported wanting themselves and their families to be treated as one unit, whilst others with lung cancer wanted to protect their families from emotional distress (Hill et al., 2003; Henderson, 1995 ; McCarthy and Dowling, 2009; Murray et al., 2004). This raises issues about developing effective strategies that meet the individual needs of all patients and their families when discussing end of life issues.

The majority of the studies about ACP reported that health or social care professionals usually initiate such discussions either through the provision of information as discussed earlier or through facilitating the process. I recognise that, because the reviewed studies were reporting trials of advance care planning interventions, it may not be known how many patients do engage in discussing end of life care without the help of health professionals.

The findings from the SUPPORT study (1995) and the study reported by Shorr (2000), where an intervention used by physicians failed to achieve the intended outcomes, need to be borne in mind when considering which, if any, health professional is 'best' placed to initiate ACP in the UK. This review of the literature found that nurses, social workers, doctors,

peers and 'skilled' facilitators have initiated and conducted ACP interventions, but there is insufficient evidence to draw any conclusions about who is the 'best' person to carry out ACP interventions.

What does appear to be frequently apparent is that ACP includes both the patient and family members. Seven studies described how patients and their families were involved in the ACP process. Maltby and Fins (2004) recommend that 'proper' ACP needs to enable the patient and their family to prepare together for decisions that may need to be made at the end of the patient's life. Some patients expressed concern that it can be difficult to discuss end of life issues with their families, and that having health professionals initiate conversations can be helpful. Vandrevala (2005) also reported that older people do not routinely discuss wishes about life-prolonging measures with their families and recommends the need for health professionals to initiate ACP discussions. However, Hill et al (2003) found that few health professionals routinely initiated discussion with people who had lung cancer about their concerns about the future.

These findings highlight a gap in knowledge about not only who is the 'best' person to initiate ACP but also about whether the relationship to the patient of the person (professional, lay or family) initiating the discussions about end of life care influences the outcomes for patients and their families. The findings of this review suggest that patients' families or surrogate decision makers were generally included in the ACP process. Three studies (Morrison et al., 2005; Ratner et al., 2001; Engelhardt et al., 2006) reported that the health professionals who initiated ACP were members of the health care team who had ongoing responsibilities for the care of the patient and their family. There is insufficient data to draw any conclusions about whether the relationship the initiator of ACP had with patients may have helped or hindered the discussion, and this is another area in the development of ACP that requires further research.

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*When is ACP initiated?*

There is insufficient evidence to suggest the 'best' time to initiate ACP. This review found that the time when ACP is initiated ranges from when people are not experiencing chronic illness or are early in their disease trajectory, to when they are being admitted to a nursing home or other health care institution at the end of life. The findings of this literature review are not conclusive as to whether ACP should be a stand-alone intervention or part of a programme of care. Only one study (Engelhardt et al., 2006) reported ACP as a development within a coordinated programme of care.

The complexity and intensity of ACP interventions also varied. Some studies reported only one discussion or interview with a patient but those reporting six to eight interviews or patient contacts over a period of time would challenge the economics of developing ACP in the UK. However, this could potentially be offset by the high cost of technological interventions that are frequently used to prolong life, and that might be foregone by some patients if they were given the opportunity to decide not to access this technology at the end of life.

*Outcomes of ACP*

There were a variety of reported outcomes, from efforts to reduce the amount of technology used at the end of life to promoting patients' comfort in discussing end of life issues. Some studies sought to improve communication between patients and health professionals, but whether improvement was achieved is still debatable in the light of the findings in this review. There is little indication that ACP in itself improved patient and family experience of healthcare at the end of life. One possible explanation for this could be that the models of ACP employed in North America arose from concerns about futile treatment and cost containment and have been driven by organisations such as insurance companies. It is only in later years that the possible benefits of eliciting patient choice and facilitating patient empowerment have begun to emerge.

A few studies that adopted an educational or ethical approach to ACP (Song et al., 2009; Briggs, 2003; Briggs et al., 2004; Ratner et al., 2001) reported that all or some of their intended outcomes were achieved. This was in contrast to other studies that appeared to use a legal framework or sought to support outcomes to decrease hospital costs associated with intensive care (SUPPORT Principal Investigators 1995; Shorr et al., 2000).

Those studies which tested whether ACP interventions improved the congruence of decision making between patients and their families (Briggs et al., 2004; SUPPORT Principal Investigators 1995; Song et al., 2009) did not report whether this then enabled patients' preferences to be realised. The SUPPORT study (1995) was the only study which followed up patients until death and measured outcomes such as place of death and the congruence with documented treatment preferences, which resulted in no significant findings. The review found no studies conducted since the SUPPORT study examined the relationship between patients' engagement in ACP and improvement in end of life care. The lack of studies reporting on congruence between patients' advance decisions or preferences for care and actual outcomes of care also begs the question whether patient preferences are stable and independent judgements or whether they are highly contextual.

One question that arises from these findings in relation to outcomes for future ACP interventions is whether future studies should focus on evaluating whether, having taken part in ACP, patients' wishes for end of life care are realised, or whether instead research priorities should focus on the impact that engaging in the ACP process has on patients and their families. Prendergast (2001) and Maltby and Fins (2004) seem to suggest that future development of ACP should focus on the process of patients and families communicating and building trust together to enable decision-making at the end of life that meets the wishes of patients and removes the burden of decision making from families. In addition, Song et al

(2009) suggest that goals for end of life care are more likely to be stable over time if they are based on people's values.

It is interesting to note that when comparing the intended outcomes of the studies with the findings from studies describing benefits to patients of ACP, only one study reported the trial of an ACP intervention that sought to evaluate whether ACP promoted patients' readiness to die (Engelhardt et al., 2006), and only four studies considered whether communication improved with ACP (Song et al., 2009; Engelhardt et al., 2006; Briggs et al., 2004; Shorr et al., 2000). None of the reviewed studies reported an intended outcome of enabling patients to achieve a 'sense of control' or studied the impact on patients of involving families in the ACP process; however, a number of intervention studies pre-dated the later studies of patients' experiences reported here.

One possible explanation for the failure of the SUPPORT (1995) intervention could be that in the USA doctors' salaries are largely dependent on 'fee for service', which may mean their motivation is to do as much as possible. As suggested earlier, the purpose of this ACP intervention was to assist doctors rather than patients. Prendergast (2001) suggests that since the SUPPORT study (1995) researchers have begun to consider addressing the communication needs of patients and physicians from the patients' perspective.

Some discussion papers (Larson and Tobin, 2000) have suggested that lack of monetary compensation for physicians in the USA has led to physicians spending less time in end of life conversations with their patients. In considering the potential development of ACP within the UK the Quality Outcomes Framework (Department of Health, 2004) provides incentives for general physicians to undertake voluntary activity in addition to 'normal duties'. This framework offers financial rewards for holding a register of patients who are at the end of life, three monthly GP practice meetings and a management plan for patients stating their preferred place of care. No incentives are offered for physicians to engage in direct

discussion with patients and their families; however, perhaps this should be viewed as part of optimal care.

## Limitations of this review

This review used a systematic approach to the literature as outlined earlier. An advantage of this method of reviewing the literature was that the results provided a greater depth of understanding about the concept of advance care planning and its development as an intervention in health care. However, reviewing the many different issues related to advance care planning has not been possible because of the specific inclusion criteria.

A meta-analysis may have provided greater clarity of the findings by combining samples from the included studies; however, there would have been difficulties in combining the varied samples from the different studies because the outcome measures were not the same. This review also has limited reliability because there was only one researcher analysing the findings, although the emerging issues were discussed in detail with both supervisors.

One of the decisions made in reviewing the literature was to focus on advance care planning and not advance directives, which was not without difficulties. Many earlier papers used the terms 'advance directives' and 'advance care planning' interchangeably. Therefore, I included some studies which discussed advance directives because they added valuable insights into helping to understand the evolving concept of advance care planning.

## Summary

This review suggests there is a gap in the literature relating to the experiences, views and needs of patients and their families in planning end of life care. There was only one study about patient and family experiences of advance care planning in the UK, and it is not known

whether ACP is culturally acceptable in the UK. Only one small pilot study specifically discussed the preferences and wishes of people living with lung cancer (Horne et al., 2006), which has meant it is not possible to draw any conclusions about the role or acceptability of ACP within this patient population.

The findings from this review contribute to a preliminary understanding of what constitutes the core components of an ACP intervention. Further research is needed to determine the components of an ACP that matches the needs of patients and families and would be culturally acceptable within the UK. There appears to be a suggestion that there may need to be different levels of ACP intervention dependent on the needs of different patient populations (Briggs et al, 2004) and the needs of individual patients (Englehardt et al, 2006). Most ACP intervention trials used participants from mixed or chronic disease populations, assuming that patients with cancer have similar needs to patients with other diseases. There is also little known about how to implement advance care planning.

Little is known about the stability of individual patient preferences, and therefore any ACP intervention should recognise a patient's individuality and regularly review a patient's preferences. There is also a gap in what is known about the benefits and risks of ACP as perceived by patients, families and staff.

A potential benefit of ACP, which is a relatively new and not widely understood concept in the UK, may be that it provides a useful link between supportive and palliative care (Martin et al, 1999). In the UK, under the Mental Capacity Act (2005) patients can make prior decisions in the form of advance refusals for treatment and care; therefore, health care organisations could in the future be obliged to provide information to ensure these advance refusals are informed decisions. Already health care professionals have a legal duty to provide information to enable patients to give consent for certain treatments and care.

ACP may be a useful tool for health professionals to assist patients and their families in anticipating and planning for end of life care. Introducing information about palliative care services during ACP may enable access to palliative care services much earlier in the disease trajectory, thereby creating opportunities for patients to benefit earlier from such services. This information provision could be a function of a future ACP intervention.

Because most papers originated in the USA there are inherent difficulties when considering the potential of the findings from this review to inform the development of ACP in the UK. The intervention trials described in this review used control groups whose 'usual care' was quite different from current practice in the UK. 'Usual care' in the USA is the provision of written information to patients about their legal right to make an advance directive and the availability of support to exercise this right, if they wish. This support is often provided by staff specifically trained in assisting patients to complete advance directives. Therefore, where ACP interventions were tested, this was in addition to an already well established legal framework for information giving. The onus for identifying those people who want to make advance decisions about their future care is on staff in health care organisations. In the UK, this type of 'usual care' does not 'fit' with current practice, nor have we yet witnessed the impact of the implementation of the Mental Capacity Act (2005) on patient care in relation to the provision of patient information or support for patients wanting to express or write advance decisions to refuse treatment.

Potential future developments of ACP would need to be mindful of the differences in legislation in the UK compared to the USA. However, the findings from the studies conducted in the USA, showing the development of ACP from a document driven intervention to a focus on a series of discussions about end of life preferences to prepare for death, may have some relevance in the UK. It is not known what training needs health care professionals have in relation to facilitating advance care planning or who in this country would be 'best' placed to initiate or coordinate such discussions.

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There are gaps in our knowledge of the experiences of people with lung cancer in discussing end of life care and treatment. In particular there is a lack of evidence about the potential benefits, risks and components of advance care planning in the UK. Therefore this doctoral study aims to explore and gain the views and perceptions of both patients with advanced lung cancer and their families about discussing and planning ahead for their end of life care. As discussed in this literature review, whether patients with advanced lung cancer have preferences and wishes for end of life care and whether they would accept advance care planning as a process for discussing end of life care has not been a subject of research either in the UK, or in other countries apart from a pilot study I conducted with colleagues (Horne et al, 2006). The following research questions have been posed.

## Research questions

1. What are the views and perceptions of patients with lung cancer about the components of care which facilitate their discussion about end of life issues in relation to their preferences and decisions for future care and treatment?

2. What are the views and perceptions of family members of lung cancer patients about the components of care which facilitate their involvement in discussions about end of life issues in relation to patient and family members' preferences and decisions for future care and treatment?

# CHAPTER 2 : METHODOLOGY AND METHOD

## Introduction

This chapter provides a description of the methodological approach, methods and procedures used in designing and developing this study. I also present the rationale for the research design and methods chosen. In addition, I will also describe the process of analysis used to develop the theoretical interpretation of the findings. The chapter ends with a reflective account of my role as researcher in constructing the interpretation.

This is a study of people's experiences, perceptions and views of living with lung cancer and their perspectives on discussing their wishes and preferences for end of life care and treatment. The study also considers the views of some family members; these contribute to the meanings people living with lung cancer make of their experiences of living - whilst living with an awareness of dying, as well as their preparations for death. I propose that the outcomes of this study will provide new knowledge about patients' experiences of discussing their end of life care as well as insights into the possible components of care that may form the development of an Advance Care Planning intervention.

Choosing a methodological approach that is suitable for gaining this type of knowledge in the field of palliative care requires careful consideration from both a research and an ethical view-point of working with people who are often deemed 'vulnerable' (Seymour et al., 2005a). Prus (2008) suggests that studies about the human condition require a methodology that focuses on the 'nature' of the human life experience. This study uses an interpretive approach with a focus on a philosophical position of wanting to understand meanings people give to their lives and a desire to hear the 'voices' of those who are facing death. Using a constructivist approach to grounded theory 'fits' with this study, which explores the human experiences of discussing end of life care.

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## Research design

The design is a cross-sectional qualitative interview approach, with semi-structured interviews conducted in two phases. Semi-structured interviews were used because they can be a flexible and negotiated approach for exploring the perspectives of people (Banister et al., 1994), as well as being useful for collecting sensitive information (Yong, 2001) .

## Research aims and objectives

### Aim

The aim of this study is to explore the experiences of patients and their family members about the discussion of preferences and decisions related to future care and treatment, to determine the care components required to develop an ACP intervention.

### Objectives

In order to achieve this aim the following objectives were developed:

1) To explore the experiences of patients with lung cancer and their current family members about the components of care which can influence their ability to discuss end of life issues and express choices and preferences for future care and treatment.

2) To identify, where possible, the care components that together may form an advance care planning intervention that could be developed and modelled in a future study.

## Methodology

The argument for taking an interpretive, yet systematic, approach to this inquiry is based on a number of philosophical and theoretical positions. Firstly, the epistemological stance in this study is that the type of knowledge sought can be generated through personal accounts

and the individual experiences of those who are experiencing the phenomena of interest. This includes my tacit and intuitive knowledge from my experience of working as a clinical nurse specialist and lead cancer nurse in the field of end of life care. This stance is influenced by an interpretive standpoint.

Interpretivism is described by Benton and Craib (2001) as the "sciences of understanding" (p.114) as opposed to scientific explanations (Delanty and Strydom, 2003), and it offers a variety of methods to help researchers understand humans subjectively through considering and interpreting their behaviour, culture and history. Interpretive methodological approaches attempt to make sense of things (Taylor, 2003) or seek understanding as a "mode of being in the world" (Gilbert and Lennon, 2005), and knowing 'how' the world is rather than 'what' the world is, or attempting to explain the world.

Different interpretive philosophical approaches may consider the use of a phenomenological, ethnographic enquiry or discourse analysis, each arising from a different theoretical perspective and useful for answering research questions posed about people's lives, experiences, activities or use of language.  There is available an alternative approach that analyses qualitative data to gain understanding about people by developing theories (Glaser and Strauss, 1967). Grounded theory as a methodological approach is rooted in symbolic interactionism, and seeks to provide explanatory theories about basic social processes (Starks and Trinidad, 2007) systematically generated from the data (Glaser and Strauss, 1967). Symbolic interactionism is deemed a theory and an approach to inquiry (Annells, 1996). As a theoretical perspective it was defined by Blumer (Prus, 2008) after being influenced by Mead and Dewey, and considers the creation of meanings about self and society as arising from interactions (Charmaz, 2006). The interpretation of meanings are in turn directed and modified through interactions (Annells, 2007). Prus (1996) defines symbolic interaction as:

*"the study of the ways in which people make sense of their life-situations and the ways in which they go about their activities, in conjunction with others, on a day-to-day basis (p.10)"*

Through provision of an explanatory framework or model, grounded theory has the potential to aid understanding about social interactions, their meanings for individuals and societies (Dey, 1999) and the relationships between them. Grounded theory has the potential to provide a structural map that aids understanding of a phenomenon (DePoy and Gitlin, 1994) and can be useful as a precursor to designing social interventions (Starks and Trinidad, 2007).

## Introduction to Grounded Theory

Grounded Theory, referred to from now on as GT, originates from a sociological tradition. Brown and Locke (2008) suggest that GT *"aims to provide a systematic process for inductively deriving categories which can be developed into coherent theory* (p.381)." Initially described by Glaser and Strauss (1967) following their study on the 'awareness of dying' (Glaser and Strauss, 1966), it provided an alternative approach to deductive methods for generating theory about human phenomena. Glaser and Strauss (1967) described GT as a method of comparative analysis systematically derived from the data to generate theory. They proposed joint coding and analysis whilst 'theoretically sampling' for more data about emerging categories. Theoretical sampling requires the collection of data from participants for the purpose of fully explicating the dimensions and relationships of a category. Another core component of GT described by Glaser and Strauss (1967) is 'theoretical saturation'. This term is used to describe the gaining of data about a category that enables researchers to offer a detailed description and explanation of it (Corbin and Morse, 2003). Dey (1999) describes this as 'theoretical sufficiency', suggesting the aim is to gain sufficient data about a category as opposed to 'saturation' of data. Theoretical sufficiency recognises that it may not

be possible to fully 'saturate' a theory given the multiple interpretations of meaning within a highly complex society.

Following on from their original writings (1967) Glaser and Strauss both reworked their descriptions, each arguing a different theoretical position. Strauss, together with Corbin (Strauss and Corbin, 1990) argued for the use of coding paradigms (Dey, 1999) in the form of axial coding or preconceived codes when analysing the data. Glaser (1992) argued for the 'emergence' of concepts as opposed to concepts 'forced' by preconceived codes. Others such as Charmaz (1995), Melia (1996) and Morse (1989) have since offered alternative conceptions of GT. Charmaz (2006) posited a constructivist approach to GT, arguing that the researcher is an interpreter involved in the process of the research, interacting with the participants and therefore a co-constructor of the findings and theory subsequently developed. She also argued there is not just one reality, but multiple realities giving rise to many different meanings (Mills et al., 2006).

Charmaz (2006) critiqued Glaser and Strauss's version of GT as being from a positivist or objectivist stance, in which there is a denial of the influence of the researcher or of any prior knowledge of the research area on the interpretation of findings and subsequent theory. On reading Glaser and Strauss's descriptions of grounded theory (1967) and their theory of the 'awareness of dying' (1966), it appears they do not give credence to the influence the researcher has on their findings. For example, they do not explain how their choice of gaining data by observation, and the impact this may have had on the actions of staff or patients, may have influenced their interpretation. Moreover, within their book 'Awareness of Dying' (1966) they added an appendix describing their own experiences of observing other people dying, but this stands alone and does not make explicit how these experiences may have influenced their study. Nevertheless, Willig (2001) suggests there is space for GT to be both objective and subjective, to describe the lived experience of the phenomena in addition to explaining wider social processes.

Moreover, Glaser and Strauss did not include quotes from interactions with participants to provide examples of how categories emerged directly from the data. In contrast, Charmaz (2006) makes use of participants' quotes derived from the interview transcripts to show how the theoretical conceptions are grounded in the data. Charmaz appears to argue that a constructivist approach to GT is superior to Glaser and Strauss's approach, because she claims an 'insider view' of the participant through in-depth open-ended interviewing; this is in comparison to Glaser and Strauss whom she suggests have only an 'outsider view'. However, Glaser and Strauss reported spending many months observing patients and talking to staff in hospitals to gain their data.

Another debate is the use of GT by researchers simply as a method of analysis rather than a methodological approach that influences the overall design and conduct of the study (Murphy et al., 1998; Barbour, 2003; Willig, 2001; Glaser, 1999). Willig (2001) attributes this to the lack of detail in Glaser and Strauss's (1967) description of GT, whereas Glaser (1999) suggests that students' training, widespread use of GT and cultural diversity have affected how GT is used. Glaser (1999) suggests that GT is still an "adopt-and-adapt method" and proposes that in the future researchers will need less justification to claim its use.

In summary, GT is recognised in the literature as both a methodological approach and a method of analysis for conducting research with people. Since its original inception GT has evolved in different ways depending on the philosophical stances taken by the researchers, such as objectivist or positivist approaches or interpretive and constructivist perspectives. One of the benefits of using grounded theory is that this approach provides a useful framework for designing and systematically collecting and analysing units of meaning from text about people's experiences or behaviour related to a phenomenon. The strength of this approach is that it uses induction (Pope and Mays, 2009) to interpret, describe and hopefully offer an explanation generated from the data, rather than testing pre-existing ideas and theories.

## The Grounded Theory approach for this study

A GT approach has been chosen for this study because it focuses on developing theories through a process of identifying categories of meaning and the relationships between them. Figure 2.1 below shows an example from my research diary where I considered some of the issues involved in choosing my approach.

Figure 2.1 Excerpt from my research diary showing how my thoughts about a GT approach were developing**.**

The more I read Charmaz and compare her approach to Glaser (1978) or Glaser and Strauss (1967) the more I wonder if I am taking a middle road as a pragmatic approach. Charmaz uses terms such as 'insider' view rather than 'outside', suggesting an 'arms length' approach is taken by non-constructivist grounded theorists. I can see how Glaser would get upset! I don't think it's about 'inside' or 'outside', but from a pragmatic viewpoint – it's about listening as best we can to what participants (and others) are saying, comparing this with others in the sample and then recognising who I am, my influence on the way I interpret what I 'hear' (and recount stories) to develop theory (explanations that are logical and make sense to participants, readers and staff in the field).

Charmaz (2006) suggests that whether a study is constructivist or objectivist depends on "*the extent to which its key characteristics conform to one tradition or the other* (p.130)". In this thesis the use of Glaser and Strauss (1967) and Glaser's (1992) systematic framework for collating, coding data and using theoretical sampling and theoretical 'saturation' or 'sufficiency', suggests characteristics of an objectivist approach. The use of axial coding as described earlier (Strauss and Corbin, 1990) was not used here because the approach chosen was to derive codes directly from participants' interviews and not to preconceive what these meaning units might be. Both Charmaz's (2006) and Glaser and Strauss's (1967) approaches appear to ask similar sociological questions of their data, for example: 'what is this data a study of?' This question and others, which seek to find out relationships between codes and categories, have been used throughout this study to develop the proposed theory.

For this study, a review of the literature prior to sampling was used to tease out my prior assumptions (Charmaz, 2006) and highlight existing knowledge about the topic area. This is congruent with a constructivist approach. Furthermore, the view that categories and the eventual proposed theory were created from the interaction between those interviewed and the researcher is a characteristic of a constructivist grounded theory approach rather than a conception that categories or theories are 'discovered' in the data (Glaser and Strauss,1967). An interpretivist approach recognises that different people have differing conceptions of reality (Charmaz, 2006). This study acknowledges this and does not claim one form of reality, rather it suggests one possible constructed reality, a reality formed from the interaction between the participants in this study and the researchers involved in interpreting the meanings within.

This study takes a pragmatic approach to these debates. I adopted an approach that allowed me as far as possible to listen to and hear the participants' views, then compare these views with others in the sample, whilst recognising through reflexivity the views and influences of and on my interpretation. The findings represent one interpretation that hopes to provide a theoretical explanation which further enhances the understanding of those to whom it refers.

*Prior assumptions*

Those taking a constructivist stance to grounded theory seek to highlight their own assumptions and prior judgements, whether these are personal, moral, ethical or social. This helps to identify the researchers existing knowledge and that gained from the participants, in an effort to understand how this may affect the analysis and interpretation of the findings (Outhwaite, 2005). A reflexive stance, defined here as a process for reflecting and making explicit the relationship and influence between the researcher and the participants (Jootun,

2009), can be used to support the identification of general and personal assumptions influencing the study.

It is important to debate the common assumptions that exist in the field of end of life health and social care and those held personally by the researcher, because the position a researcher takes may also affect the approach used in shaping the research design, method and findings (Clough and Nutbrown, 2002). Some general assumptions related to this study are that people consider their own mortality and have experiences of other people dying. With increasing longevity, some people have not experienced the death of a close family member until late in life. This lack of knowledge and experience may influence their views about discussing the future. Other assumptions are that planning patient care may help to aid a 'good death' (Marie Curie Cancer Care, 2010), which is an assumption commonly held by staff working in palliative care settings, but in practice a 'good death' is both difficult to define and likely to be perceived differently by each person (Sandman, 2005).

My choice of research questions assumed that patients and their families with lung cancer have views and preferences about their end of life care and that they may want to discuss these. Another assumption is that patients have the capacity to make their own decisions about their care and treatment. I also held the assumption that there are certain components within the concept of 'care' that can be defined by those who experience them. These pre-conceptions may be wrong, but by being aware and open about them we can judge their coherence against further knowledge gained in the field and decide if this enables us to identify 'truth' (Gadamer, 2003) or, from a constructivist perspective, to gain understanding of different realities.

## Method

### Sampling decisions

I proposed a purposive sample of approximately 20 patients with lung cancer who were likely to be in the last six months of life and at a stage in their disease trajectory where they would have had an opportunity to discuss their future care and treatment with their physician or lung cancer nurse. The decision to recruit 20 patients was a pragmatic one based on past experience, but it was ultimately dependent on the construction of categories from the data and the recruitment of patients to ensure there was 'theoretically sufficiency' (Dey, 1999) within these categories. The preliminary findings emerged from the first 11 patients and 7 family members and directed the future theoretical sampling in phase two of a further 14 patients and 12 family members to include more women and explore some unanticipated themes that emerged from the first phase. Revisions were made to the interview guide and the design of the study[1].

### Settings

A town and a city in the north of England were chosen. The multicultural and university city hosted a cancer treatment centre where surgery, chemotherapy and radiation treatment were provided. The post-industrial town had a cancer unit based in a district general hospital offering cancer diagnosis and treatment. Both settings employed lung cancer nurse specialists.

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[1] In my original research design I planned to conduct two stages. The first stage was to gain the views of people with cancer and their family members about what the care components of an advance care plan intervention would be. The second phase was to develop the intervention and test this out. This design required changing based on the views of people in the first stage and the concern to find out the meanings and perceptions of people's experiences of living with lung cancer. Although this limited the fulfilment of the original aim of the study it was an ethically justifiable decision to ensure the views of people in phase one who did not want to discuss the future were captured and further explored.

Approximately 412 patients per year were newly diagnosed with lung cancer (averaged 1995-2000, (Trent Cancer Registry, 2003) within these 2 localities. The settings were chosen because it was thought they would allow sufficient recruitment within the identified data collection period. One advantage of this setting was that I knew the area and had built up good working relationships with staff within the cancer services.

Sampling approach: People with lung cancer

*Inclusion criteria*

People were invited to participate if they:

- spoke English,

- had a definitive diagnosis of lung cancer and were aware of their diagnosis.

- were deemed to have completed 'active' treatment.

- lived in the chosen city and town in northern England.

- were over 18 years of age.

- had the capacity to consent to being interviewed.

*Exclusion criteria*

People with lung cancer were not included if they:

- Could not speak English, although every effort was made to include patients who were interested in participating whatever their first language.

- did not have a confirmed diagnosis of lung cancer, or were unaware of their diagnosis.

- were undergoing 'curative' treatment.

- lived outside the setting

- were unable to communicate or consent to take part

- were suffering from severe fatigue or were in the last days of life.

Sampling approach: family members of people with lung cancer

Through this sample I sought the prospective views of family members, who were currently caring for patients who were approaching their end of life, about expressing preferences for care. It was intended that a purposive sample of 10 to 12 family members of the patients with lung cancer would be invited to participate in a group interview. If family members preferred individual interviews, this would be facilitated.

*Inclusion*

Family members of people with lung cancer recruited to the patient sample were included if they:

- spoke English

- were over 18 years of age.

- had the capacity to consent to being interviewed.

*Exclusion criteria*

Family members of people with lung cancer were not included if they:

- could not speak English, although every effort was made to include patients who were interested in participating whatever their first language.

- were unable to communicate or consent to take part.

No restrictions were placed on which family members could take part; however, I anticipated that those attending clinic or living with the person with lung cancer would be a relative or involved in their care.

Recruitment procedure

*Gaining access*

Before recruitment began, a meeting was arranged with the lung cancer nurses to discuss the recruitment process. We discussed the barriers to recruiting patients in palliative care settings, including how health care professionals sometimes act as 'gatekeepers' (Addington-Hall, 2002). The lung cancer nurses received a copy of the invitation letter and information sheet explaining the study and a copy of the recruitment protocol. This letter and the information sheet (appendix 1) had been developed with the help of users and staff (Research advisory group[2]) before seeking ethical approval. It outlined the topic area and gave examples of some of the questions that were likely to be asked at the interview. This strategy was developed to support patients to give informed consent about joining the study and reduce the risk of patients consenting without understanding the nature of the interview, it would also reassure staff that patients were not being coerced into the study.

Gaining access to people living with advanced lung cancer and to their family members was achieved through relationships with the lung cancer nurse specialists at six hospital sites. My professional standing as a Macmillan lead cancer nurse and my previous relationship with the lung cancer nurses in the town sites (working together on the pilot study) proved useful in facilitating the recruitment for this study. All but two patient participants and one current carer were recruited through the town site.

Participants were invited to take part in the study through their lung cancer nurse specialists. The lung cancer nurse specialists did this either by giving potential participants the invitation letter during a clinic appointment or by telephoning them and sending them the invitation letter through the post. If potential participants showed an interest, the lung cancer nurse then followed this up with a participant information letter. Family members were often

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[2] This group consisted of a respiratory physician, oncologist, and lung cancer nurses from both city and town sites, a patient and a bereaved family member. Together they provided expert advice to the principal researcher.

invited at the same time as the patients. Separate letters were designed to meet the needs of patients and their family members. A patient and a bereaved family member representative on the research advisory group helped with the design and wording of these letters and supported the recruitment process. Once participants gave verbal consent to take part in the study to their lung cancer nurse and following seven days post receipt of the information letter I then made a telephone call to each participant to arrange an interview.

Invitation letters identified me as the principal researcher and also as a cancer nurse. Members of the advisory group, especially the bereaved carer, believed this would bring greater credibility to the study and assist in gaining access to people at the end of life. In collaboration with the lung cancer nurses we developed a laminated invitation guide aimed at assisting the nurses to invite people in accordance with the agreed inclusion and exclusion criteria for the study.

An invitation log was kept by the lung cancer nurses to help them to know as a team who had been invited and who had verbally agreed to take part. The log also served to record reasons for non-participation. A log of the participating patients and family members was also kept. The following recruitment flowchart (table 2.1) details the invited sample and reasons for non-participation.

Patients' reported reasons for declining participation included: feeling unwell, the content of the interview 'sounded upsetting', 'doesn't want to talk about the future', changed their mind, anticipates not feeling well, too busy and never at home, did not want to upset their partner. The reasons given by family members for declining included: patient's death, not wanting to leave their family members, visiting their wife in hospital and needing to care for their husband. If a patient was invited to take part and declined but a family member wanted to participate then the family member was given the opportunity. This happened on two occasions.

As previously stated, the majority of participants were recruited through the town hospital site. I believe this reflected the strong working relationship I had with these nurses, having been a colleague and more recently their lead cancer nurse. We also had previous experience of working together on the pilot study. By comparison, I had not previously met the nurses working in the city site. Differences in working practices also impacted on the nurses' ability to recruit, as most patients requiring curative surgery or oncology treatment were seen by the oncologists and nursing staff in the city hospital, whereas patients having palliative treatment (those with advanced disease) were seen at the local district general hospital.

Table 2.1 Recruitment Flowchart

**Phase 1**
(December 2006 – February 2007)

**Phase 2**
(December 2007– May 2008)

Sample invited:
19 patients
12 family members

Sample invited:
23 patients
15 family members

Declined:
5 patients
4 family members

Declined:
8 patients
3 family members

Died:
3 patients

Died:
1 patient

sample achieved:
11 patients
7 family members

sample achieved:
14 patients
12 family members

Final sample achieved:
25 patients
19 family members
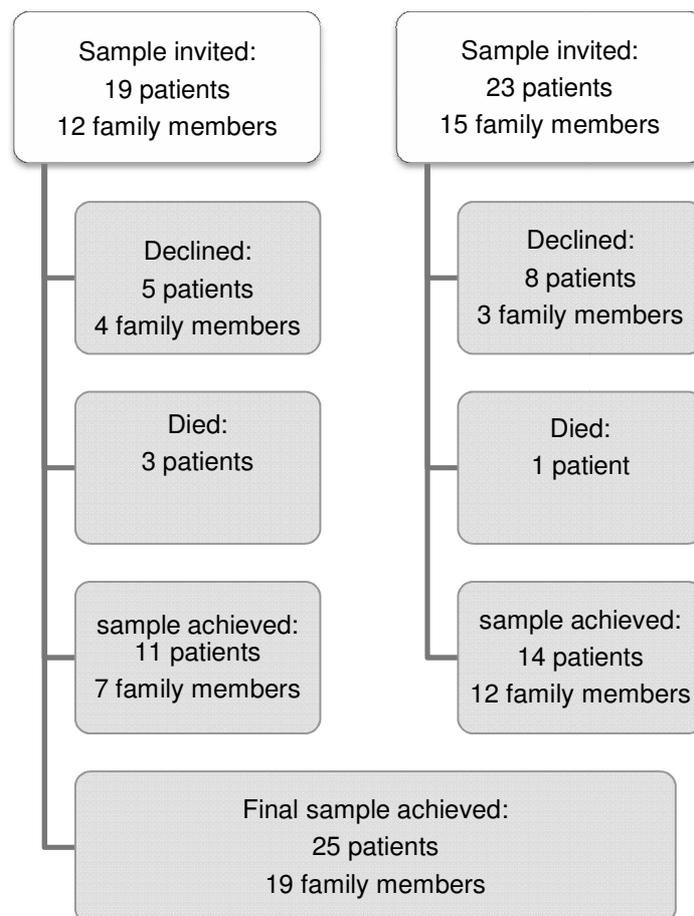
*Gate keeping*

'Gate keeping' refers to people using their position to influence, or mediate access between researchers and participants. A frequent outcome is that they are too zealous which prevents recruitment and this is usually because of concern that participation might cause the patient to become distressed, tired or that it might be too intrusive for them. This could be viewed as paternalistic and might prevent potential participants from having the opportunity to take part in research (Addington-Hall, 2002). Moreover, 'keen' recruiters could potentially coerce patients and carers into agreeing to participate (Hopkinson, 2005), which could be harmful to patients and their families. Gate keeping serves to prevent harm to patients by protecting them from undue distress.

As mentioned previously, a discussion was held with the relevant lung cancer nurses before the recruitment phase to highlight access issues in recruitment and to help them become aware of the possibility of their taking on the gate keeper role. The group discussion with the lung cancer nurse specialists took place before commencement of the study. The nurses were given protected time for this discussion, away from their regular work environment. Some reading material was provided highlighting issues of gate keeping in recruitment. The questions developed to support this group discussion are listed below.

Figure 2.2 Questions developed to support discussion with lung cancer nurses

| |
|---|
| o  Had anyone recruited participants to a research study before? |
| o  What concerns or worries, if any, did they have about recruiting patients and their families? |
| o  What did they perceive were the potential benefits and risks to patients taking part in this study? |
| o  How could I support them in the recruitment process? |

These questions enabled them to identify that they did have concerns about recruiting 'sick' people'; they were afraid of causing further distress and they also identified their desire to try to recruit people who would have a 'good' rather than a 'bad' experience of discussing future care. This discussion enabled me to clarify referral criteria and discuss the importance of getting a variety of people's experiences irrespective of whether patients themselves perceived these experiences as 'good' or 'bad'. The discussion also provided an opportunity for me to allay any fears about being judged, as they all knew me as a lead cancer nurse. They could have considered the research as 'checking up' on their nursing practice. I clarified the purpose of the research and assured them that their personal identity would not be disclosed and that any data would be anonymised.

It was evident from the recruitment log and conversations with the lung cancer nurses about potential participants that the nurses still acted as gate keepers. They did view some patients or family members as being 'too ill' or 'too emotional' to be invited to take part, not wanting to burden them with additional visits or 'intrusions'. Interestingly the lung cancer nurses reported that they had asked some patients who they did not think would wish to take part and were surprised that they did verbally agree.

## Achieved sample

A convenience sample of 25 patients and 19 family members who spoke English agreed to participate in this interview study (table 2.1). Fourteen patients declined and 4 died before the interview. Seven family members declined. Data collection was conducted in two stages, with participants recruited by lung cancer nurse specialists over two separate time periods covering 17 months.

## Modified sample

**Table 2.2** Modified Sample

|  | Single participant interviews | Single family member interviews | Joint interviews Patient/Family | Group family interviews | Total Participants |
|---|---|---|---|---|---|
| **Phase 1** | 6 (5 patients) | 1 | 7 (6 patients and 6 family members) | 1 (3 family members) | (18) |
| **Phase 2** | 7 (7 patients) | 0 | 7 (7 patients and 7 family members) | 1 (5 family members) | (26) |
| **Total** | 13 (12) | 1(1) | 14 (26) | 2(8) | **(44)** |

This first phase included 13 interviews with 11 people with lung cancer. A group interview was held with three of the family members who had also taken part in a joint interview with their husband. A family member who did not take part in a joint or group interview agreed to an individual interview. Two of the people with lung cancer (one who had his wife present) agreed to a second interview. In the second stage of data collection, a further sample of 14 people with lung cancer were interviewed (7 of these were joint interviews with a family member) and a further 5 family members who were caring for people with lung cancer who had not participated were recruited to a group interview.

## Participant profile

All patient participants had a diagnosis of advanced lung cancer and were aged between 47 and 85, with a mean age of 67 (table 2.3). The ratio of male to female was 3:1 (18 men and 7 females), which is slightly higher than the national statistics for lung cancer incidence by gender which was reported as a ratio of 4:3 in 2007 (Cancer Research UK, 2010b). Most people with cancer within this study came from lower socioeconomic classes (National

Statistics Socio-economic Classification (NS-SEC), table 2.3) and their former jobs included

mining or industrial-related work. From a review of the participants' medical records in

January 2010, it was noted that twenty one patient participants had died before August 2009

and that 4 were still alive. A detailed demographic profile of the patient participants, including

length of illness and stage of disease is given at the end of this section. Pseudonyms are

used throughout this thesis to protect participants' anonymity. Specific descriptions in the

form of pen portraits follow in the next chapter. Fourteen family member participants were

spouses or partners of the patients who took part in a joint interview. Four daughters and one

granddaughter who participated in a group interview were related to two patients who did not

participate. The details of the family members who participated in the group interviews are

found in table 2.4.

Table 2.3 Participant profile

| Patient Pseudonym | Age | Gender | Marital status | NS-SEC simplified operational category | Social Class | Diagnosis and stage of disease | Prognosis (recorded in medical notes) | Presence of AD, Living will or advance refusal (documented or reported by patient) | Duration of illness and place of death where known |
|---|---|---|---|---|---|---|---|---|---|
| Barney | 60 | M | M | 13.3 | IIIN? | Lung mass, brain metastases. No histology. Stage 4 | Stage 4 | None | 8 months (home) |
| Andy | 73 | M | M | 11.2 | IV | Non small cell lung carcinoma – squamous (NSCLC). Stage 4 | Stage 4 | None | 23 months (home) |
| Candy | 58 | F | M | 7.1 | IIIN | NSCLC adeno-carcinoma Stage 3a (unresectable) | Not documented | None | 3 years 2 months. Alive (in January, 2010) |
| Simon | 59 | M | M | 4.1 | II | Lung mass, brain metastases. | 6-9 months | Unable to access data | 11 months (hospital) |
| Bernard | 59 | M | M | 8.1 | II | NSCLC- squamous. Stage 3b | Not documented | None | 16 months (home) |
| Dennis | 73 | M | M | Not known | Not known | NSCLC- squamous. Stage 4 | Reported as poor | None | 12 months (hospital) |
| Henry | 60 | M | C | 9.1 | IIIM | NSCLC- Stage 3a | Good | None | Five years. Alive (in January 2010) |
| Clive | 54 | M | M | 13.3 | IIIM | NSCLC- squamous, brain mets. No stage noted. | Not documented | None | Seven years (place of death not known) |
| Jim | 59 | M | M | Not known | Not known | Small cell. No staging noted. | Poor | None | Seven years (hospital) |
| Ruby | 79 | F | W | Not known | Not known | NSCLC (T3,N0,M0) | Not accessed | Not accessed | 2 years 4 months (Hospital) |
| Dan | 75 | M | M | 13.3 | IIIM | T3N3 diagnosed malignant mesothelioma with pleural involvement | Not documented | Patient decision no chemo, supportive care. | 11 months (home) |

| Patient Pseudonym | Age | Gender | Marital status | NS-SEC simplified operational category | Social Class | Diagnosis and stage of disease | Prognosis (recorded in medical notes) | Presence of AD, Living will or advance refusal (documented or reported by patient) | Duration of illness and place of death where known |
|---|---|---|---|---|---|---|---|---|---|
| Stewart | 60 | M | W | 13.4 | V | NSCLC with rib metastases. Stage 4. | Not documented | None | 18 months (hospital) |
| Burt | 64 | M | M | 13.3 | IIIM | NSCLC - squamous. Stage 3b | Not documented | None | 18 months (hospital) |
| Mabel | 66 | F | M | 12.2 | IV | NSCLC adeno-carcinoma Stage 3a | Not documented | None | 13 months (hospital) |
| Paul | 73 | M | M | 13.3 | IIIM | NSCLC right, stage 3a T2N1M? | Not documented | No AD. Noted that refused surgery as no symptoms | 17 months |
| Mary | 81 | F | W | Not known | Not known | NSCLC Rt. Adeno-carcinoma T2-4, N2M0 (stage 3a) | Not documented | None | 2 years 2 months Alive (in January 2010) |
| George | 65 | M | M | 11.1 | IIIM | Pleural (right) Mesothelioma. Stage T3N0 | Not documented | Patient requested DNAR 23/02/2008 | 12 months (hospital) |
| Bob | 69 | M | M | 12.3 | IIIM | Small cell left lung/bronchus cancer | Not documented | None | 5 years and 6 months Alive (in January 2010) |
| Vicky | 79 | F | M | 12.1 | IIIN | Left Upper T2N3M1? (?metastases) Stage 3b | Not documented | Do Not Attempt Resuscitation order by Dr. Preference for hospice noted weeks before death | 10 months (hospice) |
| Colin | 78 | M | M | 12.4 | IV | Non small cell lung cancer (right) inoperable. | Not documented | None | 3 years (home) |
| Doris | 61 | F | M | 7.3 | II | NSCLC bronchus stage 4 metastasis | Not documented | None | 11 months |
| Shelley | 48 | F | M | 4.1 | II | Metastatic NSCLC stage T4 | 10-12 months | None | 2 years 6 months |

| Patient Pseudonym | Age | Gender | Marital status | NS-SEC simplified operational category | Social Class | Diagnosis and stage of disease | Prognosis (recorded in medical notes) | Presence of AD, Living will or advance refusal (documented or reported by patient) | Duration of illness and place of death where known |
|---|---|---|---|---|---|---|---|---|---|
| Edward | 85 | M | W | 13.3 | IIIM | NSCLC – Squamous cell (right lung ) and ?colonic tumour | Not documented | None | 8 months |
| Morris | 79 | M | C | Not known | Not known | NSCLC-squamous Rt. upper lobe. Large cavitating mass and ?metastases, Stage 4 | Not documented | None | 9 months |
| Bernie | 55 | M | M | 13.3 | IIIM | Left upper lobe lung cancer. Mass right kidney. Not staged | Not documented | None | 6 months |

Table 2.4  Group family member profile

| Group interview | Pseudonym used | Age if known | Family member with cancer | Relationship to person with cancer |
|---|---|---|---|---|
| One | Eve | Not known | Barney | Wife |
| | Angela | Not known | Andy | Wife |
| | Mary | Not known | Bernard | Wife |
| Two | Claire | 48 | Iris | Granddaughter |
| | Lorna | 66 | Iris | Daughter |
| | Debbie | 53 | Iris | Daughter |
| | Mavis | 61 | Iris | Daughter |
| | Chris | 60 | May | Daughter |

## Data collection

Data collection took the form of interviews. Other forms of data used in this study included: observations within the interview setting that were written up as field notes, group interview observations written by two colleagues[3]; a personal research diary and communications with the lung cancer nurses who recruited people to the study.

### Interviews in qualitative research

Interviews were chosen as the means of collecting data from the patient participants and family members because they provide a method of eliciting perceptions of experiences. Interviews have been described as "*a conversation with a structure and a purpose*" (Kvale, 1996). Mason (2005) suggests that interviewing is consistent with an epistemological perspective that views talking with and listening to people as a meaningful way of constructing data. Interviews are a suitable method of collecting data for grounded theory analysis (Payne, 2007). In an earlier study (Horne et al., 2006), interviews had worked effectively to gain preliminary knowledge about advance care planning, and, although interviewing is not without its difficulties, this method of data collection can be beneficial to vulnerable patients by helping them make sense of significant events in their lives (Corbin and Morse, 2003). Moreover, interviews provide an opportunity for those who are unable or unwilling to respond to questionnaires to share their views and experiences (Sullivan, 1998). Through the use of research interviews, patients can contribute to the future care of others by providing important perspectives that can inform improved care for future patients.

In grounded theory the primary source of data is the interview because it allows the participant to put their experience in their own words (Bartlett and Payne, 1997). The use of a grounded theory approach to interviewing allows participants to discuss and reflect on their experiences and the meaning these have for them (Warren, 2001). Charmaz (2003) suggests

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[3] A clinical nurse specialist in palliative care and a hospital chaplain.

that interviews in grounded theory provide a flexible and "emergent technique" (p.312) for gathering data to explore and elicit views about the subjective experiences of the interviewee. Interviewing within a grounded theory approach allows the initial interviews to start from the patients' narrative, building the inquiry through questions to future interviewees that are directed towards constructing the evolving theory (Wimpenny and Gass, 2000).

*Ethical principles*

The ethical principles used to underpin the conduct of this study were maintaining confidentiality and anonymity , gaining informed consent (Research Councils UK, 2009; Economic and Social Research Council, 2010), interviewing with sensitivity and gaining the appropriate ethical and governance approvals (Department of Health, 2005).  The World Medical Association Declaration of Helsinki (2008) advises that researchers must gain informed consent from participants and "*protect the privacy of research subjects and the confidentiality of their personal information* (p.3)". Methods of preserving confidentiality and anonymity will be outlined in the section on data analysis. Other ethical procedures will now be discussed.

*Ethical and research governance approval*

I gained ethical approval for this study from the local NHS research ethics committee, and I incorporated minor revisions to the patient and carer information sheets as suggested by the committee members. This process was required as participants were National Health Service registered patients (Department of Health, 2005). Research governance approval was also sought from both hospital Trusts where recruitment of patient participants would be carried out. This presented challenges as processes and timeliness where different in each organisation. Having explained the study and engaged help in recruitment from the lung cancer nurses from both organisations, we were eager to begin recruitment. We considered whether to start data collection in one hospital whilst waiting for approval from the other one.

Realising that the first few interviews would set the direction for the rest of the study led me to decide to wait for approval from both organisations before beginning data collection.

## Informed consent

Lung cancer patients and their family members were invited to participate in the study by their lung cancer nurse using the information sheet (appendix 1) and invitation letters. Due to the sensitive nature of the research topic the information sheet included a description of the types of questions to be asked in the interview. This strategy was employed to provide sufficient information for patients and carers about the nature of the interview before they agreed to take part (Banister et al., 1994).

In addition to the written consent forms used before starting the face-to-face interviews with participants, I used 'process consent' (Rosenblatt, 1999; Addington-Hall, 2002), which involves periodically checking a participant's willingness to continue the interview. This strategy sought to minimise any potential distress arising from the discussion of sensitive issues by providing opportunities for patients to stop the line of questioning or change the focus of the topic.  Family members had the option of withdrawing from the interview at any time.

## Interviewing sensitively

An ethical concern in researching sensitive subjects within palliative care is the risk of harm to the participants (Hopkinson et al, 2005) by causing emotional distress through interviewing (Corbin and Morse, 2003; Rees; Murphy et al., 1998) or emotional pain (Rosenblatt, 1999) by engaging people in conversations about sensitive topics that they may not wish to discuss.

As mentioned previously, the first strategy I used to minimise the risk of emotional distress was to inform patients and family members of the topic area before they agreed to

participate. This was achieved by outlining the topic area and question headings within the patient and family members' information sheets (Banister et al., 1994), giving potential participants greater opportunity to decide whether they wanted to take part in the research and whether they wished to omit any of the topic areas within the interview. Qualitative interviews often 'unfold', thereby making informed consent problematic; therefore, this strategy helped to find out if there were topics or areas of discussion that participants preferred not to be interviewed about.

Another strategy for seeking to minimise potential participant distress was to adopt a compassionate and "be-with" approach through engaging in active listening. Payne (1999) suggests that it is useful to adopt an active listening approach in conducting interviews as well as asking the sensitively developed questions. The interview questions were structured to move from the broad to the more specific to promote a sensitive approach to the participant (Burns and Grove, 1993). I spent time building rapport with each new participant before introducing the topic areas, and only moving onto the interview when the participant agreed they were ready. After the interview the use of general conversation allowed both the participant and researcher to debrief and say goodbye. I picked up cues from the patient's body language, verbal responses and choice of words to judge whether to proceed with the different areas of discussion within the interview schedule. Whilst not advocating entering the research interview with the purpose of providing therapy, Rosenblatt (1999) argues that 'therapist type' skills such as knowing when to back off, acknowledging and listening are also necessary in researching sensitive subjects. Examples of the use of these skills are provided later in the section on reflexivity.

Probes were used within the interview to assist in clarifying patient and carer responses, but were kept to the minimum. This position is supported by Smith (1995), who suggests that a useful strategy for semi-structured interviews is to encourage the participant to speak about the topic with as little prompting as possible. Overuse of probes can potentially lead to

participants feeling 'interrogated' or to experience emotional pain. Sullivan (1998) suggests that the interviewer must not ask additional questions beyond the limits of the study when interviewing about sensitive issues.

In research interviewing there is always an imbalance of power (Ribbens, 1989) inherent within the relationship between interviewer and participant (Bloor, 1997) because the researcher defines the research topic and interview questions and is therefore in a more powerful position (Kvale, 1996). An ethically sensitive researcher attempts to 'share' power with the interviewee (Seymour et al., 2005b), which may involve utilising skills of attentive listening and paraphrasing. People in this study were particularly at risk of being vulnerable due to their advanced disease (Seymour et al., 2005b), therefore minimising distress and attempting to balance 'power' was a priority. Mechanisms for compensating for the uneven power balance are the use of empathy (Gysels et al., 2008), building rapport (May, 1991) and gaining "process consent" from participants (Addington-Hall, 2002). Another strategy for empowering people in the interview process is facilitating joint interviews. Providing the opportunity to be interviewed alone or with another family member also enabled them to exercise choice (Morris, 2001). For example, when I returned to interview Bernard on his own, his wife Mary stayed with him. I did not think it was ethically appropriate to remind him of my request to interview him on his own, particularly as he was not feeling well. He chose to be interviewed a second time with his wife present.

As I had previously been a Macmillan specialist palliative care nurse and a lead cancer, nurse my knowledge and skills in dealing with distressed patients and families came into the fore during the interview process. I pre-empted the possibility that I may need to use my specialist palliative care nursing skills or contact a health professional if I was concerned there may be a risk to the patient or family member if I did not intervene. I decided I would first seek the patient or family member's permission before intervening to ensure I did not breach confidentiality.

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Within the interview setting, being a lead cancer nurse was not unproblematic as it may have influenced participants' responses. Participants may have felt disempowered, and their awareness of my profession may have had a negative effect on how much they felt able to talk to me about their views. They could have felt that expressing negative views might have affected their ongoing treatment. I spoke to the lung cancer nurses about this issue and they suggested that my changing into more casual clothes and not wearing my badge would help. I also planned to explain to participants that I was coming to them as a researcher, and although I was also a cancer nurse their contributions would be confidential and would not affect their ongoing care and treatment. However, I was not able to completely negate the effects of my cancer nurse role on the interviews and have endeavoured to reflect on this throughout data collection using my research diary.

Offering a choice of location for the interview was an attempt to put participants at ease (Sullivan, 1998) and balance the power relationship between the interviewer and interviewee (Parnis, 2005) by enabling them to feel comfortable in their surroundings.

Moreover, it is not possible to predict the response of participants in an interview situation. Certain skills can assist an ethically sensitive approach to interviewing. Coyle and Wright (1996) suggest that counselling skills such as paraphrasing, genuineness and empathy can help minimise emotional distress. I used words such as 'right' or silences and occasionally paraphrasing. For example, in the second group discussion I used paraphrasing to show empathy when Iris's daughters were recounting their father's death.

If despite the use of the above techniques a participant appeared to become emotionally distressed, their consent to continue the interview was rechecked. This strategy was adopted when interviewing Mabel, who became distressed after I asked her about her thoughts regarding the future and left the room for a tissue. When Mabel returned I sought her consent to continue, which she gave. If participants wished to conclude the interview, no

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further questions were asked and the patients were offered the opportunity to speak to their lung cancer nurse or a family member.

### Interviewing family members

Because of the sensitive nature of the discussion, there is also the potential for some family members to become emotionally distressed during joint interviews or group discussions when sharing or hearing others' experiences. Again, making use of my skills as a Macmillan nurse in building rapport and adopting an empathetic approach to all participants was helpful. An ice-breaker and refreshments were planned to gain rapport with the family members before starting the group interview.

As with the participants with lung cancer, all family members were given an information card with useful contact details of support staff and services in their locality, which included details of free counselling services.

### Interview Procedure

#### My preparation

Before each interview I prepared myself and the equipment. I used a digital mini disc recorder to record all interviews and focus groups. Before leaving to travel to the participant's home I spent time reviewing the interview guide, ensuring the minidiscs were correctly labelled with a participant code and sitting quietly reflecting on emerging themes from earlier interviews. I did no more than two interviews per day because of the sensitive and emotional nature of the conversations. Murray et al (2009) suggest doing not more than three interviews of this nature per week. When I conducted two interviews in a day I took a break in between to reflect, make observational notes in my field diary and recharge the mini-disc recorder. Self-preparation helped limit any problems which might have resulted had I rushed to the interview or not been focussed. Melia (2000) suggests that preparation for the interview,

which may include familiarisation with any relevant facts, is important for successful interviewing. The information the patients' nurses gave to me helped me to be aware of each person's situation and thus helped me to prepare to interview them. Preparation also helped me to listen attentively and show my interest in other people's stories (Wimpenny and Gass, 2000). I was concerned to listen not just to the words people used but to how they reacted to the questions I used. In addition, I paid attention to the behaviour of others who might have been in the room. Without preparation I might have risked missing body language (Sullivan, 1998), environmental issues, tone and intonation or lacked the ability to reflect on what meanings people attributed to their experiences. These aspects of the interaction aided later interpretation of the meanings that people gave to their experiences.

Interview setting

All but one patient chose to be interviewed at home, which had the benefit of allowing me to observe their home circumstances and aided greater understanding of what aspects of life were important to them. For example, on interviewing Mary I observed how her dog was very important in her life as she played and related with him. When interviewing George and Doris in their homes, I observed the importance of their families through the display of large family photos on the walls.

The one patient who did not want to be interviewed at home agreed to be interviewed in the counselling room of the local chemotherapy suite which was familiar to him. This meant that I could not observe his home circumstances, but it provided him with the privacy he requested. Not observing his home circumstances and other significant relationships influenced my analysis of his interview as I was left imagining what his home circumstances might have been like, rather than observing them first hand.

Interview Procedure

People who agreed verbally to participate in the study were contacted by telephone. I then organised an interview with them in a setting of their choice and at a time and day convenient to them. Those who agreed to attend a family group interview were also offered transport to the venue as detailed in their participant information.

I invited participants to take part in an initial meeting so that I could explain the research project, gain their consent and build rapport. An interview was then requested, which was conducted with all patients immediately following the initial meeting to explore their views using an interview schedule. Patients were asked if they preferred to have a family member or carer with them when they were interviewed, and some spouses had an expectation that they would be interviewed together.

With the participants' consent, all interviews were taped using a digital mini-disc recorder. The time before switching on the mini-disc was used to build rapport prior to the interview, and the time after stopping recording was used to debrief, and answer any questions about the study or questions raised during the interview.

Data for current family members was collected through the use of an audio-taped group interview. A clinical nurse specialist in palliative care was asked to be the note-taker for the first group interview and a chaplain specialising in palliative care for the second interview. They were asked because of their experience in counselling and group work and they were also available to offer support to carers if required.

## Content of interview

A topic guide, which acted as an aide-memoire designed for the pilot study (Horne et al, 2006), was adapted (appendix 2) in collaboration with the lung cancer nurses, users and supervisors for this study. The initial topic areas included:

- initiation of end-of-life discussions,

- staff and family involvement,

- components of care which aid discussion,

- patients' views on the content of discussions about future care.

General questions were used at the beginning of the interviews, building up to more specific and gently probing questions to explore emerging concepts. I used a guide of topic areas to support the group interview discussions. This was developed in collaboration with the advisory group.

## Modifications to interviews

The topic guide for the first eight interviews worked well, but there appeared to be a need to focus the discussion more on people's perspectives about the future. I gave some simple definitions of terms, such as 'living will' and 'advance decisions to refuse treatment', on a card to provide information to participants during the interview. The introduction of this information, along with my questions about future treatment decisions, were perceived as requests for views on euthanasia and appeared to distress one of the two people this was used with (figure 2.2).

Figure 2.2 Research diary entry on use of the information card

> "I don't know why, but it feels like the use of the information card (which basically introduced new information to the participant) changed the context of the interview at that point. I did wonder if (although she never said) the information slightly shocked Ruby? When she read the bit about euthanasia she said 'oh no'. But it did seem to focus our conversation on what I as a researcher wanted to get her views on. But at what cost to the patient?"

It was evident that the information provided was new to them. Following discussion with my supervisors about the effect of this new information and the apparent distress of one of the people who saw it, I decided not to use the information card again.

After the first phase of interviews I made a modification to the interview guide and used this for the second phase. The revised guide received local ethical approval, as did the second phase of data collection. This revised guide (appendix 3) included theoretical sampling topics such as views about 'carrying on as normal', 'concerns for family' and so forth, categories arising from earlier interviews.

*Managing differing expectations of interviewing.*

Participants had different expectations of their interview. For example, I perceived Mabel had a need to tell her 'story' and used the interview to do just that. Some family members appeared keen for me to speak with the person with cancer for e.g. Doris (Dennis's wife) expressed her hope that the interview would help him face the future. She appeared to perceive it would be therapeutic for him to talk about the future. This required careful handling and upholding ethical principles in conducting the study, remembering the primary purpose was not to 'intervene' therapeutically, but also recognising that participants may sometimes benefit from the interaction. One couple, Bernie and Jane, remarked at the end of the interview that they hoped that I had found the discussion useful in helping others as they had found it had helped them to discuss things openly.

Moreover, there were some participants who had varying interpretations of why they had been invited to take part, and this required sensitive handling during the interview. For example, the information letter about the study had prompted Doris and Ted to wonder if the invitation to take part meant Doris was 'sicker than she felt'. They reported feeling anxious about the interview, believing they would receive news of Doris's demise. Having palliative care skills such as being empathetic enabled me to listen sensitively to their fears and offer them reassurance before moving onto the interview.

## Single and Joint interviews

Interviews started with an introduction to explain the study. This was followed by general discussion, such as asking them how they were, to establish trust, build a rapport (Booth and Booth, 1994) and put people at ease (Smith et al., 1995). This time was also used to establish the person's readiness to begin the interview and gain their consent for me to record it.  I had not planned to interview patients with their spouse present or with their spouse taking part in a joint interview, but from an ethical stance it became a necessary part of the design. I had not stated in the patient information that I specifically wanted to talk to the participant alone, but I did explain on the phone I would like to talk specifically to them. Recognising the imbalance of power in the research interview (Ribbens, 1989), it did not appear to me to be ethically or morally appropriate to insist on individual interviews. Having a partner present might have offered the person more control in the interview. Spouses or partners of fourteen patient participant's were present during the interviews. For some, this may have provided a 'safe' setting in which to be interviewed by a stranger. For others, it appeared a more 'natural' preference stemming from a shared life together. However, I recognise that the presence of a spouse in the interview may have offered a different discussion than the one that developed in interviews with patients who were unaccompanied (Arksey, 1996; Gysels et al., 2008). Nevertheless, there was value in gaining multiple

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perspectives. I returned to two of the interviewees for a second interview to establish if a different perspective would be given when the person with cancer was interviewed alone. On interviewing Andy on his own he reiterated what he had shared in his joint interview with his wife. Although Bernard had agreed over the telephone to be interviewed on his own, his wife was in fact present during the second interview. Bernard was not feeling well and I did not feel it was ethically or morally appropriate to ask her to leave. Similar accounts were also given by Bernard and Jane during this interview.

The benefit of interviewing the person with cancer within their societal context was also evident when interpreting the different meanings people give to their experiences. My main focus remained on the person with cancer, so questions were focussed on their experiences. Family members shared their views either in support of the person with cancer or contrary to them. Some family members openly disagreed with the person with cancer or displayed different emotions. Others were quieter, letting the person with cancer take the lead in responding to questions. I was able to observe how family members positioned themselves in the room, and their non-verbal behaviour with the person with cancer and this added to the analysis and later on to theory development.

The main difference between interviewing people on their own and a joint interview was that some people confided thoughts and feelings of a personal nature, which family members were not aware of. For example, when I interviewed Dan on his own, he talked about getting frightened of losing his independence. Although it was their choice to be interviewed together, some people still used the opportunity, when their partner left the room, to talk about personal concerns they had. For example, when George's wife left the room during a joint interview he talked about concerns for his wife and family in the future. Methodologically this is important because when the researcher enters the interview setting he or she is unaware of the different social contexts and constraints within family relationships, and what the effects are when views and perceptions are disclosed to 'outsiders'. These differing social

contexts influence the public accounts given and therefore the data collected (Gysels et al., 2008).

Sometimes in joint interviews I acted more as an observer, watching the couple talk between themselves as they debated their views together, suggesting they had not previously thought about issues raised by the questions. At other times the couples gave individual answers or a joint account to questions which demonstrated that they had given thought, either on their own or together, to certain issues about the future. Where partners agreed in their response this appeared to add importance to the meaning of what they reported (Morris, 2001).

## Conducting group interviews

Two group interviews were held. One group consisted of the wives of three of the male patients who had been interviewed. The second group included one daughter of a lady with advanced lung cancer and three daughters and a granddaughter of another lady with lung cancer; neither patient had wanted to be interviewed themselves. Unlike the joint interviews, where I had not intended to gain the views of the family member, I purposely sought the views of family members and designed an interview guide for this purpose.

The group interviews were held on Saturday mornings in consultation with participants. The setting was a local church lounge because it was a central location and had ample parking and facilities to provide refreshments. As some people might not have wanted to meet in a religious building, participants were asked before final arrangements were made if they had any objections to the venue. All those taking part received a phone call from the researcher explaining the process for the interview, offering transport or travel expenses if required and confirming any needs they had in relation to attending; for example, someone from the local hospice at home service was offered to sit with their family member whilst they themselves attended the interview. One person took up the offer of transport. The National

Consumer Council (2008) suggest that offers of transport, remuneration and meeting in a friendly and comfortable environment all help to involve a cross-section of people.

Each interview started with refreshments, which allowed participants to informally get to know me, each other and the observer before the interview commenced. Group ground rules helped to ensure that there were mechanisms in place for family members to leave at any time they no longer wanted to participate. In addition, participants were asked to respect each other's confidentiality. The interview process was described and consent to record the group interview was given; this was followed by an 'ice-breaker' to get participants talking. At the end of each group interview participants were asked how they had found the experience, and this provided an opportunity for debriefing and sharing any concerns or information needs.

All those attending the first group interview participated equally in the discussion. It appeared that one participant's perception of her husband's disease was different to that of the other two, even though all husbands had advanced disease. This appeared to influence her level of comfort and agreement with the other two people's views about preparing for their dying. In the second group interview the dynamics were different. Having four members of one family alongside one member of another family impacted on the contribution from the lone family member, Chris. Whilst listening to the views of the other family members Chris commented on how this highlighted the lack of support and difficulties in her relationship with her sister and her mother. It is important to pay attention to the emotional state of interviewees to prevent harm (Murray et al., 2009). By adopting a 'be-with' approach with all interviewees I was able to pick up on Chris's discomfort and sought to engage her in the discussion by giving her eye contact and directing questions to her. Following the interview, having spoken with the observer colleague who was taking Chris home, we made sure she was provided with the information sheet that contained useful contact telephone numbers.

## Data analysis

*Data capture*

Each tape was given a code number. On one occasion the mini-disc battery failed part way through the interview. In order to minimise intrusion comprehensive notes were taken for the remaining part of the interview.

The length of the interview was determined both by the interviewee's engagement and willingness to share their views and experiences about discussing end of life care, and their level of fatigue. The length of audio-recordings from interviews with people with lung cancer ranged from 12 minutes to 62 minutes with an average of 31 minutes. The two group interviews recordings lasted 55 and 57 minutes.

*Privacy and anonymity*

To preserve patients' and family members' confidentiality and to preserve their anonymity a unique code was used for all patient and family members' transcripts and analysis documents. This method seeks to ensure patients' and family members' data cannot be identifiable to anyone other than the principal researcher.

*Storage*

Mini-discs and transcripts were stored in hard copy in a locked filing cabinet and on a personal computer. The principal researcher is the only person who had access to the electronic data files. However, for the purpose of ongoing supervision extracts of transcripts were shared with my supervisors. Field notes were stored in hard copy and only the patient code was used for identification.

*Field notes and research diary memos.*

From the early conception of this study to its completion I used a research diary to record my reflections. My conscious assumptions, new concepts and the questions posed I and others asked were recorded. Rolls and Relf (2006) identified that reflective accounts, though useful are limited by their private nature. Conversely, the private nature of a research diary creates a safe space in which one can be open about one's thoughts and feelings about conducting research on sensitive issues with people who are dying.  However, I did sometimes share my diary entries with my academic supervisors and with the advisory group members. The questions written in my diary have been used to help analyse and interrogate the interview transcripts. For me, as a visual learner, the use of mind-maps and diagrams to model the evolving concepts, aided the development of theoretical interpretations. Ongoing reflection in palliative care research is important to aid moral and ethical decision-making (Seymour et al, 2005b).


Immediately after each interview I also took field notes to capture important observations of participants within their social context.  These recordings included how I felt the interview went, what the family dynamics were, what the environment was like and key points people raised before, during and after the interview. These notes served as a reminder of the context for the interview when analysing the transcripts.


In addition, the two colleagues who assisted in the group interviews (by acting as observers) also took field notes and these supported the analysis. Research diaries (Clough and Nutbrown, 2002), field notes (Mason, 2005) and colleagues' observer notes (Fontana and Frey, 2005) provided a log and audit trail of the progression of ideas for analysis, which supported reflexivity.

*Coding process*

Introduction

Using a constructivist grounded theory approach meant data analysis began following the first reading of the initial interview and continued to be shaped during the whole data collection period (Pope et al, 2008), and was concluded during the process of writing up. It was a continuous and iterative process, taking data apart line by line into small units of meaning and then building it back together (Kvale, 1996), whilst at the same time retaining a sense of the whole. Prompt transcription enabled a continuous process of collecting data and analysing it for emerging codes and categories.

Hand coding

I decided to hand code the patients' transcripts as this allowed me to be intimate with them and did not place any barriers to my viewing them as a whole. Hand coding also allowed me to label units of meaning and asterisk or make notations by the side of the text showing links and relationships with other meaning units within the transcripts. This enabled me to begin to make sense of the data from the beginning (Pope and Mays, 2009, p738*).

Coding decisions

After the first interview I listened and then transcribed the first interview myself (subsequent interviews being transcribed by a company). I then read each line of the whole transcript looking for units of meaning and wrote a provisional code name or label to identify them (Glaser and Strauss, 1967). As far as possible, the choice of code and category names came directly from the participant's own words to retain their original meaning (Charmaz, 2006). After the next three interviews I coded each transcript, building on codes from the previous interviews, but not limiting the formation of any new ones. Categories started to emerge as I listened to people during the interviews and analysed the transcripts. In the early stages of analysis I resisted grouping codes together in an effort not to 'force' too early an

interpretation of meaning (Glaser and Strauss, 1967). After the sixth interview I started to review the codes and group these into categories of meaning. For example, the codes of 'Carry on as we are doing' (interview one – Barney and Eve), 'Just carry on as normal' (interview two – Andy and Angela) and 'Get on with life as normal' (interview three – Candy and Kevin) eventually became 'carry on as normal', a category that developed from these codes and subsequently led to the substantive category 'face death when it comes'. Codes were typed up and saved as word documents. Codes were printed out, cut into strips and sorted into categories. Where codes did not appear to fit into a category they were saved in an envelope for later consideration.

Glaser and Strauss (1967) suggest the use of one core category on which to focus the development of theory from early in the data collection. Dey (1999) suggests this could potentially limit the development of theory; therefore, in this study the analysis process did not initially limit the number of 'core' categories, but allowed as many categories as possible to be created. This was challenging in terms of gathering further data to theoretically sample for each category.

Categories were colour coded (to identify if they were from individual or joint interviews) and pasted onto a large wall board. This allowed easy visibility and reflection and continuing development of coding during subsequent interviews. Preliminary code lists and copies of early transcripts were sent to my supervisors for their consideration and as a means of checking the analysis was 'true' to the transcripts. A full list of codes, categories and substantive categories were drawn up. Photographs were taken of each step of the analysis process as an aide memoire and to provide an audit trail of theoretical decisions.

After the 11th patient I stopped interviewing to allow time to reflect on the preliminary analysis. At this stage, what I had been hearing and observing through the interviews and reading in the transcripts caused me to consider the need to modify the design of the study.

As mentioned earlier, I had planned to use the findings of the initial interviews to develop an intervention for advance care planning. The iterative process of analysis and the flexibility of the grounded theory design enabled me to change direction. I was able to place more emphasis on the views of the participants than was possible in my earlier study design. In this respect the interviews and the preliminary analysis shaped what happened next.

Once I had decided to continue conducting interviews I reviewed the topic guide for the interviews, and used future interviews to explore the meaning of what people had been saying about not wanting to discuss the future, their experiences of the disclosure of their prognosis and what they did or did not want to plan ahead for. The remaining 14 interviews sought to further explore these issues through theoretical sampling (Glaser and Strauss, 1967; Wimpenny and Gass, 2000). I refined the findings from the first set of interviews and teased out meanings of what were becoming the core categories and emerging substantive categories. In addition, I sought to sample more female participants, having only interviewed two in the first set of interviews. The aim was to gain a variety of views.

Once categories had been developed they were compared and contrasted across cases and with each other within cases to look for similarities and differences, and draw out meanings and relationships. This was done so that meanings as a whole were considered and individual codes or categories were not taken out of their context, thus ensuring codes were 'grounded' in the data (Charmaz, 2006). In analysing the transcripts silences were also considered. Charmaz (2006) suggests that silences are equally important and can show absence of thoughts or feelings; for example, the absence of talk in this study about choice was important in developing the proposed theory. Similarly, the absence of talk about 'self' was also key to understanding the importance of concern for family integrity.

## Analysing joint interviews

I was initially disappointed that I could not interview all participants on their own, because I had a preconceived belief that this would offer radically different data. I therefore decided to analyse the data from joint interviews separately from that arising from single interviews. As with the single interviews, I first read the transcript, listened to the audiotapes and coded transcripts line by line, naming each meaning unit. Having identified codes and emerging categories I compared these joint interviews with the individual ones and found few differences. The main categories were so similar that I decided to join the categories together following the completion of data collection. Both sets of data enriched the depth of the emerging categories and provided a means of triangulation.

## Analysing group interviews

Group interviews were taped and transcribed in the same way as individual and joint interviews. Preliminary codes were given to the units of meaning within the transcripts. The transcripts were coded separately from the individual and joint interviews, although the views from the other interviews influenced the interpretation. The codes and subsequent categories were used to enrich and compare interpretation of the meanings people with cancer gave to their experiences, to those given by family members. In addition, the analysis and interpretation of the group interviews also revealed different meanings for family members.

## Constructing a theoretical interpretation

### Use of self

Whether in single, joint or group interviews, as a researcher I was an additional person involved in the interaction or 'inter-view' (Kvale, 1996) who influenced the accounts produced. Recognising that people might tell me a 'public account' and might have kept their private thoughts to themselves was important when interpreting the interview transcripts. I looked at my voice to see how this might have shaped the views of those I interviewed. For example, in

considering the responses people gave about doctors not discussing the future I returned to the transcripts to compare how I had framed the question before receiving their accounts. This was also important when interpreting meanings and who people attributed these too. My interpretation as the interviewer might be different to that of someone who was not privy to the interview relationship. Remembering the relational dynamics in the interview and the behaviours demonstrated aided the interpretation of meaning and the subsequent construction of theory (Banister et al, 1994).

## Memos and theoretical sorting

During the coding and development of the main categories I wrote theoretical memos (Glaser, 1978), which were jottings in my research diary about the relationships between codes and questions and ideas about them. Memos led me to review the literature for existing theoretical interpretations about concepts. This process aided the theoretical interpretation of the findings, enabling questions to be raised such as what are these findings a story of? What social processes are involved here? Unlike Glaser (1978) who suggests memos help 'verify' categories, memos were used here to develop an interpretation and ask further questions about the data. Memos were written at different stages of data collection and theory development in keeping with a constructivist approach.

An example of an early memo in this study is described in figure 2.3 below and shows developing relationships between codes.

Figure 2.3 Entry in research diary 1.

> "'**Don't discuss the future**'[4] as a way of coping with a shortened life and the prospect of death. It appears to be a taboo – to talk about '**morbid**', '**doom and gloom**' things. Preference (which is either supported or attributable to doctors talking) is to have a fighting and positive **attitude**. Avoiding talking about the future may prevent the inevitable happening. It's too '**frightening**' to consider one's mortality and doctors' honesty (although often expecting them to be honest) provides knowledge which reduces the chosen coping mechanism ('**knowing is worse**').

An example of a later memo where theoretical ideas are further refined is shown in this second exemplar (figure 2.4), which followed coding of the final transcript.

Figure 2.4 Entry in research diary 2.

> "'**Knowing**' amount of time left to live takes away **normality** – because it removes uncertainty. Can't '**carry on as normal**' if future no longer unpredictable/uncertain. Taking away uncertainty takes away normal life – or ability to live what patient thinks is normal for them. Prediction can be harmful perhaps? Unpredictability beneficial because there is always a hope, dream, aspiration of what might be – a degree of control towards shaping the future. Predicting…removes control and ?choice from a person to live life as they wish, because certain other 'norms' they now need to face and be – the 'norm' of someone who is now dying".

This memo led to the development of the category 'face death when it comes' and helped me write about the relationships between people who said 'not knowing' was better than 'knowing' in relation to thinking about the future. This in turn supported the development of the proposed theory.

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[4] Bold font shows code names.

Written memos were sorted by photocopying the relevant pages in my research diary and colour coding them to the main categories, a process described by Glaser (1978) as *'theoretical sorting',* which enables data to be put back together in an explanatory framework. Like Glaser (1978), Charmaz (2006), places great importance on theoretical memo writing and sorting and suggests sorting memos by hand to 'play with them', which helps with developing ideas, and drawing diagrams to compare and contrast any relationships between categories. Theoretical sorting aided the development of diagrams and models in this study before I began the writing up process.

## Negative cases

Another process which aided theory development was the identification of 'negative cases'. 'Negative cases' are not clearly defined in the literature, but are suggested to be an exception or negative instance found through comparative analyses that can be used to seek alternative explanations or hypotheses in the data (Glaser & Strauss, 1967). Charmaz (2006) suggests the source of negative cases is influenced by the methodological approach used, and the researcher may find negative cases add to or refine the emerging theory, 'importing' them for theoretical sampling purposes or finding them in the data. In this study the two negative cases were found when the data was being analysed, but they were not explicitly sought in sampling. They were perceived to be 'negative cases' because they (Clive and Jim) both talked openly about death and dying and reported that they had discussed some preferences for care and treatment.

I compared the two 'negative cases' with each other and with the other transcripts for commonalities and differences, posing questions to further examine the data, for example, why are these cases different? Is it because they had both lived beyond the predicted time of

their death? Analysing these cases influenced future theoretical sampling and the development of the revised topic guide.

## Diagramming and Models

Another way of developing a theoretical interpretation is through models (Glaser, 1978) or diagrams (Charmaz, 2006). These are drawings that allow the researcher to visually portray categories and their relationships in addition to supporting the writing up of the theory. I drew diagrams in my research diary which helped me to pose further questions about the emerging theory and relationships between concepts. Eventually these diagrams informed the proposed theory which itself was presented using a diagram. Through discussion and presentation of the emerging findings I used the preliminary diagrams to help explain and test out meanings with advisory group members and colleagues.

## Member checking

I could not plan to return to patient participants to validate the findings because as anticipated most had died by the time the analysis was complete. The findings from the family participants provided triangulation of the findings from patient participants. The research advisory group and lung cancer multidisciplinary team also provided a means of 'checking' the findings for 'fit'.

## Reviewing existing theories

Reviewing the literature after coding supported the development of categories and memos, which helped discover whether the emerging theory in this study built on or 'fitted' with existing published theories. This aided the final writing up process described below. I wrote multiple drafts of chapter eight as I became aware of related theories. Some of these theories, a number of which turned out to be embryonic or at the early stages of

conceptualisation, were found in the body of sociological literature which I had not previously explored prior to data collection.

## Presentation of findings

*Writing decisions*

Writing up is an integral part of the analytical process furthering theoretical interpretation (Charmaz, 1995) the purpose of which is described by Glaser (1978) as "*the conceptual work and its integration into a theoretical explanation* (p129)". Glaser (1978) suggests the challenge in writing up is not merely to describe, but to write about the theoretical relationships between concepts, rather than writing about people. Charmaz (2006) does not disagree with this, but advocates the use of the researcher's voice (and indeed the participant's voice), tone and rhythm, recognizing the interpretation is the researchers and producing a narrative which is accessible (Charmaz, 2006) as well as credible (Charmaz, 2005). Glaser and Strauss's own writings of 'Awareness of Dying' (1966) demonstrate a lack of patients' own words to illustrate concepts, whereas other grounded theorists such as Sque and Payne (1996) have used patient exemplars to illustrate the meaning of a category and confirm to the reader that the theory was constructed from the data.

Taking a pragmatic, methodological approach to the use of a grounded theory, I have chosen to write a description of the main findings in chapters four to seven, using patients' own words as exemplars. Then I offer a theoretical interpretation of these findings in chapter eight, showing the integration of codes and categories and the relationships between them to explain the proposed theory.

*Ethical procedures*

Difficulties may occur in maintaining anonymity and confidentiality if, in reporting the participant's words, he or she is easily identifiable (Murphy et al., 1998). As described earlier

in this chapter, the procedure for maintaining anonymity was explained to participants through the information sheet. I had informed them that I might use their quotes to illustrate the results of the study and I obtained their consent to use their words and pseudonyms. I planned to preserve anonymity by listing only their gender, age and lung cancer classification alongside any written quotes used to report the findings.

The use of pseudonyms early on in the write-up was problematic as I found I began to forget the people's faces, depersonalising them, which made the subsequent reporting more difficult. In some respects I felt as if I was dishonouring them, but because I had explained that I would use pseudonyms in reporting I could not go back on this decision. On reflection I could have kept their original first names in the draft scripts changing them later before final submission.

*Use of case studies to illustrate concepts and meanings.*

I used an illustrative case study approach to introduce and describe the categories in each chapter. Using case studies can help identify, explain or illustrate a category (Stake, 2005) and seeks to provide the reader with a greater depth of insight into one person's experience. Cases can also be used to illustrate the codes and their relationships that have been constructed from the data. To analyse the case studies I used the observations made during the interview and telephone conversations, diary memos, interview transcripts, the person's demographic data, family member interview transcripts and communications with the recruiting lung cancer nurse.

The example of Shelley was used to illustrate the categories which formed 'planning for death, not dying'. Shelley was the 22nd person with cancer to be interviewed. This meant I had become familiar with the questions and had honed the later questions to theoretically sample those themes that were emerging from people's reports. I also felt comfortable myself

in conducting this interview because of my increasing confidence as an interviewer. It was one of the longer interviews I conducted and lasted approximately one and a half hours. Shelley was articulate in expressing her views and experiences, which meant this case, for me as a researcher, was easily accessible.

In summary, writing up is the final stage of analysis that begins early in the analytical process with memo writing, diagrams and early written drafts describing the findings.

## Credibility and rigour

In qualitative research, evaluating how credible and rigorous a study's findings are requires consideration of a variety of criteria. Different evaluative criteria have been suggested in the literature (Charmaz, 2005; Smith and Hodkinson, 2005; Cohen and Crabtree, 2008). Glaser (1978) proposed that the credibility of a theory is dependent on how it 'fits' the area of practice, whether it is understandable to a lay person and sufficiently generalised to be usable in different daily situations. I would argue that generalisability may not be possible in grounded theory because what is proposed is just one interpretation, one reality. Lincoln and Guba (1985) suggest consideration of credibility, transferability (as opposed to generalisability), dependability and confirmability as evaluative criteria, the latter two aspects gauged through the use of audit trails. 'Transferability' may be a useful evaluative concept because it suggests that the proposed theoretical interpretation may have relevance in other situations, populations or circumstances. Charmaz's (2006) criteria for evaluating grounded theory studies includes: credibility, originality, resonance and usefulness, the last two concepts aligning with Glaser's criteria of 'fit' and 'understandable'. However, it is not just the credibility of the proposed theory that is important, but also the credibility and rigour of the whole study. Spencer et al (2003) conducted a systematic review of the published literature on evaluating qualitative studies and developed a useful framework, underpinned by the principle that research should be contributory, defensible, rigorous and credible.

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I have chosen the evaluative framework developed by Spencer et al (2003) for this study because not only does it provide a framework to evaluate qualitative research, it also provides quality indicators that help the researcher to ask questions about the study, its conduct and findings. The difficulty with applying Glaser's (1978) or Charmaz's (2006) criteria was a lack of clarity on how to assess the whole study against their proposed criteria. I applied the evaluative framework (appendix 4) by using the questions it poses to judge each aspect of the study. During the analysis process I used the framework to consider how defensible the emerging interpretation was, making sure I had grounded the developing theory in the data. Following analysis and during the writing of the findings I used the questions in the framework again to interrogate the findings. In addition, I adapted some of the questions from the evaluative framework to use in a questionnaire that I gave to the lung cancer multidisciplinary team following my presentation of the study findings to them. The teams' answers to the questionnaire helped me 'check' the study findings for 'fit' and offered their views on the credibility of the study and its interpretation.

## Reflexivity

This next section presents reflections on the challenges and learning gained from conducting this research study. It also adds to the evaluative framework referenced above by demonstrating the rigour and credibility of the study (Tong et al., 2007; Spencer et al., 2003) and by providing information about what was happening 'behind the scenes'. I will show some of the key influences on me as a researcher and co-constructor of the findings. The following account will show my recognition of self in shaping the varying aspects of this interview study which will help the reader determine the authenticity of the findings.

## Interviewing as a palliative care nurse

One of the methodological challenges and critiques of conducting research using interviews is the effect the interviewer has on the interviewee and the resulting data (Dickson-Swift et al., 2006; Clarke, 2006). The experiences both professional and personal, that the interviewer brings to the interview, will undoubtedly shape the way the interviewer designs and uses questions (Tong et al., 2007; McNair et al., 2008). My tone of voice, my attitude towards the person being interviewed, my use of body language and my observations of their circumstances all contributed towards how the interviews were conducted. There were several occasions during the interviews when my nursing and palliative care knowledge caused me to intervene to support patients.

On one of these occasions during a second follow-up interview with Bernard, I used my palliative care nursing assessment skills. He had recently started on a clinical trial drug that appeared to have caused severe reactions. I was shocked at his changed appearance on meeting him again. His face and chest were red and covered with large weeping pustules. His breathing appeared laboured and he was weak and shaking. Mary, his wife said he was unable to eat. Before I could consider interviewing him or leaving him without interviewing him I used my nursing skills to promptly assess him. Once I was reassured that his reactions were within expected parameters I could then ask him if he would prefer to be interviewed another day. He insisted he wanted to carry on with the interview, although I would have preferred not to, being aware of his breathing and fragile state. I agreed to interview him, but I was conscious of the need not to tire him and kept the interview short. His physical appearance distracted me throughout the interview which greatly challenged my attentive listening skills. Following the interview I offered to contact his doctor, but Bernard and his wife declined this offer as Bernard had an appointment at the hospital the following day.

The other occasions when I intervened clinically were not as dramatic. Some participants had an apparent need for information or help with managing distressing physical symptoms,

which I was able to acknowledge during the interview, but which I put aside (with their consent) until after the interview had finished. Following the interview I signposted specific requests to health professionals caring for them or to other agencies for information.

Methods of managing other challenges in interviewing, not uncommon in health and social research (Rolls and Relf, 2006), such as managing the sadness and also the emotional toil of interviewing people who were ill (many who died shortly afterwards), led me to make notations in my research diary and to discuss with another health professional for peer support. Having a supportive family and my spiritual beliefs has enabled me to manage the feelings I experienced during and after the interviews.

Another area of discomfort in the interview process was sometimes being told 'secrets'. I found this disturbing at times, particularly having this knowledge in my mind when interviewing related family members at a later date. Clarke (2006) described the challenges of dealing with this during the interview and of deciding whether or not these disclosures should be included in the findings. I managed the emotional affects of these disclosures ethically by debriefing with a peer without betraying patient confidence. Although interviewing people in this study was emotionally draining at times, it was nevertheless a great privilege. I was keen not to cross the boundary between nurse researcher and nurse clinician (Dickson-Swift et al., 2006; Rolls and Relf, 2006) whilst conducting this research. I believe that using reflection in action (Dearnley, 2005; Schön, 1983) and reflection following the interviews (by keeping a research diary, field notes and regularly meeting my supervisors and talking with advisory group members) helped me maintain a professional boundary, although, as detailed below some of my interactions during the interviews appeared to act as an intervention.

## Interviewer as an 'interventionist'

It was not possible to predict the impact I might have as the researcher within the 'interview' on participants' discussions about the future, but it was something I was acutely aware of (Kvale, 1996). I took a stance that was not aimed at directing people's answers nor was my use of prompts clinically focused. It was impossible to remove the 'nurse' part of me which I have become over the past 30 years. There were also benefits in being a nurse as an interviewer, such as my use of active listening skills that sought to make my research design and interview approach sensitive and empathetic.

There is evidence to suggest that some of my interactions did appear to have influenced a few people's advance care planning decisions about future care. For example, towards the end of the interview with George, and following his response to a question about whether he had recorded his decisions about the future for sharing with his clinicians, I became aware that our conversation had caused him to consider how he might inform his clinicians about his preferences. His lung cancer nurse mentioned later that George had asked his oncologist at his next outpatient appointment about his future care and the service available to him. Although I had not intended to 'intervene' with my questions, a research interview had provoked a response about discussing the future.

## Summary

This chapter has described and argued for the use of a methodological approach that is flexible when used with people living with advanced disease and supports answering a research question that seeks to explore the meanings people give their life experiences. This approach has resulted in a large amount of qualitative interview data about people's experiences, which has been gained through a systematic process of comparative analysis, and has resulted in the theoretical interpretation now offered in the following chapters.

# CHAPTER 3 : PEN PORTRAITS

## Introduction

This chapter introduces the reader via a series of pen portraits to the participants with lung cancer who were interviewed for this study. The purpose of these pen portraits is to provide a brief description of how the interviews with each person added to the interpretation of the interview data in developing the theory of 'maintaining integrity in the face of death'.

This chapter was crafted through reflection on my field notes, which I wrote immediately following each interview. These pen portraits I believe contribute to building a description of the core categories in the emerging theory. The portraits are presented in chronological order from the first person interviewed to the last person interviewed, some 18 months later. I have given each person a fictitious name to preserve their anonymity: this was agreed in the consent process.

Many of these participants have since died and I recognise the profound impact this had on me. In my discussions with them, some shared their hopes, fears and occasionally their secrets. I am also aware of the potential impact on readers of the following portraits.

## Barney

Barney was diagnosed with advanced lung cancer. He looked much older than his 60 years because of his thinning white hair and his slow and unsteady state. We sat at his kitchen table and were accompanied by his wife Eve. Barney and Eve lived in a council house and Eve was registered as physically disabled. Their adult son also lived at home. Barney had recently started attending the local day hospice but commented on his lack of understanding about what the word 'hospice' really meant.

Barney talked slowly and sometimes in a stilted manner; his wife answered most questions for him. He had some short-term memory loss attributed to his brain metastases and sometimes appeared to 'drift off' midway through conversations. Barney and Eve talked about having discussed some wishes in relation to their deaths following a stroke Barney suffered a number of years ago. Eve worried that Barney did not fully understand the seriousness of his current illness and recounted the impact of her own mother's illness and death upon her and what impact this had on her current thoughts about her own and Barney's future care. She stated she felt that if she had been consulted about her mother's care and treatment she would have had a different experience. She reported discovering that her mother had been given a 'do not resuscitate' order, which she was not aware of. She said 'they don't tell you' and 'a patient is just a patient'. Eve also remarked that she felt the doctors didn't explain what would happen in the future and was dissatisfied with simply being told 'it's individual for each patient'.

Following this interview I reflected on the impact my questions had on both of them. Eve said to me before I left their home that 'I better get it written down' that Barney did not want to go into hospital again.

Even at this early phase in data collection I became aware of the possibility that my questions and interactions with this couple may have caused them to have thoughts they had not previously had in relation to the future. Barney died five months later at home.

Andy

I interviewed Andy, a 73 year old man with a swollen abdomen and ruddy complexion, in 2006. Andy had been diagnosed several months before with advanced lung cancer complicated by a large abdominal aneurysm. He lived with his wife Angela in an older

person's council bungalow. Andy wanted Angela to sit in with him for the interview. Andy reported that he often chatted with his neighbours whom he knew well. He stated he was the 'head' of his family of whom he was proud. He recounted the loss of his 5 month old grandchild, and often in the interview compared this loss that his daughter and son-in-law had to cope with as being far more significant than the future loss of his own life. He and his wife sat close together as we talked. Angela was tearful when recounting the news of his illness. They talked excitably about planning a holiday abroad together and had recently returned from an enjoyable trip to Prague. Andy talked about hoping to see his granddaughter graduate from university.

Andy talked about living one day at a time and not thinking about the future. He'd been told his prognosis was only six to 12 months but wanted to get on and live as normal a life as possible. Angela was quiet when Andy spoke about living for 'now' but her body language suggested she had differing views. I hoped she might share her thoughts in the family focus group she agreed to attend and which Andy commented she 'needed to attend'; he told me later that he felt she had different things she needed to say. Several times Angela said she wanted to know more about what would be available when the time came, but Andy said he didn't want to talk about that. Angela was tearful when she discussed wanting to be prepared for the future but reported during the joint interview that she recognised Andy didn't want to talk about it. Andy died in his own home.

## Candy

Candy, a woman aged 58, lived with her husband Kevin in a bungalow. Candy had until recently worked as a clerical officer. I interviewed them together as they said they did 'everything together'; after 40 years of marriage they had never been apart. Candy was diagnosed with lung cancer and remarked that the doctors had told her they were 'going for a cure'. Kevin talked about them both focussing on taking a positive attitude towards treatment

and the future. Candy reported that talking about the future is 'a hard thing to do'. She was about to undergo a course of chemotherapy as an in-patient at the tertiary cancer centre.

It wasn't until after the interview was over that Candy talked openly about herself and her hobby of making greetings cards which she sold. She appeared to struggle to focus on talking about anything further in the future than her chemotherapy treatment; she did talk about how she felt in relation to her children. She reported that she did not think they realised that, although she didn't 'look ill', she did not have the same capabilities she had had prior to her diagnosis and babysitting their children was difficult for her.

This interview felt difficult because of their joint effort to focus on being positive and avoidance of discussion about the future, although Candy did say she sometimes woke up at night frightened. I was unable to explore any further with them their thoughts about future treatment or options and they did not discuss dying. I was left with the growing awareness, as in the previous interview, that not all patients want to discuss or think about the future. Kevin's attitude about being positive is later played out in other interviews.

Simon

I interviewed Simon, a thin gaunt married man with alopecia, in his home in 2006. He was aged 59 and lived with his wife Kath who worked during the day. He was undergoing palliative chemotherapy following his diagnosis of lung cancer and brain metastases just 3 months earlier. Two of his siblings had died of cancer. Simon and Kath lived in their own semi-detached house in a city. They still had an adult son living at home. Until recently Simon had worked as a teacher of business studies at a local college.

Simon talked about writing a diary in which he kept important dates (including his date of diagnosis); he also used it to reflect on his experiences of having cancer. He talked about

wanting to spend the time he had left with his close family only and expressed annoyance at the intrusion of distant relatives flocking around to offer sympathy. His wife worked, and refused to leave the house without him, other than for work.

During the interview Simon said he didn't want to think about the future, preferring to focus on living for the present. Therefore I was sensitive to this in the questions I asked. He did talk about his experiences of the death of one of his brothers (who died of lung cancer). Simon talked about asking his doctor for information about what to expect in the future, but reported he was scared by the information he received. This experience led him not to ask for further information. Fear of an uncertain future appeared to lead Simon to focus on 'now': the present time; having experienced his brother's death he knew what death looked like.

## Bernard

Bernard was a 59 year old man with a flushed face, gaunt looking and appeared short of breath. He lived in his own home, a cottage in a rural area, with his wife Mary. Both socialised at the village pub daily. Bernard was tearful when I first asked about his illness. He had been diagnosed with advanced non-small cell lung cancer. Bernard expressed his determination to live for 'now' and not worry about the future.

I found it was not possible to interview Bernard and Mary about any thoughts or discussions they may have had about the future, because Bernard was determined to focus on the 'now'. Mary talked about looking at newspapers and searching the internet for any new drugs for hope of a cure.

They both explained that at first they hid the news of Bernard's diagnosis to 'protect' their family but had since agreed not to keep secrets. At a second interview with Bernard where he

had agreed to be interviewed on his own he was suffering from severe side effects from a clinical trial drug. Yet he remained determined to focus on living for the present. Bernard died in his home six months after this second interview.


## Dennis

I interviewed Dennis in his front living room. Dennis appeared frail and was suffering with an infection on his eyelid. He was 73 years old and married to Doris who sat on the opposite sofa to him. Dennis explained at the beginning that he was not much of a talker, so he let his wife speak to him. His physical symptoms of nausea, vomiting, pain and a sore eye were his overriding concerns. He had been diagnosed a year before I interviewed him and also suffered with other chronic diseases. Dennis and Doris lived in a small semi-detached home, where I interviewed them in 2006.

The future wasn't something Dennis wanted to think about. He and Doris had their 50th wedding anniversary coming up. Dennis reported that Doris wanted to plan for a big meal out, but he didn't want her to spend lots of money on it because he would be likely to be suffering with nausea and not able to eat. His wife talked to me after the interview while we stood in the driveway. She spoke about understanding how ill Dennis was, but how she did not know if her husband really understood the severity of his illness. She reported that she didn't know what to expect.

This was one of the shorter interviews because Dennis did not talk much. His wife's body language during the interview suggested some frustration at Dennis's lack of communication. I sensed that the future was not something Dennis wanted to talk about and that his overriding concerns were about his uncomfortable symptoms. I did not therefore pursue questions about the future or end of life care. Dennis died six weeks later in a local hospital.

This interview revealed the different requirements of couples for communicating about the future. Doris wanted to talk, but Dennis did not. This appeared to produce a tension between them.

## Henry

Henry, an ex-publican, was a 60 year old man who lived with his partner Gwen in a semi-detached house. Henry had had what he reported as a 'curative' resection of his lung two years ago. Henry said that he didn't think about his health and reported it was not something they discussed as a couple, nor had he been involved in any discussions with health professionals about his future health care. He said his attitude was to just get on with living here and now – not to be concerned with the future, although planning holidays together was important to them.

This interview was difficult in relation to discussing future preferences for care and treatment because Henry deemed himself cured and did not relate to the research topic. I therefore chose to frame the interview around hypothetical questions but both he and his partner reported they had given no thought to the future in relation to their health.

## Clive

I interviewed Clive alone. We sat at his kitchen table with a mug of coffee. The radio and washing machine were on in the background and Clive's dog was in his basket in the same room. He was a 54 year old man, still an active smoker and very open to talking about his experiences. He lived in a small bungalow with his wife Yvette who was a health support worker at the local hospital. Their teenage son who lived with them was a student nurse. Diagnosed originally six years earlier and having greatly outlived his original prognosis, he now had brain metastases.

Clive reported that his last dying wish was to say goodbye to his faithful cocker spaniel dog who followed him around continuously and kept him company. He talked about wanting to live for today. He also reported having lost two close friends because of his cancer as they didn't want to come near him or talk to him anymore. He had some wishes about the future and had already organised songs for his funeral but reported that no health professionals had asked him about his wishes and he hadn't recorded them; neither was he aware of any health professional recording them. He said he had told his wife that he expected that she would make decisions for him if he wasn't able to.

After the interview ended Yvette arrived home and chatted with us at the table. Yvette reported that following an admission to the local hospice for pain management a doctor had asked Clive if hospice was where he hoped to spend his last days and Clive's reaction was such that he no longer wanted to speak to this doctor. He reported being angry at the doctor's question, asking him about his preferred place of care.

This interview suggested that the amount of time that passes after disclosure of a poor prognosis may have some impact on the person's thoughts about the future. However, despite Clive's openness in talking to me about the future (including recent thoughts about resuscitation, funerals etc), his reported reaction in relation to the doctors asking about future hospice care reveals the difficulties health professionals may face in initiating and communicating sensitively about future preferences for care.

Jim

Jim's first words to me in the interview were 'I'm gonna die', which his lung cancer nurse had warned me might happen. Jim was a 59 year old smoker and was married to Vivienne who for part of the interview sat on the sofa opposite Jim. Their small grandchildren sat playing on the living room carpet as we talked. One of their daughters was preparing food in

the kitchen. Jim and Vivienne lived in a council house in an ex-mining village. Jim reported that he had had four different primary cancers and proclaimed he had outlived his prognosis by 5 years so far.

Jim had experienced chemotherapy and radiotherapy in the past and also reported having a near death experience due to a bleeding ulcer following chemotherapy. Jim talked to me about a secret stash of steroids which he was keeping in case his doctor stopped his prescriptions. He felt the steroids kept him going. He talked about wanting to die at home, but he also stated that after having discussed this wish with his wife he had come to a compromise, to die in the local hospice. Jim had sorted his will and told his GP he did not want resuscitating. He had a district nurse which he said was to support his wife rather than him who acted as a contact for him in case he needed it. He stated he felt 'dropped' by the hospital because he had no further regular follow-up appointments.

This interview adds to the previous one in that both Clive and Jim had outlived their prognosis by some considerable time and the time lapse since diagnosis was much greater than for the other participants in this study. This appeared to have given them both more time to consider the future and to have had some discussions with their partners. These two appeared to be 'negative cases'. Jim died at an older persons' hospital some months later.

Ruby

Ruby was a 79 year old widow who used continuous oxygen via nasal prongs following a recent hospitalisation for a pulmonary embolism. Ruby had been diagnosed with non-small cell lung cancer. She lived alone in an older people's council flat that was scantly decorated and had a stair lift to the upper floor. The flat was situated across the road from her local health centre. She reported she had a 'nosy' neighbour who frequently popped in uninvited.

Her daughter, Gill, who cleaned and visited her during her lunch breaks from work, popped in as I was interviewing Ruby, but sat in the kitchen until we had finished.

I interviewed Ruby alone in her front room. Ruby announced fairly early on in the interview - almost as a warning to me that she didn't want to know her prognosis. Ruby did not consider there to be any options for her future treatment and care and suggested she would have whatever treatment the doctors suggested to prolong her life. Ruby talked about relying on her doctor's decisions in relation to her future treatment.

In this interview I introduced an information card (mentioned in the previous chapter) part way through the interview, which I asked Ruby to read. The aim of the card was to focus our conversation more directly on the participant's discussion about wishes and preferences for the future. In introducing this information card I realised I might be taking a risk that this could be new information for Ruby and consequently the reaction which followed – 'bringing things too close' caused distress for Ruby and for me. I chose not to 'risk' using the information card with future participants. I have written about this in more detail in chapter two and the following chapters. Despite Ruby's distress at having to think about her future she did mention her wish to die at home, which she reported having told the district nurse, but interestingly not her family. She had not recorded any wishes so far. This interview built on previous participants' reports of not wanting to discuss the future because of the fears it held for them.

## Dan

Dan was a thin, ashen man of 75. He was married and lived in a semi-detached house. He was diagnosed with mesothelioma. I interviewed Dan alone at his request, although his wife was in another room during the interview.

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Dan coughed occasionally during the interview. He explained he was on morphine for chest pain and he was now able to sleep 6 hours a night. He talked about losing his independence in relation to driving his car. He was an avid train enthusiast – having been a trainspotter as a child. He had been a miner for 30 years, which he explained he did to avoid being called up for the army. Following pit closures he then became a coach driver until he retired. However, he still worked part-time, along with his wife, welcoming customers at a local superstore.

During the interview Dan talked about his life and his decision to stop chemotherapy because he didn't want to 'feel ill' for his cruise. He reported that the doctors told him they didn't know how long he had to live. Dan talked about his desire 'to make hay while the sun shines', therefore, he was planning to take another holiday shortly. He was also making plans for practical adaptations to his home such as a stair lift to make life easier for him and his wife. He died at home just 4 weeks after this interview.

## Stewart

Stewart was a 60 year old widower, orphaned as a young boy and whose wife had died of leukaemia in an intensive care unit. He already had a diagnosis of laryngeal cancer and had been more recently diagnosed with advanced lung cancer with metastases. Stewart preferred to be interviewed away from his home so we met in the local chemotherapy counselling room.

Stewart talked about his feeling that discussing the future was morbid and that he preferred to focus on living 'a day at a time', believing if he got up in the morning that was a bonus. He trusted the doctors to do what's best for him. Because Stewart preferred not to discuss the future I was unable to pursue questions about dying. He reported no time was right to have these types of discussions.

Stewart had strong views that patient choice was a political ploy of Mr. Blair (prime minister at the time) and had the opinion that hospitals were a limited resource and keeping people alive or allowing patient 'choice' would not make best use of this resource.

It was only after the audio tape was switched off at the end of the interview that Stewart talked about his experiences of his wife's cancer and talked about the doctors having asked him if he wanted his wife resuscitating. He reported how he and his son discussed the decision but he had decided 'no' to resuscitation and she died. He perceived the hospital where his wife died to be short of beds and added that resources are needed where there was a hope.

This interview added to others in which participants discussed their experiences of witnessing family members experience cancer or dying which appeared to influence their own reported feelings and attitudes towards the future, and dying. Also like many others Stewart talked about the doctors knowing what was best for him and wanting to leave medical decisions in their hands. What was unique about Stewart's experience was his rationale about limited health care resources in relation to care of the dying, perhaps influenced by the decision he made on behalf of his wife. Stewart died in the local hospital a year later.

Burt

I interviewed Burt in his home, alone at his request. He was small, quietly spoken and aged 64. Burt's medical records revealed he had been diagnosed with advanced non small cell lung cancer and also had other chronic diseases. He lived in small council/ex-mining home in a deprived area of the town with his wife who worked mornings. Burt was short of breath at times during the interview. Burt recalled playing with asbestos as a child and working as a miner in the local pit.

Burt told me he wanted to live a day at a time and did not want to plan ahead. However, unlike other participants, he talked about wanting to know his prognosis, but didn't want his wife to know. He reported that his wife was always present at his clinic appointments and also opened all the mail, which impacted on his ability to have a private conversation or arrange a private appointment with his doctor. Burt had gained a sense of his prognosis from an American television programme.

Burt talked about being frightened of how he would die and was especially concerned about whether he would be gasping for air as he died. He reported he would do anything the doctor said and would not think of refusing any treatment. Burt said *he* would decide what he accepted, but his wife could decide once he was incapacitated.

This interview added to the growing evidence that many patients do not want to plan for the future and prefer to live a day at a time, and that some harbour fears about dying. In contrast to many other participants, Burt reported that he had not been informed of his prognosis and had not asked for it, perhaps in part influenced by his need for confidentiality. Burt died three months later in the local hospital.

## Mabel

I interviewed Mabel, a thin lady aged 66, in her conservatory. Her husband was in the house but remained out of sight. Mabel lived in a semi-detached home in an ex-mining town. She was diagnosed with non small cell lung cancer in July 2006 and also suffered with arthritis. Despite appearing to be in pain Mabel remained talkative and told her story in detail about the impact of her initial diagnosis and of subsequently suffering from depression.

Mabel talked about her family and friends who had experienced cancer and about her family being supportive of her keeping a 'positive attitude'. I was unable to use questions

which sought to explore her thoughts about the future in relation to dying in any depth because she became tearful and left the room for a tissue. When she returned, having given consent to carry on, she described a bad experience of radiotherapy treatment and said her wishes about treatment had changed since her diagnosis. She explained that whereas previously, prior to her diagnosis, she would never have thought about having chemotherapy she would now go for 'any treatment' to save her life.

Mabel talked about struggling to understand her friend's attitude (who also had cancer), feeling that her friend had given up on life. Her expressed hopes were to plan a holiday for the coming year if she could arrange health insurance cover.

During the interview Mabel expressed some information needs. Following the interview I signposted her to relevant health professionals and agencies to support her needs. At the time of the interview I felt this conversation gave minimal insight into answering my research questions. In comparing this participant's views with others, there were similarities in their reports about needing to 'keep positive' and to plan enjoyable activities. Planning enjoyable events such as holidays appeared to help them to manage their future. Mabel died in the local hospital six months after this interview.

## Paul

Paul was a 73 year old man who, in spite of his lung cancer diagnosis, still worked night shifts as a heavy goods driver. He chain smoked during the interview. His lung cancer and possible metastases had been found by chance on a chest X-ray following a chest infection. Paul lived with his wife Shelly (who also smoked) and their little cat in a small 2 bedroom mid-terraced house. During the interview they told their story together, often finishing each other's sentences. They talked about their daughter who was training in alternative therapies, and

Paul explained that he was looking at herbal treatments as an alternative to surgery, having refused surgery because he saw no point in being 'made ill' when he didn't feel ill now.

He reported being upset by the surgeon's arrogance and feeling 'forced to make a decision' about surgery at the time of his clinic appointment. Both he and his wife talked about the experiences of watching others affected by cancer and how others' cancer treatments had not 'cured them' but made them ill. He claimed cancer was just 'a word' to him, suggesting it had no power over him. Within weeks of the interview he was hospitalised having fallen and fractured his hip.

On reflection, this interview highlighted the following: the influence of a doctor's communication and attitude on patient discussions about future care and treatment; the experiences of watching others who have lived with and died from cancer and the importance of feelings in relation to perceptions of illness and dying.

Mary

Mary was aged 81, widowed and lived alone in a council bungalow with her little terrier. She had been diagnosed with non small cell lung cancer and was offered radiotherapy, but had declined. Mary had been the third wife of her late husband, and she had a stepson whom she had not seen since her husband died. She had buried her husband next to his second wife to please the son. Her nearest relative was a cousin who was like a sister to her because they grew up together. Her mother and father had died when she was a child. Her remaining brother lived in the west of England and suffered with dementia.

During the interview Mary reported her desire not to have any treatment as she didn't see any point in it. She did not want to think about the future; if she did, she could not sleep at

night. She became tearful when talking about her diagnosis and appeared to be trying hard to control her emotions during the interview.

Mary reported (almost with annoyance at the knowledge) how she would not have known about her diagnosis of lung cancer had it not been found by chance on a chest X-ray during admission for a probable myocardial infarction. Despite Mary's desire to not discuss the future she did report that she had made plans for her dog after her death because she believed it was unkind to have a dog put to sleep just because its owner died. Mary had also been to the bank to put her finances in order and she had made a will. She hoped to see her 82$^{nd}$ birthday.

George

George was a 65 year old man whose face appeared ashen and whose abdomen was grossly distended. He was a retired electrician who classed himself as a professional and was 'high up' in his industry. George lived with his wife in a privately owned bungalow with their own vegetable garden. I interviewed George with his wife. He had been diagnosed with mesothelioma in the previous year and more recently had been found to have abdominal involvement.

George's family appeared important to him. Family portraits covered the lounge and hall. He reported that his family, despite living in the south of England, visited him every two weeks. George's main concerns were for his family. He reported, when his wife left the room, that he had avoided talking with his family about the future, keeping any thoughts about dying to himself, because his wife didn't want to think about what might happen in the future. However, he reported that very recently (only in the previous week or so) since 'becoming ill' he had talked to his wife about funeral arrangements. He talked about quality of life versus longevity, which for him meant time with his family, holidays together and not suffering in front

of his family. He also admitted having had thoughts about euthanasia to prevent his family witnessing suffering.

Although a self-confessed planner, having always made 5 year plans because of his belief that you get more out of life than by living one day at a time, he reported he had not discussed plans for the future with any health professionals.

He talked about understanding the pressure doctors are under, with crowded waiting rooms and the influence this has on the amount of time allocated to individual patient discussions. He had chosen to access private health care because NHS health care could not offer him treatment. He talked about his loss of faith in 'traditional medicine' following his doctor's wrong prognosis that his osteoporosis would cripple him (he had sought nutritional advice and to date had not been disabled by osteoporosis) and his unsuccessful treatment through a clinical trial. His latest aspiration to control his disease was by nutritional management, which he believed gave him a better quality of life. He reported his doctors could not believe how well he was.

I felt the interview went well even though I had been anxious because of my knowledge that he had a very poor prognosis and that he sounded quite breathless on the telephone - I was conscious the interview might tire him. He thanked me for visiting him and offered me some books on nutrition. Interestingly, at his next clinic appointment several days following this interview, his lung cancer nurse reported that he had asked her and the consultant oncologist about services he needed for the 'terminal phase', which suggested that the interview might have acted as a catalyst, causing him to reflect on future needs. However, his request may have met with resistance as his nurse reported that she had told him 'you're not *there* yet'.

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George died in the local hospital just 4 weeks after the interview following admission for management of gross abdominal ascites. Although he was offered hospice care on the morning of the last day of his life, his condition had deteriorated to such an extent that his family chose for him to remain in hospital. Interestingly, on examining his medical notes, it was recorded that he asked for a 'do not resuscitate' order within days of this last admission and although queried by his junior doctors this order was signed by him and agreed by his consultant.

## Bob

Bob, aged 69, had a diagnosis of small cell lung cancer diagnosed several years previously and a more recent diagnosis of brain metastases. Bob had received treatment in a clinical trial that included radiotherapy to his lung and brain followed by chemotherapy. He now had thinning hair and a yellowy ashen complexion. I interviewed him with his wife. He was a retired steel pole erector. He and his wife lived together in a privately owned bungalow and both enjoyed watercolour painting.

Bob and his wife reported frustration and anger at: waiting around for appointments; past and present poor experiences of Macmillan nurses; experiences of losing a daughter to breast cancer and also one of their mothers to cancer. They also reported annoyance at not being informed until recently about financial support available to them during treatment.

This interview was marked by past experiences of perceived poor support from service providers for family members with cancer and a reported feeling that they had coped on their own before so didn't need any help now. They were both guarded in answering questions about the future and Bob reported not wanting to discuss the future. He also expressed the view that his wife talked too much to others about his illness.

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This interview highlighted again how past experiences of others' illnesses influenced perceptions and feelings about future care, and poor communication with health professionals created a lack of trust.

Vicky

Vicky, a 79 year old ex-shop worker, had been diagnosed with advanced lung cancer. Eddy, Vicky's husband, was 80 years old. I interviewed them together in their privately owned bungalow. They had lived in the same village all their lives and their fathers had both been miners. Vicky, who appeared ashen and in the final stages of her disease trajectory, had a distended abdomen, laboured breathing, and she was lying down on the sofa resting when I arrived. Eddy explained their roles; Vicky was the person who looked after the inside of the house and Eddy the outside.

Vicky, whose main concerns were for her husband and how he would manage after her death, was tearful at times during the interview. She talked about the future and her efforts to try to help Eddy not to worry about how he'd manage without her. Vicky had been teaching him to vacuum and her efforts at teaching him to cook had resulted in burnt offerings. They said they had talked together about finances (Eddy was worried about finances), funeral arrangements and her final place of care. Eddy was frightened to leave Vicky in the house alone.

This interview added to a growing notion that participants perceived that talking about the future meant talking about death itself, rather than the time between then and death. Vicky said she would ask her doctor what dying might be like, but I was left with the impression she wouldn't go through with this. As with others interviewed, the concern for family appeared to be a trigger for making plans for after death.

Five weeks following this interview Vicky was admitted to the accident and emergency department (the documented reason for admission being her husband's reported inability to care for her at home) and seven days later she died in the local hospice - although her previous wish had been to die at home.


Colin

Colin, aged 78 and an ex-machinist, lived in a privately owned terraced house with his wife. They had lived in the same village for 30 years. He had not left his house in 11 weeks. They had 4 children and one of his daughters lived across the street and acted as a 'babysitter' when his wife needed to go out. He had been diagnosed with inoperable non small cell lung cancer two years previously and had experienced oral cancer ten years prior to that. He had received chemotherapy and radiotherapy treatment following diagnosis. Colin also suffered with diabetes and chronic obstructive airways disease. He sat sleepily in his chair by the window in the front room, occasionally coughing and speaking with a raspy voice, a nebuliser by his side and his right hand visibly shaking as a result of his more recent diagnosis of Parkinson's disease.

I interviewed Colin with his wife who rarely left his side and who acted as his main care-giver, often getting up three or more times in the night to attend to him. Colin's wife corrected him several times during the interview when she thought he had got his facts wrong and explained to me as I was leaving their home that he sometimes got 'muddled'.

The main issues raised by Colin and his wife were their anger at the doctor's wrong prognosis. They explained that Colin had been given 2 days to 2 weeks to live last Christmas Eve and he was still living. They explained that they had inadvertently found out the doctors prognosis when the district nurse visited to provide 'end of life' care. Colin explained that since then he had lived a day at a time, not being able to plan for tomorrow because he didn't

know what to expect. He planned his day when he woke up and saw how he felt. However, his wife reported their daughters were planning their 50th wedding anniversary celebration which Colin appeared apathetic towards.

They reported that their health professionals hadn't discussed the future with them or options for future care and treatment but their GP of over 25 years - who had a straightforward attitude and made use of jargon-free language, would be the person they would approach if they needed too.

This interview added to other participants' experiences where again prognosis appeared unsolicited and provoked feelings of anger when the patient outlived the predicted time. The hospital physician's lack of direct communication about the future had a profound effect on this couple causing them to 'lose faith' in him. Colin's inability to plan ahead appeared related to his perception of an uncertain future, with a reliance on his feelings each day to determine, what, if any, plans he made for the day. Colin died at home six weeks following this interview.

## Doris

Doris, aged 61 and a health care assistant at a local care home, had been diagnosed with lung cancer earlier in the year with a more recent metastatic spread. She had received radical radiotherapy initially and more recently palliative chemotherapy. Doris and her husband Ted, who lived in their own semi-detached house in a tight-knit mining community, sat close to each other on the sofa in their front room surrounded by large framed photographs of their family. Her grandchildren, Doris explained, were being those she did not want to leave behind. Doris appeared well, having recently returned from a holiday abroad.

Doris talked about not wanting to be informed of 'bad news', she had seen "enough at work" and didn't want to know her prognosis. Both she and her husband worried silently, but

didn't discuss it with each other or their children because they wanted to protect them. Doris said she didn't like the way her daughters fussed and looked at her. Interestingly, the information letter about this study had prompted Doris and Ted to wonder if the invitation to take part in the study meant Doris was 'sicker than she felt'.

Doris reported being upset because her lung cancer nurse hadn't visited or checked on her. Similarly, she reported being annoyed at the doctor in the clinic as she still had unanswered questions about her response to treatment and couldn't plan because she didn't know how successful or not the treatment had been. Doris and Ted reported that options for future care and treatment were not raised by their health professionals.

Some of the issues raised in this interview add to those previously described by other participants such as: doctors not explaining, doctor-patient communication, not wanting to know the prognosis, inability to plan and concern for family. This interview also raised again the sensitive nature of interviewing patients with advanced cancer and the possibility of 'doing harm' by introducing new information that can cause participants to worry about the severity of their illness.

## Shelley

Shelley was a 48 year old ex-health care technician who lived with her self-employed husband in a large private home in a small village community. Diagnosed with metastatic lung cancer in February, 2007 followed by chemotherapy, she continued to work part-time to support her husband in his work and as a homemaker caring for two teenage children.

The main issues raised by Shelley were: not wanting to discuss the future because of concerns that her family would not want to 'face it' and not feeling it was the 'right timing for them'. Her decision to have one type of chemotherapy over another was reported as being

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based on the likelihood of alopecia, wanting her illness to have minimum impact on her family. Shelley had been thinking about her future but had not opened up discussion with her family 'yet' – not until she feels unwell; preferring to leave it that way. However, she talked about secretly tidying and sorting her photos – when her family were out of the house, sorting payment of bills onto standing orders and making other practical arrangements for her family in anticipation of her death. Planning holidays away with her family or with girlfriends was also important.

Shelley had been given a prognosis of just eight months to live, which she thought she remembered asking for. She reported on the trauma they experienced as the news was broken to her and her husband. They had been seated away from each other with a table which acted like a barrier. Shelley recalled that following the disclosure of a prognosis, her husband tried to bargain with the lung cancer nurse for more 'time'. Also Shelley had wanted to ask the doctors about the progress of her disease, feeling if she knew the worst she would be able to beat it, but had not wanted to ask in her husband's presence.

This interview added a richer description of the way that concern for family well-being and keeping family life 'normal' prevented open discussion about future care and treatment. The possible timing of discussions about future care linked again to feelings of wellness or illness. Similarly, the emotional effect on the patient and family of being given a prognosis was again recounted.

Edward

I interviewed Edward, an 85 year old man at the beginning of 2008. He had been diagnosed two months previously with lung cancer and another primary tumour. Edward also had chronic obstructive airways disease and chronic renal disease. He had been a widower for six years, his wife having died suddenly from an aneurysm, and he recounted how he

would never get over the shock of losing her. They should have celebrated their 60th wedding anniversary three months following her death. Edward lived in a small one-bedroom council bungalow. He related his 'breathing problems' to thirty years of being a miner. He had an oxygen concentrator and nebuliser equipment next to him.

Family photos adorned his shelves and cupboards. He had one daughter who he involved in decision-making and a son who looked after his finances. Edward told me he had written a will and sorted out his finances but had no other plans.

Edward appeared stoical in his attitude and did not talk openly about the future. He said he was 'in limbo' in relation to treatment for his breathing and didn't perceive there were any options for treatment of his lung cancer because of his underlying chest problems. In the interview I sought to further explore the concept of 'living a day at a time' (as some other participants had discussed), but Edward discussed that he did not live one day at a time and planned to live a 'long time yet'. However, he talked about how, if he opened his eyes in the morning, he knew he was ok that day.

## Morris

Morris, aged 79, lived in a portable home in a small hamlet in a rural area on the outskirts of the study setting. He lived with his female partner and an 'adopted cat'. He had been diagnosed with advanced non small cell lung cancer with possible metastases and had also been diagnosed with bladder cancer the previous year, for which he received radical radiotherapy. He also had other chronic conditions. Morris and his partner had relocated from eastern England several years ago, wanting to consolidate their finances. Morris arranged with me to interview him while his partner was out at a dental appointment.

Morris was pale and breathless. He had his oxygen cylinder placed next to him, but he did not use it during the interview. For the past few weeks his increasing breathlessness had inhibited his ability to leave his home. Morris did not discuss his prognosis or allude to dying and therefore our conversations centred on his experiences of living. He talked about how if he felt well in the morning he would do things and if he didn't he wouldn't. His only plans for the future were for a holiday. He also talked about leaving medical decisions to his doctor and hoped the treatment he had would keep his cancer stable. The impression I was left with was a trust in the medical system to inform him about the management of his disease and make the best decisions for him.

This interview added to some of the other discussions by building on the idea that some patients do not perceive their disease and planning for the future as important, but rather concentrate their energies on living for the present, for now.

Bernie

I interviewed Bernie with his wife Jane in 2008. Bernie was a 55 year-old ex-bus driver and his wife managed an after-school club. Bernie had been given a diagnosis of lung cancer four weeks prior to interview in addition to a more recent diagnosis of pulmonary fibrosis. He also suffered with other chronic respiratory diseases. Bernie and Jane lived together with one of their four daughters in a privately owned bungalow and had been married for over thirty years. Large family photos were displayed on the walls of their living room. Having been given the option for my interviewing him alone Bernie said they had no secrets between them and preferred being interviewed together. They were both articulate and talked openly with little prompting throughout the interview.

Bernie and Jane talked about the difficulties of timely access to financial support for practical needs, in particular to adapt their bathroom to support Bernie's independence in

showering, and their concern at having to rely on future pension funds to pay for this. They talked about when they needed practical help, they needed it 'now' not in four to eight weeks time.

Bernie was quite adamant about not wanting to know his prognosis because he said otherwise he would be watching and waiting for 'it' (death). He stated that discussing the future was frightening and upsetting. However, he talked about thinking about his future in relation to funeral arrangements, putting the house, car and finances in Jane's name and preferences for resuscitation, which he'd discussed with Jane and his daughters the weekend before this interview. Jane said she was pleased that they'd discussed this with their daughters because she did not want them to think it was her idea to decide about resuscitation – she wanted them to know that this was Bernie's own wish. Bernie said his attitude was to 'be positive' – looking forward, planning holidays and creating memories together, suggesting this was his way of coping with an uncertain future. His concern for his family appeared the overriding principle governing the plans he had already made and his desire to live life to the fullest. He wanted Jane to carry on work as normal and for her and his daughters to treat him as 'normal' without fussing over him. He said life wasn't normal now – his pulmonary fibrosis had taken that away from him, but said he pushed himself to do things '*as* normal' otherwise he would just curl up and die.

Jane talked about the differences between caring for a parent who had died of cancer and now caring for her husband. She also perceived that sometimes others might think she came over as being 'hard' when she talked frankly about Bernie's illness, but talked about how sometimes she had to escape because she couldn't discuss or think about what's going to happen in the future.

I noted in my field notes following this interview:

*"I felt I had been given a real gift by Bernie and his wife in their openness and honesty with me – sharing deep feelings with me. Both were tearful about wanting to create memories together – not wanting to know a prognosis and concerns for each other. I felt like everything they said 'glued the pieces of the puzzle together'."*

I believe this interview was a real 'gift' to me on several levels. Firstly, I felt honoured that Bernie and Jane had been so open in sharing their thoughts and experiences with me, a stranger in their midst. Secondly, many of the issues Bernie and Jane talked about (with little prompting) solidified my thinking in relation to gaining further insight into the substantive categories and the interrelationships that were emerging from the interviews with the other participants. Thirdly, they remarked at the end of the interview that they hoped that I had found the discussion useful in helping others but that it had also helped them to discuss things openly.

## Summary

These 25 pen portraits have helped to introduce the people whom I interviewed and describe how the theoretical interpretation of the findings began to emerge. Each interview shaped the next, and later interviews provided a mirror of the earlier ones. The field notes from which these portraits were derived contained my feelings, observations within the home, intuition and reflections shortly following each interview. From a methodological viewpoint these contributed to the overall development of the core categories alongside the analysis of the participant interview transcripts by supporting the comparative analysis. Looking at similarities and differences between participants' stories, lives, circumstances and experiences helped shape the resulting categories without which the richness of detail would be missing.

# CHAPTER 4 : INTRODUCTION TO FINDINGS AND 'FACE DEATH WHEN IT COMES'

## Introduction to findings.

The findings from the interviews with patients with lung cancer and family members are presented in the next four chapters. Each chapter reports on one of the four substantive categories that underpin the theoretical model - maintaining integrity in the face of death (figure 4.1). The four substantive categories are: 'face death when it comes', 'planning for death, not dying', 'only months to live' and 'clinical discussions about the future'. The category 'face death when it comes' relates to the two bold blocks at the top of the diagram (living in the present and facing death). In addition, 'face death when it comes' and the remaining three categories presented in chapters five, six and seven relate to the bricks balanced on top of the see-saw in figure 4.1. 'Acting and talking', 'knowing about death' and 'family' are theoretical concepts that have been developed to help explain how people experience living in the present, whilst facing death. Chapter eight will offer the detail of the theoretical model and a critique of the theoretical interpretation against available literature.

The findings chapters start with an overview of the category, followed by a case study providing an overall description, and further descriptions of the properties of that category using participants' reports, illustrated with participants own words.

Figure 4.1 Theoretical Model: Maintaining Integrity in the Face of Death.



**Maintaining integrity in the face of death**

Living in the present

Facing death

Work

'Don't feel ill' Attitudes

'Carry on as normal' /' Day by Day'

Don't discuss future Don't think about future

Concern for family Practical plans

Knowing prognosis

Discussing future Wishes for future

Acting and Talking

Family

Knowing about death
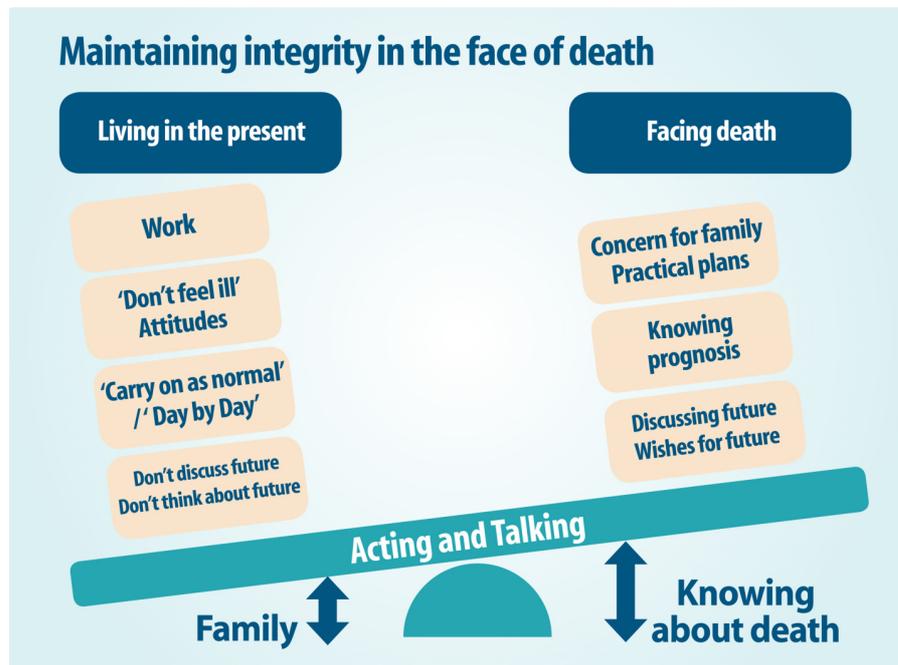
## Introduction to 'face death when it comes'

The remainder of this chapter presents the first of the four substantive categories. I have used category codes to illustrate the findings and conceptual diagrams, which has developed my conceptual thinking. These are used in each chapter along with an illustrative case study to assist me in reporting the findings.

## 'Facing death when it comes'

Planning for one's own dying and eventual death was not something that people with lung cancer report having discussed except (as will be reported in the following chapter) when practical arrangements needed to be made following death. Much of this relates to their apparent desire to focus on living in the present by 'carrying on as normal' whilst they didn't feel ill and taking an attitude of facing death when it comes, delaying death as long as possible. For most of them, facing death included neither dwelling on what dying and death

might be like, nor discussing dying openly with others, because to do so was perceived to bring fear and "doom and gloom".

Some family members talked about their experiences and views during the joint interviews and these were often similar to the patient participants' views, but some family members during the group interviews expressed other or differing views which will be discussed later.

The following conceptual map (figure 4.2) shows the main categories within the substantive category of 'Face death when it comes'. The categories labelled in normal font depict what people with lung cancer talked about in relation to their illness and their future, for example: being fearful, thinking about the future, feeling that knowing was worse (in relation to their illness), not wanting to talk about what they perceived as morbid talk and also reporting they did not feel ill . Categories labelled in bold font represent the ways they talked about how they attempted to put off or delay their death (or control the uncertain future) such as by "carrying on as normal", living "day by day" and not discussing their future.

Figure 4.2 Conceptual map: Face death when it comes
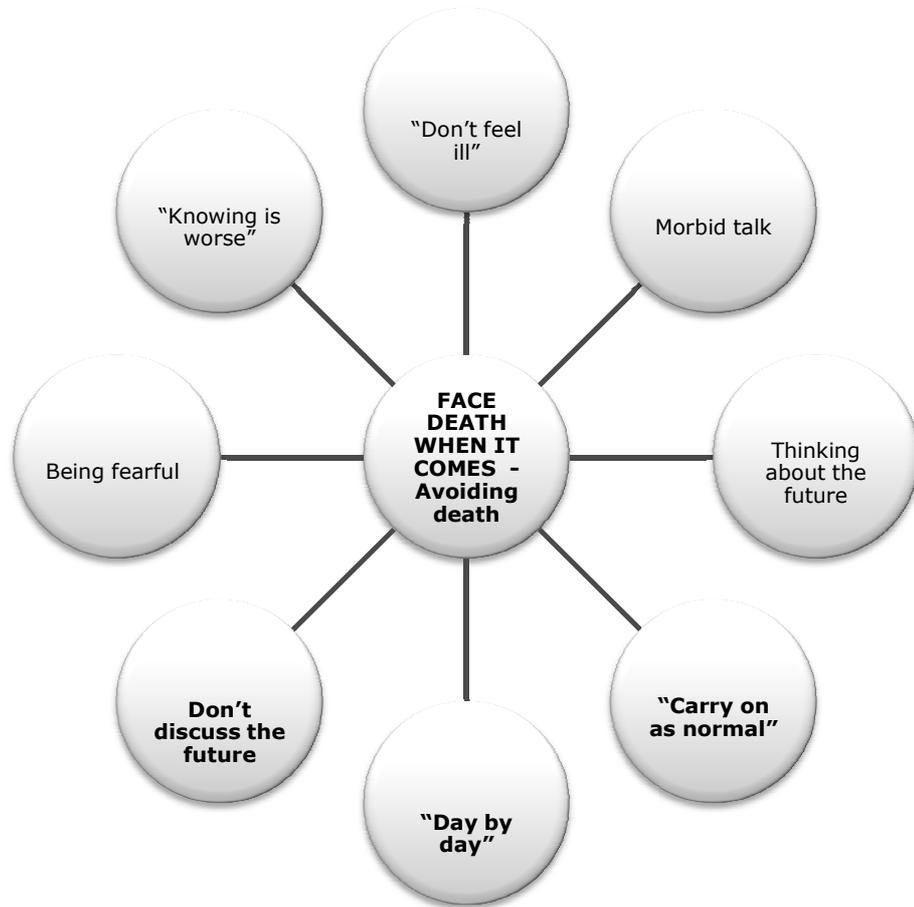


The following case study provides the reader with an overview of the core category 'face death when it comes'. Following this case study the similarities and differences from other people's reports will further enhance the descriptions of this category and suggest possible relationships between the various aspects of 'facing death when it comes' and not before.

## Case study

Bernie, who we met in the previous chapter, had been working until recently as a bus driver. He lived with his wife Jane and a teenage daughter in a bungalow. Bernie had been diagnosed with lung cancer four weeks prior to interview. I interviewed Bernie and Jane together at Bernie's request.

Bernie talked about his understanding of his chronic condition and the news of lung cancer diagnosed during a recent exacerbation of his lung disease. He talked about his hospital experience, of how he was investigated, prepared for the bad news of his cancer diagnosis and the fact that he could no longer remain on the lung transplant waiting list. He recounted how his attitude had been from the beginning: to 'cope' with his illness was to think he still had a chance, to look forward and "get on with it" (life) as normal.

Unlike most of the other people interviewed in this study, Bernie did not talk about not feeling ill. Nevertheless, like others he talked about not focussing on dying, but on living:

> Jane: "But Bernie's got the attitude of, well I've got it, can't do anything about it."

> Bernie: "Might as well get on with it. When you haven't got a chance it, we know I can't go back to what I was before, so you have to accept it and get on with it as best as you can or just go and die in a corner somewhere." (p.6, L25)

He talked about not wanting to receive sympathy from his family, which would make him feel worse, but preferred to work for his living, even if this work was now different:

> "They're both good girls. If I want owt I've only got to ask. But I don't want them coming simpering round me because that's going to make me feel worse because I'd rather do it myself. The same with Jane I don't. I do want her pandering to me to a degree but she's still an independent person aren't you?" (p.22, L17)

> "It's like I said to Jane, like it were yesterday or the day before, whenever. I got up, got perching stool in the kitchen, so I'm sat at the sink washing the pots. It's easy to sit down and dictate to everybody else because youngest daughter still lives at home, go and make us a cup of tea, do this do that. I want a biscuit with my cup of tea. It's easy when they're out just to get up and go and get a couple of biscuits and a cup of tea. And I thought well I'm eating these things and I'm getting up, if I can get up and do them I'll sit on the perching stool. I'll earn them two biscuits. Make myself work a little bit for it, just push myself. If you like it's just a target, a reward for doing something. It sounds silly and it is in some respects a bit childish but it gives me something if you like to focus on, if you understand that." (p.18, L14)

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Not thinking about the future helped Bernie and Jane avoid becoming upset. Being in hospital or talking with the lung cancer nurse about his illness or the future caused them to think about the future, feel scared and fear losing control:

> *Jane: "So therefore the times when it seems to hit home to me are, now I don't want you to get, you know, or like when such as yourself come and talk to us or Lung cancer nurse or when we go to the hospital that's when I start thinking, you know, and that is when I get more upset."*

> *Bernie: "I've been getting emotional myself."* (p.29, L1)

> *Bernie: "When you haven't got a chance it, we know I can't go back to what I was before, so you have to accept it and get on with it as best as you can or just go and die in a corner somewhere. To be honest with you both of them frighten me, you know. I can't say I'm looking forward to it either when you've got, I've still got a lot to live for."* (p.6, L25)

Although Bernie talked about never being normal again he wanted to carry on 'as normal' for as long as possible. 'Normal' for Bernie meant protecting his family, which was part of his work. Bernie explained this with reference to someone else with cancer who he met during a recent stay in hospital:

> *"You've always been there for your family you protect your family that's what you're there for and he's in a hospital having his family running round after him and he can't do his job and that's it. Really that's what it boils down to and you feel totally, totally lost".* (p.31, L12-16)

To be able to live 'as normal' Bernie reported that he did not want to know how much time he had left to live or this would be worse for him. He and Jane talked about not wanting to discuss the future and Bernie expressed the view there was 'no point' in discussing 'that side of it'. The exceptions to this were making sure there were no problems for his wife:

Jane: *"I tend to the proverbial ostrich with their head in the sand. That's the way sometimes I can only cope with it."*

Interviewer: *"Actually quite a lot of people have said to me that they cope by not discussing the future."*

Bernie: *"Or discuss it if you want to but not that side of it that's all."*
(p.29, L6)

In addition, Bernie talked about 'normal' meaning his family not treating him any differently than before his diagnosis. He talked about Jane and his family also carrying on as normal with their work and not fussing over him. Bernie talked about 'keeping it real', suggesting a mutual dependence on each family member to help life carry on as normal, as he describes below:

"*It's not normal no, and life's not going to be normal for me or for her ever again, but I want it as normal as I can possibly make it. Not only for my sake, for her sake and for my girls' sake. That's what it's all about. If they don't keep it real, I can't keep it real. And if I don't keep it real, they can't. I don't want them coming in saying do you want a cup of tea dad or do you want this dad, can I do this dad, I don't want that they've never done it in their lives have they?"* (p.22, L12)

Bernie reported that he set himself targets to achieve, like fetching his own cup of tea, and talked about having to push himself to do things and earn his way. He also talked about his view that ultimately what he was trying to do was come to terms with things changing, which had been brought about by his illness. He also reported an attitude of looking forward, the right way, not back.

Jane talked about being strong for Bernie and like him she also reported not wanting to discuss the future. She reported not being able to talk about the future because she could not "handle it", although like Bernie she did report some things they had discussed together in relation to arrangements after his death.

In summary, the key issues presented in this case study were that Bernie reported feeling better able to cope with his impending demise by 'carrying on as normal'. This sometimes required a day to day effort, and required 'work' on his part, which supported his role as the family protector. Despite reporting some thoughts and wishes about the future, he talked about not discussing the future in relation to dying and having an attitude of looking forward and getting on with life that enabled him to 'cope'; he saw the alternative as "*curl up and die*".

I will now report in more detail on each of the categories in this substantive category 'face death when it comes', by providing examples from other people with cancer who were interviewed in this study. In addition, I make reference to the diagram in figure 4.18 (a continuum for discussing the future) available at the end of this chapter, to illustrate how people's reports about thinking and discussing the future appear to oscillate along a continuum.

## 'Face death when it comes'

People with lung cancer reported that they would face or deal with "it" (death) when the time came, when it actually happened and that "it" was not something to face then or worry about then. For example Doris, a 61 year old health support worker, talked about not being able to pre-empt what might or might not happen. Doris talked openly in the interview about her diagnosis and experiences of cancer treatment. When asked later in the interview about who she would discuss concerns for the future with she said she did not want to be talking about the future. Death was a road people did not want to go down (Figure 4.3:1) and worrying about death was something to do when death arrived. In the meantime people worried about waking up in the morning. For many, facing death was seen as too frightening to consider, as I will report later in this chapter.

One person's views did not concur with others. Vicky, a 79 year old ex-shop worker who was interviewed jointly with her 80 year old husband, talked about "it's got to be faced, it will come", suggesting that death for her was inevitable. Vicky was very frail at interview, and died five and a half weeks later, in contrast to most of the others who lived longer. In contrast to his wife, Eddy wanted to 'hold back' death. The other three people with lung cancer who died within four to six weeks of interview (Dennis, Dan and Colin) did not talk about facing death, but rather about facing each day as it comes.

## 'Don't feel ill'

Eighteen of the twenty five people with lung cancer talked about their feelings, especially in relation to feeling fit and not feeling ill, therefore doubting their diagnosis or that death could happen soon. Shelley, aged 48, was still working part-time to support her husband's business. She had been talking to me about doing as much as she could to plan for her burial so her husband and sons did not have to manage that, but also about how she did not feel ill, therefore didn't think 'it' (death) could happen soon (figure 4.3:2 and figure 4.18, box 4). In addition, Shelley reported how her friends told her she was brave to be thinking and planning for her death, but she said she questioned whether she would be so brave if she felt ill (figure 4.3:3).

Figure 4.3 Face death when it comes

1. "*And I just think if I get to be poorly, I know myself if I'm poorly and I'm going to think to myself yeah things need to be, I'll do it then. But at the present time I feel okay and I'm not going to be discussing what's going to happen if I die or God knows I don't want to go down that road, not as yet anyway, no I don't*". (Doris, Joint interview with husband Ted, p.25, L8)

2. *"My friends all find it really strange and I think I'm dead peculiar because I can talk about it and I can, I mean one of my friends knows exactly what I want at the end… But I'm not saying when I actually feel ill I might be quite so brave but so I just think I'm doing everything I can do now to make life easier later."*

(p.3, L3)

3. *"Whilst I feel well and it's not, it isn't me, it's just like well it can't really happen soon because I feel too well."* (Shelley, single interview, p.3, L25)

Not feeling any "different" or not feeling ill sometimes led to feelings of guilt, "feeling a fraud" or queries about whether this was normal for people living with cancer. Not feeling ill also contributed to people feeling 'normal' and not feeling the need to discuss the future with others (figure 4.18, box 1). Feelings of perceived 'fitness' were seen as important because they were used by participants to judge whether they could plan or not for further treatment (figure 4.4:1).

Figure 4.4 'Don't feel ill'

1. Paul: *"As I am now I'm quite fit, quite normal - cancer, to me, is a word."*
   Sheila [Paul's wife]:*" Not a death sentence."*
   Paul: *"No, it's an illness. You know, it's something that's there, and that's all it is, so how can you plan, you know."*
   Sheila: *"You don't know how you'll react do you? I mean you can say how you're going to react when you get worse or anything like that."* (Paul and his wife Sheila, joint interview, p.15, L11)

2. *"The only reason, I weren't, I didn't feel ill but I needed oxygen all the time."* (Ruby, single interview, p.6, L8)

3. *"I was so fit, everybody, oh you do look fit. I mean people keep saying now, by, you do look fit, you know"* (Dan, single interview, p.5, L29)

4. *"And like I've got two daughters and they're both very, I mean, you protect them. And if I can feel all right and think I'm going to let them think that I'm all right, I will do. I'm not going to have them worrying."* (Doris, joint interview with her husband Ted, p.26, L 3)

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Lack of symptoms such as a cough or pain also supported feelings about not being ill. In addition, reference to their age or previous conditions were reported by some as contributing factors that they appeared to use for rationalising not feeling as well as usual.  Some people like Ruby, who had recently come home from hospital, was experiencing difficulties in breathing and required continuous oxygen, still claimed she did not feel ill (figure 4.4:2) . The importance of seeing how one felt the next day was also talked about, especially in relation to living "day by day" and coping with an uncertain future. Keeping fit was also important and holidays were one way participants reported they could keep fit.

Words describing how people 'appeared' were reported in relation to not feeling ill. People with lung cancer talked about what others had said to them such as they "looked well', "never looked poorly", "fit as a butcher's dog", "fit as a fiddle", not looking any different and not looking like someone with cancer. Dan, who talked to me about getting frightened (whilst his wife was upstairs), said he felt himself "going down" and yet reported looking fit (figure 4.4:3).

Some participants talked about how, if they 'felt all right', they would continue to let their families believe they were still well. For example, Doris, recalled how her daughters spent a month crying following the news of her diagnosis. She reported wanting to protect them from further worry by letting them believe she was well (figure 4.4:4).

Participants' reported feelings of wellness appeared to be an important related factor in their decisions about whether there was a need to engage in discussions or not. For example, Sheila, Paul's wife, suggested that to discuss the future when you weren't ill was to "*pre-empt what might happen…*" (Sheila, joint interview, p.16, L12). Health professionals were also reported to use patients' expressed feelings of wellness in relation to planning future treatment or clinic appointments. This sometimes left patients and their families confused (figure 4.5:1)

Figure 4.5 'When I am poorly'

1. *Jane (Bernie's wife): "And they said that they will monitor it on how Bernie's feeling. And I said to lung cancer nurse I says well what do you exactly mean by how he's feeling, how can you monitor it, you know."* (Jane, during a joint interview with Bernie, p.6, L6)

2. *"But I don't think he'd be able to go into the bedroom or anything. So I don't know. I'll have to ask him when I am poorly. It'd be the best time for that I think. He definitely couldn't cope at nursing me because he's a man and not many of them do."* (Shelley, single interview, p.6, L10)

3. *"But it's so hard to accept that Paul's got cancer. I mean the word's there, we know he's got it but it's so hard to accept that he has when he doesn't feel any different. If he was feeling ill, if he was in bed, not that I'm wishing him to feel ill but if he was feeling ill, if he was in pain, it would be easier to accept than it is when you're just told by an x-ray, oh by the way …"* (Sheila, Joint interview, p.18, L4)

For some people, feeling ill appeared to be a trigger or tipping point indicating that it was time to discuss the future with a family member, friend or health professional. For example, I asked Shelley about whether she had talked about future care and treatment with anyone and who tended to make decisions in the family. She told me she "did everything" and although she reported not feeling ill she was thinking about the future, but not talking about it with her family (figure 4.5:2).

For a number of family members the issue of the person they were caring for not looking ill or appearing 'still well' impeded their ability as a family member to discuss preferences and plans for the future. Eve reported that when looking at her husband he "appeared normal" and, like others, reiterated her husband's reports that he did not feel ill. Sheila, (Paul's wife), said that she found it hard to accept her husband was ill because he didn't appear ill (figure 4.5:3). Similarly, Lorna, one of four daughters caring for Iris, a person with lung cancer, reported her difficulties in being able to plan for her mother's care at the end of life. Lorna talked about her mum appearing fit (figure 4.6:1).

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Figure 4.6 'He doesn't feel ill'

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1    *"We can't make any new plans.  Because originally when they first told us they gave
     her six weeks, which brought us up to Christmas week, and she's still here.  And we
     don't know what's happened, you know.  She's fitter than us.  Everything that they
     told us she's doing the opposite, you know"*. (Lorna, Group interview 2, p.2, L15)


2.   *Mary: "How does he feel in himself, does he feel really ill or?"*

     *Eve: "Well it's difficult to say.  He doesn't, he doesn't feel ill but he's
     getting  weak, and he's not realising that - I mean I can see it, other
     people can see it, but he doesn't himself, and he still wants to do the
     things."*

     *Mary: "Yes" (*Mary and Eve, Group interview 1, p.2, L7)

---

Some family members' reports mirror those from people with lung cancer in relation to

their relative not feeling ill, and therefore not feeling that they as family members needed to

plan for a death in the family. Conversely, from other family members' points of view, they

reported seeing changes in their relative's appearance, which they recognised as a decline in

health. Examples of this were reported by Eve (Barney's wife) and Mary (Bernard's wife) in

the first group interview where they discussed their husbands' illness and the difficulties they

experienced in discussing the future with them (figure 4.6:2).


In summary, family members reported observing changes in their partners or mothers

(recognised as either disease progression or reaching the end of life) but also talked about

them not appearing to be ill. These two perceptions were experienced as contradictory and

presented a dilemma for them. On the one hand, they witness changes which suggest dying;

on the other hand, these signs are sometimes less obvious or masked by people living with

cancer, suggesting the person may not be close to dying. As reported here, people living with

cancer sometimes do not report how they are feeling, wanting their family members to

believe they are well, in an attempt to protect them from the inevitable fate (figure 4.18, box 3).

## Knowing is worse

A number of people with cancer talked about not wanting to know what the future held in relation to how long they had left to live. Although they talked about this in relation to their prognosis, it also related to participants' desire not to face death until death was upon them. They talked about preferring to be ignorant, not wanting to know when they would die and 'hiding from reality'. When answering a question in an interview about his own thoughts about the future, Simon described to me how he had asked the doctor how he should plan for the future and the doctor had disclosed his prognosis (figure 4.7:1).

Figure 4.7 Knowing is worse

1.  *"And, uh, I don't really know which is worse sometimes, you know, because you get that ooh, it's the not knowing isn't it that's, you know. But I think sometimes knowing is worse. So, I don't know, um, and I don't know if, if it's kind of hiding away from it, you know, hiding from reality or, you know, putting yourself in a bit of denial about, you know, what's happening. I, I don't think I am putting myself in denial, I think, you know, I'm fairly – I'm optimistic but pragmatic or realistic as well, you know, about, you know, what the consequences could be"*. (Simon, single interview, p.3, L12)

2.  *"I think for future, seeing a future patient, I just don't think they should say to people, unless you ask and you specially want to know, I don't think they should. Because all the time it's like oh, my year's nearly up, you know. Can you imagine like if Bernard lasts two years, he's going to get to two years and he's going to think when am I going now then, what's going to happen? And it's the scariest thing knowing that they've said that to you. It really is."* (Mary, group interview 1, p.8, L23)

Others also expressed regret about knowing their prognosis and the greater certainty of death. This will be discussed in more detail in Chapter six 'Only months to live'. Some family members also reported that they did not want to know how much time their partner had left

before dying, because they could not bear the emotional distress of knowing, or the fear they felt (figure 4.7:2).

Other family members felt that their relative would not be able to handle any further bad news, but they reported that, as family members, they wanted to know what to expect in the future, how their partner's disease would progress and how they would recognise this, so they could make plans to care for them. These needs appeared specific to them as 'carers' and will be discussed further in the section on 'carrying on as normal' and the following chapter on 'Planning for death, not dying'.

## Morbid talk

Planning ahead for dying or death was reported as being 'morbid' for some people; they talked about not wanting their life to revolve around discussing what may happen or to think about "gory details". This stance was also supported by family members' reports during joint interviews.

Planning ahead for practical issues like funerals was deemed morbid. For example, Henry, a 60 year old ex-publican interviewed with his partner Gwen, talked about feeling the need to organise his funeral because his children did not live locally, but reported "…*but it's being a bit morbid isn't it, planning that*" (Henry, Joint interview, P6, L25).

Participants talked about how "dwelling" on their illness could cause them to feel depressed or cry. Ways of managing this were reported as not "moping around" and not allowing other family members to show them sympathy, in addition to avoiding discussing the future. This was also supported by family members' reports. Vicky (who we heard about earlier) and her husband Eddy talked about some of Vicky's symptoms and held differing views about facing death. Vicky, who was dying, talked about having to face death. On the other hand, Eddy talked about holding back death (figure 4.8:1). Vicky was trying to 'put on a face' for her husband and manage her own feelings but she did not always find this easy.

Figure 4.8 'Morbid talk'

> 1. *"I'm doing all the doctor tells me, and I can still laugh, so. I can still cry like but, if anybody's a bit sympathetic or owt like that I cry…"* (Vicky, joint interview with husband, p.8, L6).
>
> 2. *"They have meetings. He (consultant) says he 'don't get the feedback which I'd like to because it's all, it's all doom ain't it, doom and gloom' with him ain't it? 'Locked door, he says don't lock that bloody door'."* (Ted, husband of Doris, joint interview, p.10, L9)

There was recognition by some family members that giving bad news is "doom and gloom" for others, such as doctors. For example, in a joint interview with his wife, Ted (Doris's husband) recalled the lung physician's comments (figure 4.8:2).

In summary, some people reported finding it morbid talking about, or planning for, death. Sometimes this was recalled as causing emotional distress.

## Thinking about the future

Although people with lung cancer talked about not wanting to discuss things that brought an atmosphere of "doom and gloom", and said they did not want to know about the future, some talked about having thoughts about the future in their heads (Figure 4.18, box 2). For some, thoughts were about what they might miss, for example: whether this would be their last Christmas or what practical arrangements they needed to make for their family in the future. Others reported thinking about not being around, or 'feeling totally lost'.

Some talked about trying not to think about the future by keeping busy through working, carrying on caring for themselves or not allowing 'time to think'. Others talked about lying awake at night, at home or in hospital, thinking about the future. Mary, an 81 year old woman who lived on her own, told me she did not talk about dying, but did think about it (figure 4.9:1).

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Figure 4.9 Thinking about the future

> 1. *"I can go to sleep, if I go to bed and I don't think about it, I can sleep. If it gets on my mind before I go to bed, I can't sleep and I'm up and down. I'm either reading or on, I can't sleep, so I don't think about it, I try not to anyway, but some days it's there and you can't help it, can you?"* (Mary, single interview, p.4, L22)
>
> 2. *"So really I just don't speak to anyone, I just sort of keep my thoughts, thoughts in my head because, you know, it's, we've got two boys and it's difficult to speak to those, you know."* (Eve, Group interview 1, p.11, L13).

Some people with lung cancer felt their spouse would not want to think about the future, which led them to not discuss their own thoughts with their family. Likewise, family members in the joint interviews also talked about having thoughts in their heads or realising their husband or wife were 'ticking things over', but neither talked about these thoughts with each other [figure 4.18, box 3]. Conversely, for Vicky, despite not wanting to dwell on the future, she talked about the need to "think about it", although this was in relation to writing a will and ensuring finances were in place for both her and her husband's future [figure 4.18, box 4].

Some family members reported watching their spouses or mother trying to get on with life, at the same time witnessing the deterioration in the person's condition, the fear and panic the person with lung cancer expressed and the inability to discuss the future. Few family members directly discussed their own thoughts about their loved one dying. When I asked them to whom they talked if they were not able to discuss things with their husbands or mother, some, like Eve (Barney's wife), reported they kept their thoughts to themselves (figure 4.9:2).This led to some, like Claire and Kath, feeling isolated, unable to discuss the future with their husbands and having no one to share their own fears and concerns about the future with. Some talked about feeling that they coped less well and that they had more thoughts about their husbands dying than their husbands did.

## Being fearful

Thirteen people with lung cancer who were interviewed talked about being frightened. For some, this was related to thinking about the future at times when they dared to look ahead. For others, this fear was about being swamped with too much information about their cancer, feeling frightened to ask for further information or frightened because they did not know what was happening in relation to their disease progression. Others feared future cancer treatments in relation to the side effects experienced or the dread of visiting the cancer centre. Seven people talked about the fear they felt when they were called in to see the doctor or informed of their diagnosis or prognosis. People with cancer reported receiving news about three main areas: that they had a diagnosis of cancer, that the cancer had spread, that they were dying and had little time left to live. Some of the terms used by people to describe their fear in these situations were: 'ultra scary' and 'scared stiff'. Others, like Bernard, described physical reactions of fear related to waiting in clinic for palliative chemotherapy (figure 4.10:1).

Figure 4.10 Being fearful

1. *"So frightened, I'm absolutely wet through with sweat..."* (Bernard, joint interview, p.7, L1)

2. *"Sometimes I got, like I went this time and I said look, I'm getting frightened again, and I did this before, I said I'm getting frightened, you know, the way I'm going down. I was so fit, everybody, oh you do look fit…. But no, but I don't, I'm not frightened of the end, don't get me wrong, you just think, well how's it going to be, you know, will I just go to sleep and then that's it, or am I going to be there gasping for days on end? But I know I tend to shove it in my mind at the back and forget about it, you know."* (Dan, single interview, p.5, L14).

3. *"Uh, it doesn't bother me; I'm not frightened of it or anything like that. It doesn't frighten me at all, whatsoever. When I think there's something else comes in as well, and the way you treat people as well, and all that. I've always tried to treat people properly, you know. When you come out, you drive a car don't you? Right. So every day do what I do, let somebody out of a street end. That's your good deed for the day. [laughs]. Especially somebody who's working, because I don't work and I think oh, yeah, I'll let that lorry out, he's working, I'm not".* (Stewart, single interview, p.8, L 32).

4. *"And I still would want him at home because he'd be scared. It's strange, and he'll say this to me sometimes, he'll sit there and say I'm scared, what's going to happen to me? And I say Bob, don't even think about it."* (Mary – Bernard's wife, Group Interview 1, p.16 L17)

5. *Lorna: "I'm the scared one. It's like when my mum fell I pulled the cord and I don't know whether it's because it's not being used for such a long time it took me ages. I pulled it about six times before Town Control came through. And they said straight away send for an ambulance. And I thought I don't want her in hospital. And they said going to hospital, you know. And it was.*

   *Debbie: We had to decide".* (Lorna and Debbie, Group Interview 2, p.20, L6).

For people with lung cancer, being given a poor prognosis can cause fear and other emotions, and the impact of this will be explored in more depth in chapter six 'Only months to live'.

Other people talked about being frightened of the cancer spreading, being taken off medication which was providing some quality of life, losing control or having pain when dying. Dan, aged 76, had stopped chemotherapy because he wanted to go on a cruise, and talked to me about being breathless, recognising that he was deteriorating and thinking about 'how' he would actually die (figure, 4.10:2). This fear of what dying would be like was also echoed by others. The experience of other family members or close friends dying was also talked about in relation to whether they might follow the same course.

Stewart, a 60 year old widower, appeared to be a 'negative case'. In answering a question about his views on thinking about the future he talked about the future being in the 'lap of the gods' and that he was not frightened of it (figure 4.10:3). Although Stewart's comments suggested that he was not frightened I recognise that this was his presentation to me, and that his own personal thoughts might be quite different. He appeared to use

strategies to combat unhelpful thoughts by trying to think of ways to help others. Others' attempts to avoid fear or approaching death will be discussed in detail later in this chapter.

Family members reported witnessing their partners expressing fear and feeling scared. Some talked about observing their husband's expression of fear or panic and how this made them feel. Mary, who was present in the interview with her husband, confided with me and others later within the group interview (figure 4.10:4). They also reported their own fears and 'panic' in relation to their own experiences of living with and caring for their family member. This was related to fear of not being prepared to meet their partners' needs, knowing the prognosis, not knowing what the dying process would be like or feeling scared of what they might face when visiting the person they cared for and having to make decisions (figure 4.10:5).

For some, like Angela, fears were related to not having previously experienced caring for someone with cancer before. In comparison, one family member (Mary) talked about not being frightened because she had cared for her father when he was dying. She felt this experience informed her about what help and equipment was available and what the dying process was like. Nevertheless, she reported her husband's fear, which brought her sadness.

## Strategies for avoiding death

In relation to the substantive category of 'facing death when it comes' this next section reports what strategies people employed to avoid being frightened and avoid death, strategies such as: not discussing the future, seeking to 'carry on as normal' and for some trying to live 'day by day'.

## 'Don't discuss' the future

As mentioned previously, in each interview with people who had lung cancer I asked them what thoughts, if any, they had about the future, and whether they had discussed these with anyone. Some people talked about how discussing the future was 'a hard thing' to do.

Most of them reported not engaging discussions about the future. For some people, discussing the future was not viewed as being important, and for others, like George it was not something that could be done with those close to them. I had been talking to George, who lived with his wife, about whether anyone had initiated discussions with him about the future. He described how he had been thinking about the future, his knowledge of a work colleague's recent death, and the distress of not being able to discuss the future with his wife, as figure 4.11:1 and figure 4.18, box 3 illustrate.

Figure 4.11 'Don't discuss' the future

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1. *"I think the most distressing part of this, isn't for me, it's for people around me. Now that's what I fundamentally believe in, and I know when they couldn't talk about it last spring, I didn't even dream of bringing it up."* (George, joint interview, p.5, L25).

2. *Bernard: "I would say to them there's no need for it… As I've said, we're content aren't we, with the, with the lifestyle we've got. Yeah. And we don't want anything; alterations, nothing do we?"*
   *Mary: "No."*
   *Bernard: "Apart from help. That's all."*
   *Interviewer: "Practical help?"*

   *Bernard: "Yeah".* (Bernard, joint interview 2, wife Mary, p.3, L33)

3. *Ruby: "I tend, yeah, I tend to put things up, as I say, out of my mind, you know. Yeah. Because it somewhat seems final to me, you know what I mean. Well you probably don't know what I mean, but it's bringing it to me what, what could happen and what I've got, you know. So."*

   *Interviewer: "Are you saying that it's easier for you to not think about future decisions? You'd prefer to…"*

   *Ruby: "Yeah, yeah. It's awful to say but I've shut my mind to It, you know, I. Yeah, I prefer to go day to day. You know…I'm a bit of a coward."* (Ruby, single interview, p.9,L13)

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4.   *"I didn't even dream of bringing it up, but when we had the last meeting - when was It love?"*

*Winnie (wife):  "What last meeting?"*

*George:  "You know when I'd been to see Dr …… last week?"*

*Winnie: "Last Tuesday."*

*George: "I just said to her, I said we need to talk about things.  And so we had*

*started to think about the future".*  (George, joint interview, p.5, L25)

Others reported that there was nothing to talk about at the moment, that they did not want to discuss health matters, or said talking about the future was something they had never done. For some, discussing the future or dying was something they did infrequently, whereas for others it was something they refused to talk about. When, in my second interview with Bernard, aged 59, who lived with his wife Mary, I asked him when would be the best time for a health professional to discuss any wishes he might have for the future, he said he did not think a discussion was needed (figure 4.11:2). Bernard's view that he did not want to discuss the future and preferred to carry on with the lifestyle he had was shared by others.  Some people with lung cancer, like Ruby, to whom I had showed a card containing information about advance decisions and living wills, expressed the feeling of finality if one talked about what could happen in the future.  The interview questions themselves sought to promote discussion about the future. After having been shown the card, Ruby seemed troubled by what she read, and said it was bringing things "too close" to her (figure 4.11:3).

On the other hand, there were some occasions when discussing the future was reported as necessary: for example, George, (who we heard about earlier), changed his view about discussing the future following news of his illness progression as illustrated in figure 4.11:4. He went on to talk about asking his oncologist for more detailed information about his cancer progression and telling his own general practitioner that he felt he was seeing the beginning of the end (figure 4.18, box 5). George was in many ways a 'negative' or 'deviant case'

because unlike most of the other people interviewed he had been a planner all his life, and wanted to plan ahead to help relieve the burden on his family.

Some people with lung cancer reported how, although they understood the need for some family members to talk about the future, they personally did not want to hear a discussion because it did not help them in trying to carry on life as normal. Doris had been talking to me about both her daughters crying for a month following her diagnosis of lung cancer and how this made her feel. In the following exemplar Doris explained to me, and her husband who was present, how their behaviour affected her (figure 4.12:1).

Figure 4.12 'We don't talk about it'

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1. *"And you can see them looking at you and I think stop it. But it's true. I do with you in bed don't I? I say what are you looking at me for? You know and it's true, yeah, I don't want that, I'm not that person, you know. And I think the more they talk about it and I know they've got to talk about it, but at times I don't want to hear it."* (Doris, joint interview, p.26, L10).

2. *"But, it is, it's just not knowing, you know, I'd rather know, but I know Steve doesn't want to know and so that's why I'd like the opportunity to, you know, actually talk to a doctor."* (Kath, Simon's wife, single interview, p.5, L12).

3. *"But she, I don't know if she knows in her heart of hearts that it's terminal, but nobody's told her it's terminal. She knows that she's got a tumour in her lung but that's as much as she knows. I think she knows. We don't talk about it. But what she talks to my sister about I really don't know."* (Claire, Group interview 2, p.8, L8).

4. *"Um, as far as Andy's illness is concerned, I'd like to make plans, [clears throat] I'd like to talk to him about certain things, but it's a cleft stick because Andy's saying I'm going to conquer it, I'm going to see my granddaughter qualify, and how can you say to him, you know, we really ought to sit down and talk about your future care, um, because it might give him a blow where he thinks well, she's got no faith in me fighting this. So it's, it's a cleft, and so on this particular issue, um, the person I'd like to plan with I can't."* (Angela, Group interview 1, p.1, L4)

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Doris's daughters' reported behaviour and their talking about her illness and future appeared to impact on Doris's ability to manage her own feelings in relation to her diagnosis.

Jim and Clive were different to the others. They talked about some decisions regarding their future care which they had already discussed, either with their wives, or in Jim's case, with his district nurse and lung cancer nurse (figure 4.18, box 6). Jim had experienced four different types of cancer in his life and outlived his first prognosis of bowel cancer by seven years. Clive had had surgery to remove his affected lung, followed a year later by removal of a brain tumour. He was still alive one year later. The details of the type of discussions they had will be reported in the following chapter on planning for death, not dying.

The female carers reported their own difficulties in discussing the future with their partner or mother. Mary and Angela talked about never speaking to their husbands about dying because it was something their husband or partner did not want to do. Kath (Simon's wife) reported how her husband was too scared to seek further information about the future. This made it difficult for them as carers to plan ahead for both themselves and their families, for example in trying to find out wishes about funerals or gaining the information they themselves needed to be aware of in order to know what to expect in the future. Kath had talked about her dilemma of wanting to know more about what to expect in the future in relation to Simon's progressing illness, but felt unable to ask because he did not want to know (figure 4.12:2).

Most carer participants were afraid of initiating a discussion about the future with their husband or mother because it was hard or they feared it would upset them. Claire (Helen's daughter) had been sharing with the group that she had not initiated any discussions with her mother about the future, but recognised that it might be possible that her other sister had (figure 4.12:3). A difference in family relationships may impact on whether family members feel able to initiate discussion about the future.

Mary could not talk to her husband about the 'afterlife' because she feared this would invoke thoughts in him about dying. Family members also feared being seen to be disloyal, as for example, Angela (Andy's wife) explained at the beginning of the first group interview (figure 4.12:4). In contrast to the people with lung cancer, some of the carers voiced a desire to discuss and make plans for the future. This will be reported further in the next chapter - Planning for death, not dying.

## 'Carry on as normal'

Carrying on as normal was talked about by most people and linked closely to not wanting to know about what might happen in the future and a desire not to discuss the future. Carrying on as normal had different meanings for different people.

Many people with lung cancer who were interviewed talked about the need to just 'get on with life as normal', carrying on as they always had done as much as possible, with no changes to their lifestyle. They talked about just wanting to enjoy their life. Barney, age 60, who lived with his disabled wife, talked to me about just wanting to "carry on as we are doing, here" at home. His 'carrying on as we are doing' meant not being admitted to hospital again and walking to the local betting shop each day.

Mary, an 81 year old lady, who lived alone and had recently experienced the death of friend with cancer, talked about 'carrying on as normal', not thinking about dying and just getting on with life. Mary's carrying on life as normal meant placing little value on her illness (figure 4.13:1).

Figure 4.13 'Carry on as normal'

1. *"Yes, because when I was in hospital, I felt guilty, I said, I feel guilty being in here. Because you see I seemed all right, because it never troubled me, and I never thought about that, it was just the heart attack I'd had, and I thought that's all what it was until the x-ray. So no, I think carrying on just as normal. I mean there are odd days that I feel a bit tired and my back hurts, but I've always had a bad back, so that's no trouble, I've always had that."* (Mary, single interview, p.6, L12)

2. *"We do carry on as normal. I do absolutely everything and they all sit around letting me doing it. It doesn't matter if you turn around and say oi poorly one here, three healthy people, you'll be all right. It's like, that's all I just get, I just do everything. Life is no different then how it was. I'm still going to work. I am lucky that if I didn't feel very well I could just come home, and when I had my chemo I worked, I carried on working then. I only work supposedly Mondays and Thursdays. But if I'm tired, I can do whatever I want really. Which I did when I had my chemo. So I'm not, people say well why don't you pack in work because then you'd have more time. And I say, I'm going to stay at work life's normal. It's normal for the kids. If I pack it in, they won't believe that I'm not poorly. They'll think that there's something wrong and she's not telling us."* (Shelley, single interview, p.7, L1).

3. *"Just keep going. I just keep going. And I'll just keep going until it's either cured or I have to stop, you know. But, like we say, as it is now, as far as I can see, it ain't going anywhere, and just so that those at [City] can have their surgery I'm not going to go through that to give up what I've got at the moment, you know. We've got a life. We can go out. We can go off if we want. I work. If I go and have surgery all that's finished. And I don't want that."* (Paul, joint interview, p.4, L21)

4. *"It's easy when they're out just to get up and go and get a couple of biscuits and a cup of tea. And I thought well I'm eating these things and I'm getting up, if I can get up and do them I'll sit on the perching stool. I'll earn them two biscuits. Make myself work a little bit for it, just push myself. If you like it's just a target, a reward for doing something. It sounds silly and it is in some respects a bit childish but it gives me something if you like to focus on, if you understand that."* (Bernie, joint interview, p.18, L18)

5. *"Do what I want to do. Go for a pint, still have a fag, do a little bit of work when I can."* (Jim, joint interview, p.4, L1)

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For Bernard and Simon, carrying on as normal meant no interference from distant relatives or neighbours. Bernard talked about not wanting any alterations in his lifestyle in response to a question about the best timing of health professional discussions about future care. He expressed the view that for him carrying on as normal was getting on with his life and trying to enjoy life, and wanting that for his daughters too. Simon discussed how he wanted his own family around him without the interference of distant relatives offering sympathy, many of whom he had not seen for years.

For many people work was seen as something very important in relation to 'carrying on as normal'. Candy, aged 58, who was just starting a further course of chemotherapy, talked about life carrying on normally with her husband going back to work to provide for their finances. Dan, who we heard about earlier, retained his position as a grocery store greeter one day a week. Although he had not been fit enough to work over the previous few weeks (prior to interview), he talked about how his work enabled him to get out of the house and allowed him to carry on as normal. Shelley, who worked for her husband, was continuing to work because she reported that while she stayed working life was normal and it would keep life normal for her husband and teenage sons (figure 4.13:2). Likewise, Paul, a 73 year old man diagnosed with lung cancer and who still worked night shifts as a heavy goods driver, was determined to carry on working. When I asked him about his thoughts about the future he talked about how he had refused surgery for his lung cancer because he did not want to stop work (figure 4.13:3).

Some people like Andy, a 76 year old man who described himself as the head of the family, talked to me about the need for family members to continue with their work. Others said that they themselves needed to carry on and keep busy with household chores. There appeared to be a moral duty to continue working even when jobs outside the home were not possible. For example, making a cup of tea for themselves was valued as work (figure 4.13:4).

Planning holidays also helped keep life normal. Doris talked about planning holidays and deliberating on whether to book one because of her condition. She explained that she had decided to book a holiday and risk losing money because she reported "you can't live your life on ifs and buts". Travelling abroad and enjoying as many holidays as possible within the time they had left, or having a drink and meal at the local pub each night, which had become their lifestyle over the past years, was important. Bernard and his wife Mary recalled how other people with lung cancer at the local chemotherapy outpatient unit disapproved of their lifestyle and they recalled how they had defended their trips to the local pub as "trying to enjoy life as normal".

For other people this 'carrying on as normal' was expressed as not wanting to know their prognosis. For example, Bernie discussed that he did not want to know what time he had left because he wanted to "live as normal a life as possible". This will be discussed in greater depth in the chapter 'only months to live'.

Some people talked about 'carrying on as normal', as 'doing', but recognised it was now at a different pace than before, and they used words such as 'plodding on'. For Jim, a 59 year old who had reported that he was dying, carrying on as normal meant doing what he wanted (figure 4.13:5). There was recognition by some that things might take longer than normal to do, but that did not matter. Carrying on as normal was reported as seeking to keep life 'real'. Figure 4.14 exemplar 1 from Bernie (interviewed with his wife Jane) came from our conversation about thoughts for the future and what his views were in relation to other interviewees' comments on needing to 'carry on as normal'.

Figure 4.14 'Keep it real'

> 1. *"It's not normal no, and life's not going to be normal for me or for her ever again, but I want it as normal as I can possibly make it. Not only for my sake, for her sake and for my girls' sake. That's what it's all about. If they don't keep it real, I can't keep it real. And if I don't keep it real, they can't. I don't want them coming in saying do you want a cup of tea dad or do you want this dad, can I do this dad, I don't want that they've never done it in their lives have they?"* (Bernie, joint interview, p. 22, L10)
>
> 2. *Angela (Andy's wife): "…what he's turned round and he's said, he said that we get on with life normally, and we'll deal with whatever it is when it comes. I know what I want. Andy: We've got to live a normal life because if we don't it's going to be horrendous. Angela: I want to make sure that he's not on his own, that I'm with him. Andy: I mean that's the main thing to me, for as long as possible we carry on as we've always carried on, falling out, shouting at each other …"* (Andy and Angela, joint interview, p.12, L17)
>
> 3. *"We're just, it's like he's normal. It's hard, because I think about it more than he does I think, he's totally - I mean we were talking about, there was something about pensions on the news the other day, and he's saying to me oh, it's not for six years yet, so I'll be all right. And that's what he thinks. You know, he doesn't, he doesn't feel like he's dying. He feels fine. So while ever he feels like that we just carry on as normal, you know".* (Mary, Group interview 1, p.4, L18)

As with Andy and others, the need to keep life as normal as possible provided a sense of control in the lives of people with lung cancer. An alternative to not living life 'as normal' was living a 'horrendous life', as Andy explained within the context of discussing preferences or wishes for the future (figure 4.14:2).

Family members, such as Mary (Bernard's wife), supported their loved ones' wish to 'carry on as normal' whilst they were feeling fine (figure 4.14:3). Family members also talked about 'learning to live with it', getting out the holiday brochures, 'going along with it' or treating life 'as normal'. These issues were discussed in relation to living in the present rather than discussing what might happen in the future.

The wives and daughters of people with lung cancer independently reported similar accounts of their loved ones feeling well and wanting to 'carry on as normal'. In contrast to the reports of the people living with lung cancer, family members talked in the group interviews about supporting their partner to 'carry on as normal', even though they themselves reported watching for their partner to die (figure 4.15:1).

Figure 4.15 Trying to keep 'life normal'

1. Angela: "And there's all these things that's going round in your head, and Andy's saying well, I'm all right now, but. He's getting more and more chest infections, and he had to see the doctor the other day that's changed his antibiotics and he's told him that it is the cancer that is now creating, but this is his own local doctor, not the specialist, that is creating the infection a lot more and more. So he were a little bit, um,[slight pause] down, and he's been having a lot of chest pain, and doesn't like to tell you but I was saying to you weren't I, I can see, like you said, I can see it in the face."

   Eve: "You can, you can see when there's something wrong can't you."

   Angela: "I can see at times he's grey, and he's not normal, but they won't admit it. And it's as if they don't want to share it with you, and that's making you worse because you don't know what they're going through. And if they tell you I'm alright you don't believe them because you can see in their face they're not well". (Angela and Eve, Group interview 1, p.6, L20)

2. Eve: "But although we try to live normally, we're finding it difficult because he's getting, he is getting weaker. Just imperceptibly..."

   Mary: "But you can see it and he can't."

   Eve: "I can see it. And like we can't go to town anymore because he's just not got the ability to walk like he did do and, you know, he gets really tired, and I guess it must all be part of the, the cancer. I mean I don't really know but I guess this is what it is."

   Mary: "But he's still going to plant his onions on Boxing Day"

Some family members gave further examples of the difficulties in supporting the person living with cancer to carry on life as normal when the person they were caring for became weaker (figure 4.15:2). In some ways family members appeared to collude with these patients in trying to keep life 'normal', but in other ways they saw them dying in front of their eyes and sometimes found this support or pretence of 'normality' difficult for themselves.

These accounts from people living with lung cancer suggest a need to protect life and living within their social context, denying death any power to change theirs or their families' lives. Similarly, living 'day by day' was one way of trying to make 'carrying on as normal' possible.

## "Day by day"

Ten people with lung cancer talked about living 'day by day', or one episode at a time and 'taking each day as it comes'. This was within the context of a question asked about their thoughts for the future, and their response appeared to reflect an attitude or a 'philosophy' towards not thinking about the future (figure 4.18, box 1). It was also sometimes linked to views about the need to 'soldier on'. For some people, 'living day by day' related to an inability or the lack of a desire to plan for the future, not wanting to worry about the future. Ruby (who we heard about earlier) had been talking to me about her wish not to think about the future and discussed living day by day (figure 4.16:1).

Figure 4.16 'Day by day'

1.  *Interviewer: "Are you saying that it's easier for you to not think about future decisions? You'd prefer to …"*

    *Ruby: "Yeah, yeah. It's awful to say but I've shut my mind to it, you know, I.*

*Yeah, I prefer to go day to day.  You know."*

*Interviewer: "Right."*

*Ruby: "I'm a bit of a coward" (*Ruby, single interview, p.9, L18)

2.  "*So yeah I just take every day as it comes and if I don't feel brill*
    *then I don't do very much.  Or if I just think I don't want to do that, I have a*
    *think and I'm not going to do it now.  So it does make you think that life's for*
    *living."*  (Shelley, single interview, p.8, L3)

3.  *Interviewer: "Some of the other things that people have said to me is that it's important to,*
    *for them, not just to carry on as normal but for them, they talked about living a day by*
    *day.  What's your thoughts about that?"*

    *Edward: "Well I don't live day by day.  I just take every day as it comes.  Oh*
    *yes I take every day as it comes.  As far as I'm concerned I'm going to live*
    *forever.  And that's how I conduct myself.  I think it's, well I think it's best that*
    *way.  There's no good moping and you're worried and, I mean if things got out*
    *of hand well fair enough.  Well you'll have to just think about it.  But other than*
    *that well I've no problems."* (Edward, single interview, p.5, L16).

Shelley, a 48 year old ex-health care technician, talked to me about taking 'every day as it comes' in relation to her illness and of having had to recently cancel a holiday abroad due to her illness and this now influenced how she did or did not plan ahead (figure 4.16:2). In later interviews, while theoretically sampling, I explored the category 'day by day'. Edward, a widower aged 85, talked about not living 'day by day', but instead taking 'each day as it comes', suggesting these were possibly different concepts (figure 4.16:3).

Taking 'every day as it comes' appeared to be about an attitude of accepting what the day brought them in terms of how well they felt and what they were able to achieve that day, of being grateful for living that day. It may be that the perceived control of the situation distinguishes the two concepts of living 'day by day' and 'taking each day as it comes' from each other. Attitudes towards the future and towards their illness appeared to influence

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people with lung cancer and their families' thoughts about living 'day by day' and accepting 'each day as it comes'.

In contrast to all the other interviewees, George reported a different view. For him it was not just about living day by day but about balance and getting the most out of life (figure 4.17:1).

Figure 4.17 'Take every day as it comes'

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1. *"I've always been one that looks to the future, always in life. I mean I joke with people I have a five year plan right. My plans are there as a guide, not as something to drive you. So it's actually, life isn't about just living for today, because you've always got to be aware there is a future and there is past. The past can modify your thinking for today and the future, so it's getting the balance. It's getting the balance. So it's not just live for today, because I think if you live for today you lose, well you won't get as much out of life."* (George, joint interview, p.6, L19)

2. *Mary: "We know he's not going to last forever but, as you say, you take every day as it comes."*

   *Eve: "You take every day and it's a blessing."*

   *Mary: "You enjoy every day. And it is, it's a blessing, and while, you know, while they're feeling well, I think that's the main thing isn't it".* (Mary and Eve, Group interview 1, p.14, L8)

3. *"Just take very small steps, you know, plan a few weeks, a few months at most at a time and just, you know, take it one day at a time really. And don't try to rush things, uh, don't try to cram things into a few months what, um, you know, you've had a lifetime to do really."* (Kath, Paul's wife, single interview, p.5,L18)

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Many talked about getting on with living and for most this involved 'carrying on as normal' which appeared to be of primary importance to all those interviewed living with lung cancer.

Similar to the people with lung cancer, family members talked about 'taking each day as it comes', counting each day as a blessing or a bonus. For some like Mary this may have related to her recognition that her husband was not going to 'last forever' and therefore, like Eve, needed to make the most of their time with their husbands (figure 4.17:2). As was the case with people living with cancer, family members, also talked about taking small steps, planning for now, but not necessarily the future (figure 4.17:3).

## Summary

People living with lung cancer appeared to avoid discussing the future, which meant not engaging in morbid talk and not thinking about the future. This appeared to be an attempt to avoid death [figure 4.18]. They expressed feelings of fear and disclosed that knowing what might happen was worse for them than not knowing. Not feeling ill appeared to be used as the reason or justification for giving little consideration to the future, or death. Feeling well or not appearing ill was a marker for people in relation to initiating a discussion or agreeing whether or not to talk about the future. People employed strategies such as not discussing their future with others, seeking to preserve normality and living 'day by day', which appeared to provide an element of control for them within their social relationships.

Interestingly, three of the five people who agreed to take part in the study, but later refused, stated their reason as not wanting to discuss the future. A further three invited to take part by the lung cancer nurses who were recruiting to the study also expressed a wish not to talk about the future or their illness. These findings are also supported in the most part by their families' reports, although families expressed different needs in relation to discussing and planning for the future.

The following diagram (figure 4.18) referenced earlier may help to explain what factors may cause someone to begin discussing their future with others.

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Figure 4.18  A continuum for discussing the future

3. Think about dying/future, but don't discuss with anyone (fear of upsetting family, too difficult, not right time)

4. Discuss future with family member/s or friend only about practical issues (Will, funeral)

5. Discuss future/dying with family **or** health professional (not both) often in recognition of change in condition or concern for family.

2. Think about dying/future, but put to the back of mind

6. Discuss openly with family and health professionals

1. Don't think about future or dying, not important or necessary

Avoiding death

Facing death

Note: Person may never choose to reach this point

# CHAPTER 5 : PLANNING FOR DEATH, NOT DYING.

## Introduction

In the previous chapter I reported on people's experiences of not wanting to face death or discuss the future and wanting to 'carry on as normal'. This chapter now reports on people's views and experiences of when they did make plans for the future. Although I aimed to explore how people plan for their future health care and treatment, findings show that what was important to people were the social aspects of planning for death and dying. The findings highlighted an absence of discussion about choice or options for planning future treatment or care. The people with lung cancer and their family members did not talk about being offered or wanting choices for treatment or care, they talked about planning for their families or those they were leaving behind, when they were no longer present. This was more important than thinking about or planning for their preferences or the act of dying itself.

## Planning for death, not dying

The category and its properties described in this chapter form 'planning for death, not dying' and involve: concern for the family and others, discussing plans for the future with others, practical planning for 'when I'm gone', preferred place of care and other wishes for the future. Concern for the family appears to be the main factor that caused people with advanced lung cancer to plan ahead for their death. This concern for the family was reported to cause them to engage in discussing the future, often initiating the discussion themselves at a time when they reported it felt 'right'. Conversely, for some, the concern for their family prevented them from discussing the future with their family, and may have led to secret planning, discussion with health professionals or others, or alternatively to loneliness and isolation. The following diagram (figure 5.1) depicts the properties and dimensions within this category.

Figure 5.1 Planning for death, not dying

**Concern for family** - Discuss/not discuss future

*Plans for while I'm still living*

*Plans for 'when I'm gone'*

D
E
A
T
H

Holidays

Christmas

Anniversaries

Garden

Work

Funeral

Will

Care of body

Ongoing support for family

Getting ready (e.g. organising, tidying, employing a cleaner).

Legacy

Teaching
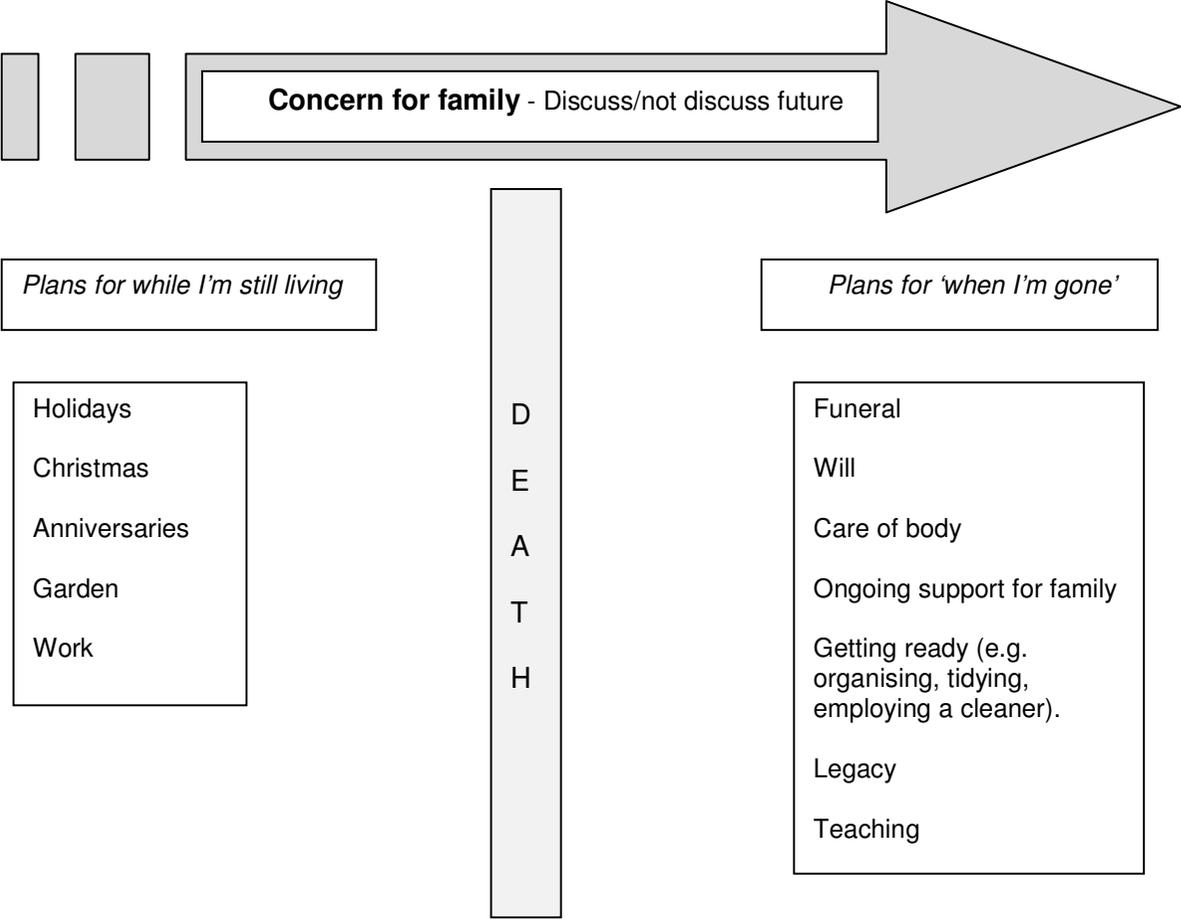
The following case study provides the reader with an overview of the core category of 'planning for death, not dying'. Following this case study the similarities and differences from other people's reports will further enhance the descriptions of this category and suggest possible relationships between the aspects of planning for death. For the most part there was little reported about anticipating the dying event itself.

## Case Study

Shelley was 48 years old and lived with her husband George, who was self- employed, and her two teenage sons Greg and Tim, aged 18 and 14 respectively. Shelley had been diagnosed earlier in the year with inoperable lung cancer. As an ex-health care worker she expressed a good understanding of her disease. She had left hospital work to support her husband's business and was still going into his office two or three times a week when possible to provide him with office support. Shelley was interviewed alone at home.

Shelley talked about not feeling ill and her concerns for her family. She reported that these concerns had led her not to ask questions of her doctors because, as she later described, her family could not face 'it' (the prospect of her death) at the moment:

*"I would actually like to be able to ask somebody is this normal to feel this well when you're supposedly so ill? But I don't because of my husband. He's been a lot better than I thought, doesn't cope with hospitals or illnesses. And he always insists on coming to clinic with me. There's a lot of things I don't ask that I'd like to know because he's there."* *(p.1, L11)*

She talked about her plans to wait until she felt unwell before talking to her family about decisions she needed to make. She said that she did not know what her husband and sons wanted and although she had some thoughts about possibly dying at home she could not decide that without them. She stated she would "*do whatever him and the kids would rather me do really*" (p5, L25). Shelley explained that she would want to involve them in decisions about her future. At the time of her interview she reported it was difficult to involve them

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because she thought they did not really want to think about it. She reported that while she was well it was not the right timing and that she "*daren't ask him*" (her husband).

"*I don't really want to burst the little bubble that they're all living in at the minute. So if I can sort it myself I will. And if not I'll just have to wait.*" (p.4, L12)

This appeared to lead Shelley to plan ahead, but secretly, on her own, when her family were out of the house. She planned 'practical' things such as putting utility bills in her husband's name and writing lists such as:

"*…lists of what you need to do when you're going on holiday and how the washing works, because you're lucky if they put clothes in the tumble drier. And things like that.*" (p.2, L8)

Her husband was away skiing when I interviewed her and she was using the time while he was away to organise and make practical plans as the following example demonstrates:

"*I do keep trying to empty things but it's trying to do it like that's why I'm doing things now because George is away.  I mean George is away, kids are at, one's at work, one's at school, so they don't realise what I'm doing.  I do have to do all the photographs because I've got masses and masses of photographs.  And they're all still in the, a lot of them are still in the sleeves that you get them from, you know.  And I know when they all are.  I could tell you where we are, dates, just about and everything, but George wouldn't have a clue.*" (p.13, L21)

Her explanation for her practical planning was that it would make it easier on her family when she died; otherwise she said it would be a 'nightmare' for them. There was also a sense of preserving family memories of her as part of the family as a legacy for future generations.

Shelley's reports of previous decisions she had made during the course of her illness also appeared to be based on concerns for her family. She reported that their decision for her to receive outpatient chemotherapy rather than inpatient chemotherapy was based on the need to support her son who was sitting his GCSE exams at the time, by being home at night. She talked about how it would have been unfair not to be there for him. Her decision to wait for a clinical drug trial for second-line treatment of her cancer (that had less outwardly visible side effects) rather than standard chemotherapy was based on concerns not to distress her family by her appearance.

Shelley talked about how she was organising a plot for her ashes in the local church cemetery. She reported how she had discovered how to do this through contacts in the village and through talking to her friends. She had talked about buying a plot in the context of relieving her family of the burden of organising this. Efforts to organise things for her family might appear to her friends that she was being brave, whereas she reported that she was trying to make life easier. Shelley hinted that planning ahead such as organising a plot for her ashes did not feel 'real' because she did not feel ill.

> "But I thought if I've got to go and book I'll have to go and do it because I don't want to have to leave them to do it. And she's well could you do it? I went yeah. But I'm not saying when I actually feel ill I might be quite so brave but so I just think I'm doing everything I can do now to make life easier later." (p.3, L19)

Shelley talked about her previous experience of her father's death from bowel cancer and her mother-in-law's death from lung cancer. She explained that she knew "how bad it would be" for her family and reported that she thought they would "suffer more than me", having witnessed her husband's reaction to his own mother's death, leaving her alone to watch and wait for her mother-in-law to die. Shelley talked about sorting out her mother-in-law's loft where she had also kept personal belongings from her own childhood. She had asked one of

her sons whether he would want to keep any of these items to hand down to his future children, she excused his disinterest, because he was a boy.

Shelley's concealment from her family that she was planning for them, together, possibly, with her inability or unwillingness to discuss the future and her dying with her husband, may also be partly explained by the following statement. This statement was made in relation to her reports that she did not know whether her husband would wish her to be at home or in a hospice when the time came:

> *"And as I say I wouldn't ask him now because he'd think I was lying about how I felt. He keeps ringing up now. Are you all right? Yes I'm fine. Is the pain in your back gone? Yes. I told you I must have laid funny. I was in Tesco on Saturday and I just couldn't move. I normally go on my own but I'd forced him to come as punishment. I'm glad he'd come actually because I felt dreadful. But it's gone. I've just got a bad back and laid funny in bed. That's how I go you see. It's nothing to do with having cancer. No it's irrelevant."* (p.6, L24).

Shelley appeared to dismiss her pain as irrelevant and dismissed her husband's concerns; at the same time she appeared grateful for his concerns. Later in the interview she described her reasons for continuing to work as being because she did not want to be in the house too long on her own. Being alone caused her to think about things too much, which she said was "not a good thing". Shelley appeared to oscillate between planning ahead without upsetting her family out of concern for their well being, and not dwelling too much on the future for her own well-being.

This then links back to issues of importance for people living with cancer, namely the need to 'carry on as normal'. This act of trying to sustain or portray 'normality' by carrying on as normal and acting within family roles and responsibilities helped people like Shelley to plan ahead whilst living with the knowledge of a limited future.

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## Concern for family

In addition to Shelley, seventeen other people discussed their concerns for their families. Concerns expressed were predominantly in relation to not wanting to upset or worry their spouses or children. People appeared to try to protect their family and others from worrying by not discussing the seriousness of their disease or the prospect of dying. They talked about their views of how witnessing their family's worry was sometimes overwhelming for them, as Doris (Dennis's wife) describes in figure 5.2:1

Figure 5.2 Concern for family

1. *"She wants to know the ins and outs of what's happening, and I suppose it's just because she's worried isn't it? I mean they come and the granddaughter comes with them, they think they're doing you a favour sometimes.  But, oh, it is a bit too much isn't it?"* (Doris, Dennis's wife, joint interview, p.3, L 23)

2. *"…we were, we felt like we were left on our own.  Not so much me, it's the wife that was getting left out all the time. Because nobody to talk to her, cos, alright, I know what's going to happen to me, I'm going to snuff it eventually, and the wife's going to be left and she's got to sort everything out after that, and it just seemed she was getting dropped out. At least when the district nurse comes in, Jane is nice, talks to Viv (wife) as well as me and that, and she's very nice isn't she.  Anything you want to talk about she'll talk about it."* (Jim, joint interview, p.8, L9)

3. *"I don't want to be laid there four, five or a couple of weeks with him (son) stood by me bed, they know there's no hope but why, you know, put them through it. I just want it to end quickly."*  (Clive, single interview, p.6, L1)

4. *"…it's your personal dignity thing. You've always been there for your family you protect your family that's what you're there for, and he's in a hospital having his family running around after him and he can't do his job and that's it. Really that's what it boils down to and you feel totally, totally lost."* (Bernie, joint interview, p.31, L12)

Other reported concerns were about practical plans for when they were gone (figure 5.1), such as planning a funeral. Some people did not want to leave the planning of their funeral as a burden for their families. Others considered the financial needs of their families or the ability

to cook or look after the house after their death. Some men expressed concerns about the impact their illness and demise had on their wives. Jim had reported concerns about his wife's (Vivienne) need for emotional support. This led him to ask for a district nurse to visit to provide support for her (figure 5.2:2). Some, like Shelley, talked about their belief that dying would cause more suffering for their families than it did for themselves.

People with cancer also expressed concerns about family members' ability to provide care for them when they became dependant. Although Andy commented that his family wanted to care for him at home, he talked about waiting to see what his needs were and recognised that there might be limitations to his family's capabilities to care for him when he was actually dying. Some people were concerned about the timeliness of dying; not wanting their family members to be waiting and watching them die (figure 5.2:3). Others were anxious whether their husbands or wives would be able to maintain their jobs and independence. In addition, some talked about family members or partners not being well themselves or having their own families to care for and not wanting to burden them further.

Some men expressed concerns about protecting their family and talked about this as their job. They talked about the loss they would feel when they were no longer able to protect their family. Bernie, who had been discussing how he thought protecting his family was an issue of personal dignity, described his observations of a fellow patient during a recent stay in hospital (figure 5.2:4). This 'work' to protect one's family from harm may explain a relationship that appears to exist between 'carrying on as normal' (as discussed in the previous chapter) and concern for family well-being. This 'work' for the men with cancer related to their role within the family and appeared to define them. The 'work' of the female participants centred around organising their home in preparation for their death, such as: organising photos, teaching their husband to cook or finding a suitable cleaner (figure 5.1). People did not want to relinquish their roles of mother, father, grandmother and grandfather. These roles, that appeared to be determined by gender, shaped the way they functioned within their social

context. The anticipated loss of these roles appeared to influence their desire, or not, to plan for their or their family's future.

People talked about having discussions with their family about putting adequate plans in place to protect them from circumstances, for example: from the burden of decision making, or financial embarrassment. Not engaging in discussions was also talked about as a form of protection, from a concern not to emotionally upset or worry their spouses or children because they would not want to think about losing them. Some reported not asking their doctor questions in clinic because their families were present and they wanted to protect their family members from emotional distress. People felt it would be a burden for their relatives or cause their family suffering if they discussed the future with them.

Some people commented that the fact of informing their family they'd started to think about or make plans for the future had upset their family. Seeing this family distress reinforced the desire to protect them from becoming emotionally upset (figure 5.3:1). Andy talked about how he wanted to protect his family from his thoughts about not wanting to be resuscitated, which were seen as potentially upsetting for them (figure 5.3:2). Others had concerns for their family and sought to protect them from distress because family members had their own lives or had suffered previous losses themselves.

Figure 5.3  Not wanting to distress family

1. *"My sister's girls, the three girls, because one, she gets upset a bit.  Because I told her I'd been to the bank.  It wasn't my idea to go to the bank, it was the bank sent for me actually.  But I said, well I've been and I've squared a lot of things up that I didn't know about, that some were in the wrong place.  And she got upset.  So they, I think they have an idea.  I don't know, I never talk about it you see, I don't want to, I don't think about it, because probably it will come, I don't know."* (Mary, single interview, p.4, L15)

2. *"You know, I mean I haven't even put it in the will, that's just my personal - because I know straight away I'm going to upset me wife, me daughters, me son, and if they tell the grandchildren this will be fourteen people that's going to be very upset, and while ever I can avoid it I will. I see no reason for them to be upset more than is necessary. I mean Angela says every morning are you alright? Usually I say half of me or, you know, something silly. I, uh, no, I've got more concern for me family. I mean I've had 72 years, so I can't grumble that much."* (Andy, single interview, p.5, L5)

Family members within the group interviews talked about their own concerns for the people with cancer they lived with, wanting to care for them and to be prepared when death came. Families talked about the difficulties in planning because they did not want to distress the person living with cancer by talking to them about the future. This suggests a mutual collusion between the person with cancer and the family member not to distress each other.

## Discussing plans for the future

As mentioned in the previous chapter, few people discussed planning ahead for the future. For most of those who had discussed the future, this was framed in relation to 'carrying on as normal' or living 'day by day'. Planning holidays, celebrations, planting a garden or planning a trip out with friends supported the creation of 'normality'.

Discussing and planning holidays were viewed as important. Ten people discussed planning a holiday. Anniversary celebrations, Christmas and birthday parties were other examples of planning for the future (figure 5.1). Sometimes people related the need to plan a holiday as having a target or having an attitude of not putting things off to another day. Discussing and planning holidays provided something to look forward to (figure 5.4:1) and appeared to support the preservation of self. Sometimes holidays were talked about in the context of reactions to a diagnosis or prognosis.

Figure 5.4 Discussing plans for the future

1.   Bernie: "You've got to have something to look forward to.  My daughter's getting
     married in September so I'm looking forward to that.  So you've got have some sort
     of target.  We've got a holiday.  I'm still going away in May for a holiday".

     Jane: "We've arranged oxygen and everything in place."

     Bernie: "But like say you've still got to have some sort of target, else
     otherwise you might as well just crawl off in a corner somewhere hadn't
     you?  I'm not crawling in a corner type."

     Jane: " No." (Bernie, joint interview with Jane (wife), p.3, L16)

In addition to holidays and other celebrations, other types of reported discussions most

people focussed on were plans for after death rather than the dying process. For example,

nine people had discussed and prepared a will, putting into place financial arrangements for

those they were leaving behind (figure 5.1). A previous illness or past experience of the death

of a wife, husband, parent, friend or neighbour had sometimes been the trigger to people

discussing plans for after death, such as writing a will. The specific plans for after death will

be discussed later in this chapter.

Decision-making

In addition to concerns for the family, issues of trust, differing decision-making styles and

types of decisions to be made were reported. Some people talked about not even wanting

their family to be aware of their diagnosis or prognosis or for them to be involved in any

decisions about their care. In contrast, while others reported wanting their children involved in

discussions, they said this should not happen until they were dying. Until that time they did

not want to bring up the topic with them. Others talked about wanting to involve family

members in discussions about care and treatment and were happy for them to be present at

doctors' appointments. A few patients who had reported having discussed the future with

others talked about leaving decisions about the future to their wives, husbands or other family members (figure 5.5:1). Others remarked that the doctor knew best how to care for them and left decisions about future care to them. This will be reported on further in Chapter seven (Clinical discussions about the future). There appear to be variations in the amount of involvement that some people wished others to have.

Figure 5.5 Decision-making

> 1. *"I've discussed it with my wife, you know, about the future and, you know, saying about, you know, planning for the future, and she, um, my wife's, um, stand on it is at the moment that, um, you know, get the chemotherapy done with and then let's, you know, and I think that's mine as well actually"* (Simon, single interview, p.4, L25)

Despite concerns about for family members following their death, few people reported initiating discussions with their family about the future specifically in relation to the dying process. Only four people reported talking about dying. One of these explained that he talked in general to his wife about who was going to die first. Jim, Clive and George were the only ones interviewed who talked about having discussed dying with their wives.

## Discussing Dying

It is worth exploring these 'negative' cases to understand the context of their discussion about the future with their families. George reported that he initiated a conversation with his GP about his recognition that he was dying and he also initiated a discussion with his wife about the future. He had initiated the conversation with his wife once he started to feel unwell and had received news from his oncologist that there was no further treatment. George talked about having discussed his funeral with his wife as well as his wish for 'minimum care' when he could no longer eat. As a self-reported planner he believed in being in the 'driving seat' but he was equally concerned not to burden his family, choosing to wait for the right time to initiate a discussion (figure 5.6:1).

Jim talked about having discussed the dying process with his wife and the nurses involved in his care. Jim, aged 59, had lived for seven years with cancer, having experienced three different cancers including lung cancer. This was different from other people with cancer in this study. Jim had discussed with his wife a number of issues relating to the future that included not wanting to be in pain when he was dying and where he wanted to die. He had also informed his lung cancer nurse of these wishes and discussed resuscitation with his district nurse.

Clive, the other person who had discussed dying with his wife, had outlived his prognosis by 6 years. He talked about having written a will; he said that he wanted a wake before he died and had expressed wishes about being buried. Clive reported having discussed that he did not want his wife and son to watch him ending up like 'a cabbage'. Instead he preferred a 'quick death'. Clive explained that he deferred to his wife Yvette on health decisions, believing that she knew his wishes about the care of his body after death and that she would advocate for and respect his wishes if he could no longer speak for himself. Unlike other wives, Yvette was a health care worker, and as Clive said, had seen people die many times before.

The difference between Jim and Clive compared to other participants is the longer length of time since diagnosis. Jim and Clive recalled being told that they had only months to live, a prognosis which they had both vastly outlived. Unlike in George's case, what is not known is whether there was any influence from health care professionals on Jim and Clive's decision to start a discussion with their families or whether it was Jim and Clive's idea to initiate these discussions. What is apparent is that all three reported initiating discussions with their families out of concern for them.

When asked, interviewees for the most part denied the involvement of any health professionals in initiating a discussion about future care. The possible influence of the disclosure of a prognosis on people's ability or desire to discuss or not discuss the future with their families and health professionals' discussions about the future will be discussed in the following chapter 'only months to live'.

As a researcher I am aware that people may have had earlier discussions with families about the future, which they may have chosen not share with me. In addition, there were two people I could not ask about discussing the future because they had clearly expressed a desire not to 'go there', and there were a further two for whom I had to refocus questions about the future towards past experiences of discussions in clinic.

In contrast to the individuals with cancer, nine family members talked about wanting to discuss the future, particularly in relation to practical plans. They described the difficulties and barriers that prevented this.  These views were shared in the group and individual interviews with family members. Some family members commented that they had already discussed plans for the future. This seemed to relate to previous experiences of the deaths of others such as family, friends and neighbours or was prompted by previous illnesses.  For example, Eve reported having discussed funeral plans when Barney had had a stroke, (figure 5.6:2).

Figure 5.6 Discussing dying

1. *"I mean I've had a lot of pleasure in life in planning.  I mean like planning your garden and stuff like that, now that's not just, you're doing something today but you're hoping to see it achieved later in the year, so it's not just live for today.  And I've taken this on board in just the same way.  So right from the word go, mentally I've been thinking, but I knew I couldn't talk to my family about it, and it's only just now that, it's difficult, it's difficult for Wendy more than it is for me, because I've got a really clear idea as to what I'd like to see happen, which we did talk about the other day.  That's the funeral arrangements, you know coming on to that yeah."* (George, joint interview, p.6, L25)

2. *Eve: "Um, as regards making plans, well we've already, before Barney was diagnosed we'd, we'd already spoken about, um, what we would like to happen to us, our funerals and that kind of thing." (Eve, Group interview 1, p.1, L14)*

3. *Angela: "I want him at home, to look after him myself, as long as is humanly possible."*

   *Eve: "Yes, I want that as well, exactly that."* (Angela and Eve, Group interview 1, p.15, L1)

Wives appeared to be the ones who planned special events such as Christmas meals or anniversary celebrations and who expressed views about the place of care for their husbands (figure 5.6:3). Some people with lung cancer talked about not necessarily agreeing with their families' wishes to care for them; for example, Andy preferred to wait and see what his care needs would be (figure 5.7:1). By contrast, for family members, barriers to discussing the future were related to not wanting to appear disloyal to their husband or wife (figure 5.7:2), or to emotionally distress the person living with cancer. Some people with cancer preferred to leave decisions to their family, unaware of the isolation this sometimes caused (figure 5.7:3).

Figure 5.7 Family wanting to make practical plans

1. Andy: "*To be quite honest, my family's said you're going nowhere. Sarah (daughter) is a trained carer, she was in charge of I don't know how many for a private company. Uh, the eldest girl, if you look straight across there, there's a gap between them terraced houses and Angela's (wife) the one on the left. So I mean she's only 50 yards away, and Angela wouldn't, uh, no matter what cost it was to her, I don't think she'd - it'd have to be a push on them. I mean I'll be honest, I haven't thought that far ahead personally, but I mean our Sarah's said quite straight out, me dad's going nowhere, we'll look after him. I said that's all well and good if you're capable. So we'll just have to wait and see".* (Andy, individual interview, p.2, L 20)

2.  *Angela: "I know with Andy, um, he's accepting, we're accepting what's there, and he's saying we're getting on with things, and he knows that when the crunch comes, um, I'm there for him and we're going to keep him at home as long as possible. But actually things that we may need when that time comes, um, it's hard to discuss when somebody's convinced that we're going to fight something. And you can't, you just cannot be disloyal. And I feel, you know, totally disloyal by saying Andy, this is one thing we can't win. Do you know what I mean? We know it's going to happen, um, [slight pause] and you do, you feel disloyal. You can't."* (Angela, Group interview 1, p.2, L24)

3.  *Kath: "I mean I've read up on the disease but what they haven't done is told us how it's going to affect him. What, you know, um, how incapacitated he's going to be, um, what sort of effects it's going to have on his body, what should I do etc, etc. Um. I mean, as I said, I've searched the web and read about the disease but they don't tell you anything specific, um, like what I should do, you know, um, what the effects will be on his body, you know, how it will affect him. Um, I mean they give you all the symptoms of lung cancer, but they don't tell you how to deal with it. What to look out for, contact a doctor, you know, look out for this, that and the other. But then that's about as much as they say, they don't say, you know, how to cope with it"*

    *Interviewer: "And how does that make you feel?"*

    *Kath: "Um. [slight pause].Yeah, very isolated, um, because to help him I need some knowledge of what to do. And I feel quite isolated in the fact that I don't know what to do. And I want to help him as much as I can, through it, you know. So. So, I mean at first when, um, he was diagnosed and six months, I didn't know whether I should go back to work or not. I, it, so I didn't know whether I should go back to work, what am I supposed to do, am I supposed to take six months off, you know, because they said six months, you know, it's like what am I supposed to do. I don't know what to do because I've not been in this situation before, you know, sort of thing."* (Kath, wife of Simon, single interview, p.8, L 24)

Some family members appeared frustrated at not being able to make plans because the person they were caring for was 'still well', 'determined to get better' or did not want to worry about the future. Some people reported a preference for focussing on 'making the most' of life by keeping positive and not 'looking on the dark side' or accepting their lot and being

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grateful for their life. Others reported not knowing what to expect in the future and therefore not knowing how to plan or what to plan for.

Family members' perspectives on discussing the future were about making practical plans, but unlike most people with cancer these plans also related to practical issues about the dying process such as access to equipment. Knowledge of where to access help such as nursing support, drugs, respite care at night, financial support for caring and emergency medical care were things families talked about wanting to discuss. The level of their knowledge and understanding of the dying trajectory also differed, and this was something which was not talked about by people with cancer, and many people found it difficult to discuss with health professionals. Sometimes lack of knowledge and the inability to discuss their needs with the people living with cancer appeared to leave family members feeling isolated as mentioned earlier (figure 5.7:3). Furthermore, family members reported it left them lacking peace or feeling afraid of not being prepared for the death event (figure 5.8:1).

Figure 5.8 Family wanting to prepare

1. *Angela: "I think it's just maybe the little bit (experience), although I've had sisters that's had it [cancer] it's been their families and I've only sat in. Um, and there's things that if he needs this, this and this, it's automatic there for you, but there might be some things I might have to buy. And I don't know if there's anything I've got to get that I've not got it. Do you know what I mean? I'd like to know a list of what we have to have in the eventuality that we may need to have in, because I don't want to be running around at the last minute."*

2. *Mary: "I think that's a gradual thing though."*

3. *Angela: "And that's my fear, that there might be something I need and I should   have prepared for that I haven't done." (Angela and Mary, Group interview 1, p.20, L12)*

What is evident in these findings is that people with cancer and family members place different meanings on the concept of discussing plans for the future, whether these are plans to prepare for the dying process or plans for after death.

## Practical planning for 'when I'm gone'

As previously reported, most plans made by people living with advanced lung cancer were related to practical issues, for example: funerals, wills, finances and distribution or destruction of possessions such as clothes (figure 5.1). Others had made plans such as arranging for a house cleaner to support their partner in housekeeping and another person had accumulated a secret supply of steroids in anticipation that his general practitioner might stop prescribing them. Some plans related to preferred place of death as patients wanted to support their families by making arrangements so that their families did not have the burden of looking after them at home.

Fifteen people described plans for funerals or wills. Ten people had either made plans or communicated wishes about their funeral either to their family or friends. For some, this included whether to have a church service and what songs they wanted to be sung, for others it was a decision about whether they wanted to be buried or cremated. Some, like Mary, had written these wishes into their wills (figure 5.9:1) or joined a funeral plan to prepare financially for their own funeral. Nine people reported having made a will and some talked about sorting out their finances. Four of these nine people had also made plans for their funeral.

Figure 5.9 Planning for 'when I'm gone'

1. *"But it's all in the will anyway, what's going to happen.  Because I'm not going to be buried, I'm going to be cremated.  And I've told them where I want my ashes to go.  I don't want them with my husband because he's with his first wife.  I put him there you see, so I shall go with my mum and dad."* (Mary, single interview, p.5, L9)

2.   *Angela: "And then, at the same time, we have made a will, um, but if anybody says*
*anything to Andy he'll say oh, as far as I'm concerned when I'm dead, just take me to*
*crematorium and put my ashes where you want. So we can't discuss, so if it was to*
*happen to Andy I don't really know - even my own funeral arrangements, he doesn't*
*know. And my mum made her funeral arrangements before she died, and I'm quite*
*happy to make mine because the way I look at it is if anything happens to me, same*
*as when it happened to me mum, everything went into place, the hymns, the colour*
*the gown, everything was there and the family didn't have to say I wonder if this was*
*what my mum wanted. She'd picked it herself. And I would like to do the same for*
*me, and I would really like to know if anything happened to Andy what he would*
*really want. But he just does not want to discuss it at all."*

*Eve: "Well we spoke about this actually. My mum died two years ago and, you*
*know, when your parent - this was the last parent, it really focuses your mind*
*because you've then reached the top of the tree haven't you, you know, as regards*
*your family. And so we spoke about it and decided, and when we made our wills we*
*wrote it into the wills, you know, that we wished to be buried and all this kind of thing.*
*So, you know, in a way we don't have to speak about that because it's already there*
*and, you know, we decided we want a woodland plot so, you know, it's, it's already*
*there."* (Angela and Eve, Group interview 1, p.9, L21)

Two family members reported knowing what their husbands wanted for their funeral. One of these was Eve whom we read about earlier. Some family members had differing views. For example, during an interview with his wife Angela, Andy talked about not wanting a gravestone or church service. Angela then reported later in a group interview (figure 5.9:2) that Andy would not discuss his funeral with her. Angela's comments on the differences in religious views between them may help explain the difficulties they faced in discussing and making plans for the funeral.

The daughters of one person with cancer talked about planning their mother's funeral for her because they knew what her wishes were, even though they reported they could not talk to their mother about future care. Another daughter of a different person with cancer claimed

that she did not know her mother's wishes and also that she was not able to talk to her about the future.

## Wishes and decisions about dying

Some participants expressed views about things they did and did not want for their future care and treatment. As discussed earlier, many people wished for or planned for a holiday. There were only a few who expressed wishes for the future that also related to dying. These wishes ranged from preferred place of death, for example at home or in a hospice, to more specific wishes such as not dying in pain, seeing the pet dog before death or wanting to donate an organ.

Some wishes were reportedly shared with family members before or after the start of the illness. Other people had wishes that they reported had not been shared with family members or others. Some people said they had not thought about their wishes prior to the research interview and then shared some thoughts with me. Others declined at interview to enter this realm of conversation. A small number of people expressed views related to the dying process which for the most part were offered within the context of questions about future treatment or care. The views or wishes expressed were for a quick death and some had thoughts about resuscitation.

## Preferred place of care

There were seven people with cancer who talked about their preferred place of death. All seven patients stated they did not want to spend their last days in hospital, with three wishing to be at home and the other four preferring to die in a hospice. One of those wanting to die in the hospice (Jim, who had been diagnosed the longest of all the people with lung cancer), had wanted to die at home but talked about reaching a compromise for his wife's benefit

(figure 5.10:1). Some had shared these wishes with family members and others like Ruby who lived on her own had not (figure 5.10:2).

Figure 5.10 Preferred place of care

1. "*I don't want to go into hospital. I want to go into hospice. I want to die at home. The wife don't want me to die at home, and I don't want to die at hospital so we come to a compromise, if possible, and go to the hospice when the time comes*" (Jim, joint interview, p.5, L1)

2. *Ruby: "Well I, myself, if I get really ill I'd like to be at home and have visit, you know, have the doctors and nurses coming here. Uh. And I have said that. I've said, you know, I don't want to die in hospital to be honest I've said, and uh, I said I'd rather be at home. And I know my family will look after me and anything, you know…"*

   *Interviewer: "And who have you discussed those, your wishes with?"*

   *Ruby: "Only with the nurses and, you know, talked to the nurses".*

   *Interviewer: "The district nurse?"*

   *Ruby: "Yeah. Yeah. Um, but I didn't, I didn't to my kids because I don't bring dying up, you know, I don't bring it up if I can help it."* (Ruby, single interview, p.7, L12)

The example from Ruby highlighted a possible conflict between Ruby's expectations that her family would look after her so she could die at home and her family's lack of knowledge of this wish because she had not wanted to talk about dying.

Those who expressed a preferred place of care did not wish for hospital care. Hospice was viewed by some participants as the next best alternative to hospital when home was not an option. Several people had already experienced hospice services either through the day hospice, from an admission for symptom management or from visiting friends who had died

in the hospice. A few people who had experienced hospice talked about their earlier fears of using that service because of the stories they had heard (figure 5.11:1). Once people had 'hospice' explained to them or they had experienced hospice services for themselves, they said these fears disappeared.

Figure 5.11 Hospice

1.  "*I mean if I had to end my days like that (in hospital) I'd rather end it in Hospice, if I was here in ….(town), because they are fantastic up there.  You know, they're so caring. They can't do anything for you but they just care for you. And to me that place is fabulous.  I've been in there once before. When I first had my lung out I went into have my medication sorted out.  And they're marvellous in there. People say things about hospices, but they're not true.  They do work hard to keep you going.  I mean I wouldn't like to spend me, the last of me days in hospital.*" (Clive, single interview, p.9, L25)

The nine family members who were interviewed separately from the people with cancer reported similar views about place of care. Family members said they thought people would be happier at home, easier to treat and that they would be better able to provide 24 hour care, unlike in the hospital. But they did express concerns for themselves as carers being able to fulfill their husbands' or mothers' wishes to be at home. These concerns were reported as a lack of knowledge about what to expect and what equipment they might require including where to access it. What is not known, apart from one family member in this study, is the relationship, if any, between preferences for place of care and family members' previous experiences of caring for someone who died.

## 'A quick death'

Five men from the sample of 25 expressed a preference for not being kept alive on machines and lingering on for weeks. They held hopes of a 'quick death' (figure 5.12:1). Two

of these were men who had outlived their prognosis. One man reported that his wife had died

some years previously in an intensive care unit. He related this to a shortage of beds. This

may have influenced his wish for a quick death.  Another had initiated discussion about dying

with his general practitioner out of concern to plan for his family. A third man hoped he would

not be aware of his dying. Three of these people who wished for a 'quick death' linked this to

not wasting resources, talking about "no-hopers" occupying limited National Health Service

beds.  For the others a 'quick death' meant not suffering and their family not having to endure

watching that. It also meant quality rather than quantity, viewing a longer dying process as a

painful experience. These reports may have been influenced by gender or the knowledge

they had that I worked for the NHS.


Figure 5.12 'Quick death'

> 1. *"And if it does come I hope it's quick.  I hope I'm not lingering for bloody weeks and*
>    *weeks in bed.  When it does come, I hope it's going to be pretty quick. When it comes, it*
>    *comes with a vengeance and gets over with it, so I'm not hanging about bloody in pain or*
>    *owt.  That's what we've discussed isn't it?"*
>
>    *Vivienne:  "You don't do pain do you duck?"*
>
>    *Jim: " No, I don't do pain."* (Jim, joint interview, p.5, L8)


Other preferences expressed related to care of their body after death (figure 5.1). Three

of the men with cancer discussed the care of their bodies after their death. Two participants

were Jim and Clive who had outlived their prognosis. One talked about his wishes to donate

his organs for research but, when he looked into it and discovered he would have to donate

his whole body, he declined. The other was concerned not to die in hospital because he did

not want to be infected with MRSA or other germs. He stated that this would require his body

to be burned when he preferred to be buried. The remaining person placed little importance

on his physical body. He compared his body to a car engine, which, when it 'packed up',

should be got rid of.

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Five people with cancer offered a variety of views about resuscitation in the context of questions about future decisions or preferences. Andy, who had a secondary diagnosis of an aortic aneurysm, reported having been clearly told by his doctor that he was not for resuscitation and that he had been informed this was written in his medical notes. Jim had told his general practitioner he did not want resuscitating, whereas Clive just assumed that the doctors would write that in his notes. Burt said he'd leave the decision about resuscitation to his wife. Ruby stated she still wanted attempts at resuscitation as she would not want the doctors to give up on her. Only Jim had communicated his own wishes to his health professionals.

Three wives of people with cancer also expressed views about resuscitation in joint interviews. Eve, Barney's wife, talked about her experience of the doctors discussing resuscitation with her when her mother was dying but reported that this topic had not been broached in relation to her husband. Mary, Bernard's wife, reported that, like Ruby, she did not want the doctors to give up on Bernard, she wanted him resuscitated.

## Summary

The main findings described within this chapter are that people, if they plan, plan for care of their body or their estate, and do this out of concern for their family or others. Planning had different meanings for people. For some, like George, it was something they talked about having done all their lives. Others reported that planning had led to disappointments and subsequently caused challenges in trying to plan ahead. Some had focused plans on the next step in treatment or getting their family ready for their death. Where they did plan for their death the important issues to plan for were: preparations for the funeral, care of the body after death, establishing a will to set out financial arrangements for those left behind, enabling a 'quick death' without pain and, for seven people, planning for a preferred place of death.

The participants' reports in this chapter provide a narrative about selflessness in the face of an uncertain and limited future. Rather than focussing on autonomy, or individualism, people with advanced lung cancer in this study concerned themselves instead with protecting and planning ahead for their family and others.

# CHAPTER 6 : ONLY MONTHS TO LIVE

## Introduction

This chapter reports on the main category 'only months to live', which relates to people with cancer being given a prognosis[5] or a prediction of the remaining time they have left to live. Some people reported that doctors told them the remaining life they had left to live was only months or weeks, which a few people had outlived. For others, a prognosis was reported as vague, with doctors using words rather than numbers to communicate their chances of recovery. The final section of this chapter reports on the distressing effects on people living with lung cancer and their families of receiving, or not receiving a prognosis.

## 'Only months to live'

The substantive category 'only months to live' is made up of the following categories: 'disclosure of a prognosis', 'doctors work in numbers', 'outliving prognosis', 'the 'effects of a prognosis on the person with cancer', 'knowing is harmful' and the distressing 'effects of prognostication on people's families and friends'. Findings reported here also include participants' perceptions of receiving a prognosis which in their view is wrong, or they outlive the predicted time. The diagram in figure 6.1 provides a representation of the core dimensions and properties of this category. The core categories are in bold font with related properties in normal font.

---

[5] Prognosis is defined by Glare and Christaxis (20008) as "the relative probabilities of the various outcomes of the natural history of a disease" (p.5).

Figure 6.1 'Only months to live'



| Disclosure of a prognosis (solicited or unsolicited) Doctors 'work in numbers' |
| --- |

| Effect of a prognosis on the person with cancer.<br><br>knowing is harmful - removes uncertainty and hope for more time. Fear of asking for information. People marginalise their prognosis. |
| --- |

| Effect of prognosis on family and friends: anger, inability to plan, fear, distress. |
| --- |

Predicted death

| Outliving prognosis - consequences are: loss of faith or trust in doctor, inability to plan, life on hold, guilt. |
| --- |

Actual death

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## Case study

Simon was a 59 year old man who I interviewed alone whilst his wife Kath was at work. I returned at a later date, with his and Kath's permission, to interview Kath about her own views and experiences. Simon disclosed that he had been diagnosed with advanced lung cancer and brain metastases, which had caused the recent loss of sight in his right eye. Simon had experienced the death of two siblings in the previous two years. One brother, aged 70, had died of lung cancer.

Simon talked about his diagnosis and his own perceptions prior to diagnosis of what was causing his illness and his potential fate.

> "so I understand that, uh, because it's spread it, it, it's, um, you know, the lymph nodes, uh, they said they'd found lymph nodes on me chest. I weren't quite sure what that meant, but I knew enough, you know, to know that that's one way that cancer can spread, either through the lymph nodes or, or, or through the bloodstream. And, um, so, you know, I suspected that it was lung cancer so, I mean I know that if they didn't treat it, um, I'd probably got, you know, maybe nine months, maybe a year, you know, before it'd". (p.1, L6).

Simon's past experience of his brothers' deaths gave him prior knowledge of cancer and its consequences. When the consultant explained to Simon about his tumour being malignant, Simon nevertheless commented that he did not know how serious his illness was at that time:

> "…four weeks after surgery, you know, we went to see him, uh, and he, he, he explained, you know, what had happened. That was the first time, you know, I knew really that, um, that the tumour was malignant. And, uh, and then he's saying, you know, you've got serious problems Mr. . [Simon] you know, he's going on and I'm thinking, hmm, and so [laughs], you know, I don't know." (p,1, L17)

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Simon then talked about summoning up the courage to ask about what he should plan for the future. He reported that the consultant responded by disclosing the remaining time Simon had left to live:

*"I kind of just summoned up, you know, the bottle from somewhere anyway to ask him, you know, what I should I plan for the future. And then that's when he told me, you know, six, nine months, maybe a year if you're lucky. And like I say, good job I were sat down otherwise I'd have fell down, you know."* (p.1, L22)

Simon commented later in the interview the effects this disclosure had on his desire and ability to seek further information about his disease. He talked about whether the fact of knowing his future was so limited was worse than not knowing:

*"So I don't really know what to expect, um, and I've not really explored or read up on that yet, or asked about that. [Laughs]. I don't really, you know, I'm frightened to ask the doctors sometimes. Uh, you know, I mean after, you know, after being so bad that last time and, you know, um, I sometimes think I don't know what I want to know any more. You know. It's, um."*

*Interviewer: "Right, a bit worried about what they might say back, or?"*

*"Yeah, you know, you might get the answer you want. And, uh, I don't really know which is worse sometimes, you know, because you get that ooh, it's the not knowing isn't it that's, you know. But I think sometimes knowing is worse. So, I don't know, um, and I don't know if, if it's kind of hiding away from it, you know, hiding from reality or, you know, putting yourself in a bit of denial about, you know, what's happening. I, I don't think I am putting myself in denial, I think, you know, I'm fairly – I'm optimistic but pragmatic or realistic as well, you know, about, you know, what the consequences could be."* (p.4, L6-19)

For Simon, the disclosure meant that he feared asking for more information about his illness in case he heard more than he wanted to know or could 'cope' with. Simon appeared to manage this disclosure by taking "one day, or one episode, at a time" and reported a

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determination to "fight this". He talked about not really talking about the future with his wife, but commented that his wife suggested focusing on having his chemotherapy and then thinking about the future, as reported in the previous chapter. Several times Simon reported not wanting to think about the future, wanting to live for now and he attempted to rationalize this by commenting on still "feeling quite well". This links to the category of 'facing death when it comes' (chapter four), putting off thinking about the future because death is not "near enough".

Towards the end of the interview, when I asked for Simon's views about what doctors and nurses could do to help in planning and thinking about the future, he talked about the scientific approach doctors used. Simon appeared to question the usefulness of ratios, and whether or not they were helpful in making sense of his own prognosis.

> "I also understand that, you know, doctors, uh, they like to work in numbers, you know, they like to have a scientific approach to things don't they, you know. You know, one in three respond to this and so many respond to, you know, it's that kind of thing, which."
>
> Interviewer: "Is that helpful or?"
>
> "Which, I don't know. I don't know really. I don't, um, to me I don't think about it one way or the other, you know. Um, you know, a 60:40 chance and you think well, is it a 60:40 or 40:60 chance, which way and what have you, and you think well, I don't know. You know. Um. You know, again statistically driving a car's one of the most dangerous things you can do isn't it. You know, so. Or, um, I don't know.," (p.2, L29)

Unlike many others, Simon talked little about the effect of the disclosure of his prognosis on Kath (his wife), other than her desire not to attend her gym classes because of not wanting to leave him in the house on his own in the evening. However, he did talk about how his outlook now was to focus on his family and in particular his four children.

Kath, in her interview with me some weeks later, was very emotional about Simon's prognosis. She related his knowledge of his poor prognosis as the cause of his wish not to talk about the future:

*"Well, I've always been with Simon, um, when we've talked to the doctors. And, um, that first meeting with the doctor when we went back for the results, um, when Simon asked him how long, you know, and he says you're looking at six to nine months, um, that was a big blow to us, and Simon's not really wanted to know anything about it since then, so I've not asked. Because I've not spoke to the doctor by myself. So, and Simon, I don't think he could handle, you know, any more bad news like that, so I've, I've not pushed it."* (p.2, L8)

The desire not to force further discussions about Simon's prognosis or the future led to Kath also reporting a desire to not talk about the future with Simon or seek further information for herself. This appeared to have a huge emotional effect on Kath as she was not able to gain either the information she reportedly wanted about Simon's disease progression or an understanding of what she may expect as he declined. Again this links back to the previous chapter about difficulties in planning for the future out of concern for others. Further views about living with someone who had 'only months to live' and those of other wives and families will be explored later in this chapter.

## Disclosure of a prognosis

The characteristics of the disclosure of a prognosis reported in the interviews with people with lung cancer are depicted in table 6.1

Table 6.1 Reported characteristics of the disclosure of a prognosis

| Person with lung cancer | Report of Prognosis disclosed (Y/N) | Words used/numbers given | Person asked for prognosis | Family member asked for prognosis | Reported not wanting to know | Reported wanting to know | Reported self-awareness of dying |
|---|---|---|---|---|---|---|---|
| Barney | Y | Barney reported told Incurable. Wife reported told weeks to live | ✗ | ✓ | ✗ | ✗ | ✗ |
| Andy | Y | 6-12 months. "20% chance it'll kill you." | ✗ | ✗ | ✗ but wife didn't want to know | ✗ but reported appreciated being told truth. | ✓ |
| Candy | N | N/A – "going for cure" | ✗ | ✗ | ✗ | ✗ | ✗ |
| Simon | Y | 6-9 months | ✓ | ✗ | ✗ | ✓ | ✓ |
| Bernard | Y | But told terminal, bad. Wife reported 3-6 months without treatment, 18-24 months with. | ✗ | ✗ | ✗ | ✗ | ✗ but know it's serious |
| Dennis | Y | Can't operate, not much can do now | ✗ | ✗ but would have liked to | ✗ but reported not knowing what to ask | ✗ | ✗ |
| Henry | N | ✗ | ✗ | ✗ | ✗ | ✗ | ✗ |
| Clive | Y | Cancer spread | ✗ | ✗ | ✗ | ✗ | ✓ |

| Person with cancer | Report of Prognosis disclosed (Y/N) | Words used/numbers given | Person asked for prognosis | Family member asked for prognosis | Reported not wanting to know | Reported wanting to know | Reported self-awareness of dying |
|---|---|---|---|---|---|---|---|
| Jim | Y | 2 months (7 yrs ago). 6 months ago, given 1 month. | ✗ | ✗ | ✗ | ✗ | ✓ |
| Ruby | N | N/A | ✗ | ✓ (daughter) | ✓ | ✗ | Won't discuss dying |
| Dan | Y | "Same golden ball as you"; "working on quality not quantity" | ✓ | ✗ | ✗ | ✓ | ✓ |
| Stewart | Y but no reported time given | "Can't be cured" | ✗ | ✗ | ✓ | ✗ "ignorance is bliss" | ✗ |
| Burt | N | N/A | ✗ | Didn't want wife to know | ✗ | ✗ | ✓ via TV |
| Mabel | N | N/A | ✗ | ✗ | ✗ | ✗ | ✗ |
| Paul | N | But confused as told 5 more years if had surgery | ✗ | ✗ | ✗ said no one told them how long | ✗ | ✗ |
| Mary | Y | Told "wasn't good in more ways than one" | ✗ | ✗ | ✗ | ✗ | Aware really ill |
| George | N | ✗ | ✗ | ✗ | ✗ | ✗ | Yes (aware less than 12 months), told doctor "we've seen beginning of the end" |

| Person with cancer | Report of Prognosis disclosed (Y/N) | Words used/numbers given | Person asked for prognosis | Family member asked for prognosis | Reported not wanting to know | Reported wanting to know | Reported self-awareness of dying |
|---|---|---|---|---|---|---|---|
| Bob | N | N/A | ✗ | ✗ | ✗ but said "didn't want to go there" | ✗ | ✗ |
| Vicky | Y | Told 'no cure' | ✗ | ✗ | ✗ | ✗ | ✓ |
| Colin | Y | 2 days to 2 weeks, also prev. 6-8 months for mouth cancer | ✗ | ✗ | ✗ | ✗ did say better off knowing | ✓ |
| Doris | N | N/A | ✗ | ✗ | ✓ | ✗ | ✗ |
| Shelley | Y | 8 months by Dr, 12-18 mnths by nurse | ✗ | ✓ (husband) | ✗ | ✗ | ✓ |
| Edward | Y | Nothing much we can do | ✗ | ✗ | ✗ | ✗ | ✗ |
| Morris | Y | Won't be able to cure it | ✗ | ✗ | ✗ | ✗ | ✗ |
| Bernie | Y | Told 18 months with treatment | ✗ | ✗ | ✓ | ✗ | ✓ |
| **Totals** | **16** | | **2** | **2** | **4** | **3** | **11** |

Simon was one of 16 people who reported being informed of the probable course of their disease, but unlike Simon most of the others did not talk about having asked for a prognosis or having being given the option to receive this information. Two of those who received a prognosis reported not wanting to know, although it is not known whether this was a subsequent reaction to having been informed rather than a preference prior to the disclosure.

Doctors were reported to have used words or amounts of time to convey their prediction of the outcome of the disease. Words recalled included, for example: 'can't be cured', 'terminal', 'bad', 'not much we can do now', 'working on quality not quantity'. The use of predicted time left, such as weeks or months to live, will be discussed later.

Dan, who was 76 years old, was the only other person with lung cancer in the study who talked about asking how much time he had left to live. Dan was anxious to find out whether he would be well enough to go on a planned cruise with his wife. He reported that at first he did not appear to receive the 'truth' he requested, but after further probing and disclosing his own self-awareness of his demise he said he received enough information to make his decision (Figure 6.2:1).

Figure 6.2 Disclosure of a prognosis

> 1. *"I said look, all the way through Mr A and Mr. B (oncologists), they both have been very open, they've said that there's no cure, but they can retard it, how long have I got? We don't know, you've got the same golden ball as I have, could be a week, could be a fortnight, could be five weeks, could be five years, we don't know, it's under mentioned finish kind of thing. So I said fair enough. Anyway, I said, I know what's going off and I want the truth. Right, so that was it. Anyway, so he said well I'm working on the quality of life and not quantity, which I said that's fair enough." (*Dan, single interview, p.3, L12*)*

Three family members sought to find out the prognosis of the person with cancer during the clinical consultations. Shelley, who we met in the previous chapter, said that her husband had asked for her prognosis, as did Ruby's daughter. Unlike Shelley, Ruby had subsequently intervened and refused to have her daughter's question answered because she did not want to know (figure 6.2:2). Eve, Barney's wife, had asked the doctor how much time Barney had left.

Nine people did not report that they had been given a prognosis. What is not known is whether they did receive a prognosis, but did not talk about it at interview. One of the nine people, Burt, talked about not being aware of his prognosis and expressed a desire to know what time he had left to live. This was problematic for him because he did not want to ask his doctor or nurse in front of his wife Jane who was always with him at his doctor's appointments (figure 6.2:3). Burt used information gained from the television to estimate a

sense of how long he had left to live. He did not explain why he did not want his wife present. When I asked him later about how the doctors would know he wanted this information without his wife present Burt said it would need to be "*like a secret service talk*" (p.6, L29) and recognised this would be difficult to achieve.

People appeared to attribute different meanings to whether or not they received a prognosis that they were terminally ill. For example, Candy, aged 58, talked about caring for her mum and brother who had died of cancer (figure 6.3:1) and compared their prognosis to her own circumstances where she had not received a prognosis and could therefore think more positively. Doris did not want to know her prognosis and also commented that she had been told by the doctor she was going to be cured and this had never been retracted. She talked about knowing others who were receiving chemotherapy and how they had been told they were terminally ill, whereas she had not (figure 6.3:2). For Doris, the absence of a prognosis of a terminal illness meant she was not dying.

Figure 6.3 Comparing prognoses

1. Candy: *"I think it was hard for us because I nursed my mum with cancer."*

   Interviewer: *"Did you?"*Candy: *"Right 'til, 'cos she lived with us, and then, uh, my brother, about three years ago,he was only 56, he died of cancer.  So there's not, we know quite a bit, you know, but they was both terminal and said they've only got a certain amount.  I haven't been down that road, so this is why we can look at it a little bit differently, you know, so."* (Candy, joint interview, p.6, L20)

2. *"I knew a lot of people had chemo and was told they were terminal, just told them straight out and, you know, you're terminal, which he's never said that to me… So he's never said it, he's never said the treatment had worked."* (Doris, joint interview, p.17, L13)

3.   *"Yeah, I'd want, I'd want to know what was what and what to expect.  But, it is, it's just not knowing, you know, I'd rather know, but I know Steve doesn't want to know and so that's why I'd like the opportunity to, you know, actually talk to a doctor."*
(Kath, individual interview, p.5, L11)

4.   Sheila: *"Doctor C said to him, if you have this operation and it's successful you could live another five years.  But he hadn't said how many years he was supposed to live in the first place.  I mean he could live another five and probably without the operation could live another ten."*

Paul: *"It could knock five years off."*

Sheila: *"I'm just being a bit sarcastic that way because to tell somebody you could have an extra five when you've not told them what the expected time really is nothing is it, they're not giving you information that way."*

Paul: *"And by opening up, like I say, it could knock five off, you know.  So, no, I don't…"* (Paul, joint interview, p.7, L7)

Eleven people who talked about receiving a prognosis did not state whether they had wanted to know a prognosis or not, although most of these appeared to have an awareness of the severity of their illness or dying status. Only four men (Barney, Dennis, Edward and Morris) who had received a prognosis did not talk within the interview about being aware of dying or having a serious illness. However, not talking about one's own awareness of dying does not necessarily mean these four men were unaware of the situation. They may have chosen to tell a particular account to me as a nurse researcher. Alternatively, Barney and Dennis, whose wives were present during interview, may have chosen not to disclose their own awareness to protect their wives.

Family members talked about prognostication in the group interviews. Eve, Barney's wife, talked openly with the other two wives in the first group discussion. Eve said that when she

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asked the doctor: "*how long, you know, Barney might have, he, he said well, probably just a few week*s" (group interview one, p.1, L26), which for them meant he would not live beyond Christmas. Barney did not discuss this in the joint interview. In addition, Mary discussed how they had been given a predicted time left in relation to probable outcomes both with and without chemotherapy treatment. Bernard did not talk about this; Mary reported that he was forgetful. Kath, (Simon's wife), talked about wanting to have a sense of prognosis, but she said she could not find this out because her husband did not want to know (figure 6.3:3*). As was the case with Burt, for some people, asking for information to be disclosed when family members were present at the clinical consultation, was problematic.

## Doctors work in numbers

Six people talked about doctors or nurses using numbers to give a predicted amount of time left to live. These were either numbers of weeks, months, years, ratios or measurements of the size of their tumour. For example, people talked about being given a period of time left to live such as two weeks, six to eight months and five years. Sometimes this created confusion when people outlived their predicted time left which then seemed to create difficulties in relationships with the health professional who had disclosed the prognosis. This will be discussed in the following section: 'outliving prognosis'. Some people reported having received partial information about their prognosis. This left them to guess what their prognosis was by the number of additional years they were led to believe they would live if they received treatment (figure 6.3:4). For some, information about prognosis was more complex. For example, Andy had been given both a prognosis of six to twelve months (table 6.1) and also that there was a 20% chance his aneurysm would kill him before his cancer did (figure 6.4:1).

Use of ratios was reported in relation to predicting the chance of survival or chance of further debilitation from disease. This created confusion when people tried to interpret the meaning of this. For example, Simon, who we met earlier, talked about whether the doctor

meant a 60:40 chance of survival or a 40:60 chance of survival. He was unsure which was meant. Mabel reported being given a 1 in 100 chance of being in a wheelchair with oxygen as an outcome of her disease. This information reportedly caused Mabel distress because not only had this been unsolicited (figure 6.4:2), but it also caused her concern because she did not want to end up in a wheelchair, having experienced this previously when she had broken her foot. People also reported being told they had a 2 in 10 chance that the chemotherapy they received would be successful. This was also open to different interpretations.

Figure 6.4 Doctors work in numbers

| |
|---|
| 1.  *"He (hospital consultant) said, "You've got an enlarged aorta and", once again, "I'm sorry, I can't do anything for you", he said, "And there is a 20% change it'll kill you."* (Andy, joint interview, p.1, L11) |
| 2. *"He said there is a 1 in 100 chance you will end up in a wheelchair with oxygen…did not want that to happen"*. (Mabel, single interview, p.1, L28). |

Furthermore, other people with cancer reported the use of size when doctors described the growth of their tumour. This meant improved chance of survival to some people but to others it created confusion. For example, Paul reported that the doctor had compared the size of his lung tumour as somewhere between a cherry and a tomato (figure 6.5:1). Paul found this comparison problematic and dismissed this description because he didn't know what type of tomato the comparison related to, a cherry or a beef tomato.

Being informed by doctors that scans showed tumours had shrunk by centimetres provided hope of a cure to some people. For example, Bernard talked encouragingly about his tumour shrinking from 7cm to 3cm (figure 6.5:2) and yet he was receiving palliative treatment only. Interestingly, no one reported being told their tumours had increased in size. What is also missing from the data are any reports about health professionals initiating a

discussion to offer an explanation or further prognosis to people who had outlived the original predicted time they had left to live.

Figure 6.5 Size of cancer

1. Paul: *"He said he'd found a small amount in the right lung. In the bottom of my right lung, yeah, but that was it. It was Dr B that said what they'd found was just a bit bigger than a cherry."*
   Sheila: *"And not as big as a tomato."*
   Paul: *"Yeah, so I dismissed that part."*
   Sheila: *"So it could have been a beef tomato couldn't it, you know." (*Paul and Sheila, Joint interview, p.2, L23)


2. *"It were only in the right lung, not both, and halfway through chemo, the chemotherapy treatment I had a scan and it had shrunk it from 7cm to 3cm, and that was only halfway through the treatment. So Dr W (oncologist) was really, really, really pleased, you know."* (Bernard, joint interview, p.3, L2)

## Outliving prognosis

Four people reported outliving their prognosis. These were Jim, Clive, Shelley and Colin (table 6.1). There were others who knew of people, including celebrities, who had outlived their prognosis. These reports appeared to be used to rationalise the inadequacy of medical science or as a source of hope for more time. For example, Jim, (figure 6.6:1) having previously outlived his prognosis, talked about his personal knowledge that doctors don't always predict accurately. On the other hand, people like Andy (figure 6.6:2), who was still living within his predicted time left to live, looked to others' experiences as a source of hope: hope that their prognosis would also be wrong and that they would live longer.

People talked about feelings of anger, frustration and lack of faith or trust in the health professional who disclosed the prognosis when the prognosis turned out to be incorrect (figure 6.1). For example, Colin and his wife Teresa expressed anger towards the doctor who had offered a prognosis of just two weeks when Colin was still alive more than a year later. Colin had given away personal possessions, made plans for his death and his family had anticipated his imminent death (figure 6.6:3). Again, Shelley talked about her awareness that she had cheated death and sought to get on with living life as normal (figure 6.6:4).

One possible benefit of outliving their prognosis was that these people had talked about making preparations for their death (figure 6.6:5). They had also reported awareness that they were dying (Table 6.0). Jim, who early in the interview announced he was dying, reported having twice outlived his prognosis. Firstly, he reported being given a predicted time to live of two months, which had been more than seven years ago and then six months ago he had been given a prediction of one month. This may explain his reported attitude of 'live for today'.

Figure 6.6  Outliving prognosis

1. *"And I've had one or two with cancer, and all the advice I'd give to them is look at me, it's five years, they gave me two months to live and I'm still plodding about, so. What they tell you don't always work out.  So that's the only advice I can give them is live for today".* (Jim, joint interview, p.13, L12)

2. *"As far as I'm concerned, and it's like when I walked out on a sports pitch, whether it was football, rugby, cricket, whatever, I'll impose my will, I'm going to fight it and whatever, and I shall take the same attitude.  I mean they've told me six months to twelve months.  [Pause].  Jane Tomlinson's carried on for six years, and look what she's done in that six years, I mean it's absolutely fantastic.  I mean my own doctor, I spoke to him and he said he'd just lost a patient, [pause], they gave her just over a month to live he said, and she lasted sixteen years."* (Andy, joint interview p.5, L17)

3. *Colin:* "*And there's only one we didn't have faith with and that's Dr A. Because he says oh you've only got two days to a fortnight to live. And as soon as we got in, we got, the nurse come, district nurse come, and she says oh have you picked an undertaker? And we says what for? Well you're going to die. And she got these forms out, like being in there, well how did they word it last?*"

*Teresa:* "*You know, we made plans. Like, when they told him he'd only got two weeks to a fortnight he gave a lot of his things away. And he, it's things that were personal to him he gave away because he didn't think he were going to live to, which was a bit – then see he'd bounce back again.*" (Colin and Teresa, Joint interview, p.1,L17; p.10, L19)

4. "*When we went to New York, it was actually eight months, and I thought well I'm not supposed to be here now so I'll get on the plane anyway.*" (Shelley, single interview, p.12, L11)

5. "*The only thing I want to do is just write out a few songs for the service, you know, my favourite songs and some of them that's personal to me and Yvette. Just write down them and get them, a mate of mine's a DJ in Surrey so he'll come up and he'll have a, he'll prepare a tape for them. And he's already got the list and he's already done the tape, well the disc.*" (Clive, single interview, p.7, L4)

6. *Lorna:* "*She was waiting for Debbie's son to go because he'd been to see her and he said he'd be home after Christmas and she said she'd be waiting for him. So we thought that's what she's waiting for. That went too. And then we thought her birthday.*"

*Debbie:* "*That went.*"

*Lorna:* "*That went. Then there was a baby that might have been born on my mum's birthday but it was born a week later, so that went. Then my dad died on 13th February, 27 years ago, we thought maybe that. And the hospice have got all these dates …. And it's like this plan that's in action now is for six weeks.*"

*Debbie:* "*But then the six weeks is nearly …*"

*Lorna:* "*That's nearly up. So it'll be another six weeks.*"

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> *Mavis: "I think what we find frustrating for a family, and I don't know if you've found the same thing Claire, is once the prognosis was made that's been it."*
>
> *Mavis: "We don't know anything more."*
>
> *Lorna: "You don't know any more. So hopefully on Monday we'll be able to either see the specialist that made the prognosis. It's been organised. N (lung cancer nurse) is going to get something going on Monday. Either mean her going back in to hospital to a clinic to be reassessed or we just go and discuss with the specialist, but we feel totally in limbo because we don't know what's happening."* (Mavis, Debbie, Lorna, group interview 2, p.11, L5)

Some family members found it difficult when people with cancer outlived their prognosis. For example, some felt 'totally in limbo' (figure 6.6:6), as though their life was on hold (figure 6.1). Once a prognosis had been made, that was viewed as the end, without any further assessment of the patient who was still alive after their predicted date of death had passed. The family were left to guess whether the prognosis had been wrong, whether the cancer was still growing and how, if at all, they were to plan for the future.

The effect of a prognosis on the person with cancer

Being given a poor prognosis appeared to have a huge emotional impact both on the individual and on their families (figure 6.1).Ten people talked about the emotional impact on them. As mentioned in chapter four, the removal of uncertainty as a result of receiving a predicted outcome of their disease appeared to cause feelings of depression or fear (figure 6.7:1). Reactions of shock were also reported by some people, as reported for example, by Simon in figure 6.71:2. It is important to note that because of the nature of advanced lung cancer some people were given a prognosis at the time of diagnosis. Therefore, it is difficult to try to distinguish between the shock of a diagnosis of cancer and that following a prognosis of the outcome of the disease.

Some people talked about their prognosis being an educated guess (figure 6.7:3), which may suggest an attempt to rationalise or deny the accuracy of their prognosis. Some talked about others, such as celebrities like Jane Tomlinson, who had outlived their prognosis (figure 6.7:4), and this allowed them to hang onto that hope for themselves. Others talked about dismissing their prognosis because they still felt so well (figure 6.7:5). A 'negative case' was Paul, who talked about his reaction being different to that anticipated by his doctor because he did not demonstrate the expected emotion when faced with the seriousness of his disease (figure 6.7:6).

Figure 6.7 The effect of a prognosis on the person with cancer

1. *"Well, at the time you're just scared stiff, because you don't know if you've got a future. Uh. Now, um, it's just live in hopes isn't it."* (Bernard, joint interview, p.2, L18)

2. *"And then that's when he told me, you know, six, nine months, maybe a year if you're lucky.  And like I say, good job I were sat down otherwise I'd have fell down, you know."* (Simon, single interview, p.1, L26)

3. *"Well, I mean Dr Tan, he turned round and said, I said I'm thinking about maybe going away with the family in Easter, he says don't wait while Easter.  Well I mean in some respects I suppose that's a bit of a downer, but [pause] not with me.  Because, uh, I know it's an educated guess on his behalf, but it's still a guess to a certain extent, so."* (Andy, joint interview, p.9, L10)

4. *"I mean they've told me six months to twelve months.  [Pause].  Jane Tomlinson's carried on for six years, and look what she's done in that six years, I mean it's absolutely fantastic."* (Andy, joint interview, p.5,L19)

5. *"So that's the understanding I've got is that I've, both me lungs are affected and that's it. But I don't feel as though I've got it, so. [laughs] I've never coughed, never coughed anything up."* (Stewart, single interview, p.1, L22)

6.  Paul: *"When Dr W first told us, the only one that had a reaction was Dr W himself and the wife. I don't know what he expected me to do, jump up in the air or just collapse on floor like.*

    *Sheila: When he asked you three times, 'are you aware what I'm telling you?*

    *Paul: Yeah but I'd just no reaction, and I hadn't. Like I say, I've no feelings one way or the other.*

    *Sheila: He gave it up as a bad job last week didn't he? Paul: Yeah. I'd no feelings one way or the other."* (Paul and Sheila, joint interview, p.15, L17-21)

As mentioned previously, four people reported receiving inaccurate predictions of the amount of time they had left to live. Those who were then given a second prognosis appeared to report experiencing less emotional impact. For example, when he was asked at the start of the interview (figure 6.8:1) about his understanding of his illness, Jim talked in a 'matter of fact' manner about his cancer and his attitude towards his prognosis. It is important to note that it is possible that people report their stories or views differently to a stranger within the context of a research interview, than they might to others with whom they have a different relationship.

People with cancer talked about wanting to be able to live life as 'normal' following disclosure of their prognosis. Rather than creating a sense of certainty about the future, the disclosure of a life-limiting prognosis appeared to create uncertainty about the future. For example, Bernie did not know whether to have his dental crown repaired because he was not sure if he would be alive in a year to benefit from it (figure 6.8:2) and Bernard reported being unsure if he had a future (figure 6.8:3). On the other hand, for some individuals the disclosure had the opposite effect, creating attitudes of wanting to make the most of life (figure 6.8:4).

For those who did not report having been given a prognosis, the unpredictability of the future appeared to foster hope for more time (figure 6.8: 5), but others reported uncertainty

from not having been offered a prognosis (figure 6.8:6). Some, like Doris, who had talked about refusing to ask or receive a prognosis, did this because they said they did not want to live with a 'death sentence' over them (figure 6.8:7).

Figure 6.8  An uncertain future

1.  Jim:  "I'm gonna die. I had cancer seven year ago. Yeah, they give me two months to live.  I'm still here seven years come this weekend."

    *Vivenne:  "This weekend."*

    *Jim: "And [coughs] about six months ago they give me a month to live, and I'm still plodding about. And I've got cancer in four places, so I think it is going round from one to one so it's going to last a bit longer, [laughs] basically. I'm not worried about dying, you know, What's gonna happen's gonna happen, there's nowt I can do about it so just going to enjoy life what I've got left."* (Jim and Vivenne, joint interview, p.1,L5)

2.  "*I broke my crown, so I've got to go and have it done, and I says to her well why bother just leave it, why pay for it when I might not be here in a year's time, so."* (Bernie, joint interview, p.23, L8)

3.  "*Well, at the time you're just scared stiff, because you don't know if you've got a future. Uh. Now, um, it's just live in hopes isn't it, because Dr W's parting words to us the last time we saw him were we've contained it.  But that's at the moment isn't it? Who knows what tomorrow brings?  Nobody, do they.  You know, as Dr W says, we don't have a crystal ball, just take it as it comes…"* (Bernard, joint interview, p.2,L18)

4.  "*So yeah I just take every day as it comes and if I don't feel brill then I don't do very much.  Or if I just think I don't want to do that, I have a think and I'm not going to do it now.  So it does make you think that life's for living."* (Shelley, single interview, p.8,L5)

5.  *Susan: "We're hoping that … Bob: That I've got a few years left."* (Bob and Susan, joint interview, p.10, L24)

6. *"But nobody's said how long, you see. Nobody's said five, ten or anything, or we can cure it. Dr. E says he can cure it but I don't believe him."* (Paul, joint interview, p.16, L18)

7. *"But there again I don't think I'd want to know if it was terminal. So I'll be quite truthful on that point, because I couldn't live with a death sentence, I just think this, I'm quite fit and I can do what I want, I don't want to wake me up in the morning and thinking is today going to be the day? I wouldn't want to know that anyway. I just think take each day as it comes. That's my philosophy."* (Doris, joint interview, p.1, L13)

8. *"Bill didn't, you know, he's not taking it on board how serious it really is. So, you know, it's difficult."* (Eileen, group interview 1, p.1, L27).

The wives of the husbands with lung cancer talked about the effect this news had on their husbands. There were reports of the person with cancer not wanting to talk about their prognosis. Some wives recalled that the person with cancer seemed not to take the seriousness of the news on board (figure 6.8:8) and others recognised how scared their husband appeared.

## Knowing is harmful

The five people who reported either not wanting to know their prognosis, or not wanting to 'go there', talked about their anticipation that living with this knowledge would be worse for them, than not knowing. They suggested that the knowledge of a prognosis would be harmful. Stewart thought it was a "mind game", which he did not want to get into and expressed the view that what you did not know could not hurt you (figure 6.9:1). He also added later that to know whether his death was imminent would damage his ability to focus on remaining positive. Ruby said that if she were to acquire this type of knowledge it would 'bring things too close' for her. Similarly, Doris reported that she could not live with a death sentence (figure 6.9:2), and Bernie (and his wife Jane) talked about wanting to know good

news, but not bad. Although all five did not want to know their prognosis, they did want to know other information such as the extent of their disease, updated information about the spread of the cancer (figure 6.9:3), or whether chemotherapy treatment had worked (figure 6.9:4).

Figure 6.9 Knowing is harmful

1. *"I'm a different person to anybody else, 'cos I'm ignorance is bliss. What you don't know can't hurt you, so I'm one of them. They can either tell me or not tell me. Too much information, you know, can drive you round the twist. [laughs, rubs hands together]. So I'm quite happy."* (Stewart, single interview, p.3, L7)

2. "*But there again I don't think I'd want to know if it was terminal. So I'll be quite truthful on that point, because I couldn't live with a death sentence...*" (Doris, joint interview, p.1, L13)

3. "*Only that I don't want them to tell me, uh, you know, how long I've got or anything like that. No, I don't want to, I don't want to know that. Uh, I would like them to tell me how far, uh, how it's advancing or, or decreasing, you know. Because, as I say, last time I went I didn't, I didn't get to know anything. So I'm hoping this time I have a scan and I know that, what's happening, you know, because I don't really know how it's going.*" (Ruby, single interview, p.14, L5)

4. Ted: *"Dr A (oncologist) hadn't come and said so and so, so and so, them cells on you what's gone. Nobody's ever said owt about them have they?"*

   Doris: *"Have they gone …"*

   Ted: *"Have they gone, have they gone with chemo, you know what I mean? I asked the question, how long would this, because you know, the way that chemo works for quite this time and I asked him that and he said I don't know. I thought well how can I know if, why, how can we know if you don't know, but he said I don't know didn't he?"* (Doris and Ted, joint interview, p.15, L2)

Effect of a prognosis on family and friends

People with cancer and those family members present during the joint interviews talked about the emotional effect the disclosure of the prognosis had on the family (figure 6.1). The typical effects resulting from the disclosure were: anger, such as experienced by Colin's children (figure 6.10:1), fear (figure 6.10:2) and crying (figure 6.10:3). People used words such as 'absolutely devastating', 'scared to death', 'berserk', 'floored', 'disastrous' to describe the effects of the disclosure on family members.  Perhaps this partially explains these in reports (chapter four) in which patients did not want to discuss the future out of concern for families' well-being.

Figure 6.10 Effect of a prognosis on family and friends

1.  Teresa: "So my eldest son, I mean I know he's got a bad temper, I have, and we've all got it.  Me eldest daughter, she went berserk didn't she?  Colin:  She says if I see that doctor, she says I'm going to floor him." (Colin and Teresa, joint interview, p.2, L26)

2.  Susan: "Well, it was quite frightening when he first said and it felt as if Bob was going to…"

    Bob:  "Die any day."Susan: "Die quite early and there was nothing they could do for him really, that was a shock." (Bob and Susan, joint interview, p.10, L1)

3.  "You know, I mean my grandson there, Adrian, the one in blue, came in and Angela's brother and his, and her sister-in-law were here, he gave me a cuddle and he just said, "I'm going to go and sit in the car Granddad", and I thought well that's unusual, he's going to sit in the car.   When I turned round he was breaking his heart in the car." (Andy, joint interview, p.1, L20)

During the group and individual interviews family members described the effect of the prognosis on themselves. The wives in the first group interview reported 'horrific nightmares' or waking up in tears (figure 6.11:1), crying, never wanting to hear bad news. These wives talked about waiting for their husbands (Barney, Andy and Bernard) to die. There were reported difficulties of communication with their husbands following the disclosure of a

prognosis because they did not appear to want to talk. They discussed together how they did not think doctors should disclose a prognosis (figure 6.11:2) and Angela reported never having asked for a prognosis. She said that knowing was like a time bomb in her head (figure 6.11:3). Mary agreed with this and talked about being both annoyed and scared about receiving this unsolicited information.

Informing the children about the prognosis was also problematic for the wives of people with cancer. They reported avoiding telling the 'truth' to grandchildren (figure 6.11:4) and it was suggested by Angela that it was hard to tell grandchildren because they did not have the answers themselves. For other family members, knowing their mothers' prognosis meant there were difficulties in talking to their mothers about the future (figure 6.11:5), putting their lives on hold and waiting for their mothers to die (figure 6.11:6). Some questioned the accuracy of the prognosis or felt uneasy when death did not happen and they were left wondering when it would. Family members' reported experiences and views echoed those of people with cancer, demonstrating the difficulties and the distress it caused them on receiving news of the prognosis.

Figure 6.11 'Nightmares' and 'time-bombs'

1. "*When we first found out, I don't know about you, I had nightmares.  When we first found out with the first couple of weeks, I had horrific nightmares.  I'd wake up absolutely sweating and shaking, and then I just used to wake up in the morning, as soon as I woke up I'd got tears.  I just couldn't control it, I used to just wake up crying.*" (Mary, group interview 1, p.5, L9).

2. "*I do not think they should ever say - I mean when they said that to me and my husband, three to six months if it doesn't work, 18 months two years tops, you know, like why are you saying that, how do you know.  And it really annoyed me.*" (Mary, group interview 1, p.8, L10)

3. *Angela: "Well, we've never asked, and what we'd said is we didn't want a time bomb in our head."*

*Mary: "No, exactly."*

*Angela: "Ticking away."*

*Mary: "You don't.*" (Mary and Angela, group interview 1, p.9, L1)

4. "*I mean three grandchildren who we see very, very often, you know, and they don't know. So we just kept the news, you know, they know granddad's poorly but that's it. You see, because we have, um, we had to have a hospital bed so that's downstairs so, of course, they question why has granddad got a bed, you know. But because he's suffered with his knees and he had a stroke, we just sort of say well, he's not very well, and his knees are poorly and he has to rest, and leave it at that. Which, you know, you can only tell children so much can't you*?" (Eileen, group interview 1, p.11, L23)

5. "*… the doctor told my mum in the hospital after he had called me in and told me, and so she knows but she doesn't want to acknowledge it and that, which makes it very hard because we can't talk to her about it.*" (Mavis, group interview 2, p.6 L1).

6. "*Because we've felt because we've been given the six weeks and we knew that it was a give or take on the six weeks, I think we'd geared ourselves to six weeks. And then once it got over the six weeks it hit us because we'd been putting in hundred percent; sleeping on the floor, sleeping on the settees and just the fact of being there when we're not used to being there and being away from our own homes.*" (Debbie, group interview 2, p.10, L8).

## Summary

The disclosure of a prognosis appears to have the effect of taking away uncertainty and a person's current sense of 'normality', perhaps replacing this with another norm, the norm of a 'dying person' within a predicted timeline. People with cancer reported different interpretations of the information disclosed to them about their future. The sixteen people with

cancer (table 6.1) who reported receiving a prognosis appeared to suffer emotional distress at this disclosure, and they either rejected the information or marginalised the prognosis by reporting that they were 'not feeling ill'. They reported that the scientific approach used was confusing. Some considered knowing what time they had left to live to be harmful, as it made them feel angry or reduced their ability to hope for more time. In some cases people said that the knowledge of what time they had left to live caused them to be fearful of discussing the future. Similarly, family members described the emotional effects that the disclosure of a prognosis had on them and how this sometimes left them 'in limbo' when the person with cancer outlived the predicted time left. Finally, for those who outliving the predicted time left to live it they reported loss of faith or trust in the clinician who disclosed this information; however, for a few, the disclosure enabled them to discuss and make plans for the future.

# CHAPTER 7 : CLINICAL DISCUSSIONS ABOUT THE FUTURE

## Introduction

This chapter reports on the findings related to clinical discussions about the future and incorporates how people with cancer talked, or did not talk, with their health professionals about future treatment and care. The previous chapter reported on people's reactions to receiving news of their prognosis. This chapter now considers people's perceptions of their clinician's knowledge, advice, decisions and explanations about their future, together with their responses to this information. The findings include reports of participants' trust and faith in their doctor and the other health professionals involved in their care. Findings include the influence of families and the past experiences of other people's cancer treatment or deaths on the participants' personal decision-making. Information is usually required to make a decision. Lack of information may affect a person's ability to decide; some may cede their right to decide to others; others may refuse to make a decision. In this chapter we will see that the doctor may be deemed to be the most knowledgeable person to decide what is best for the future.

## Clinical discussions about the future

This substantive category has two main properties which are: informing practices and decision-making. These two main properties are highlighted in bold in the following diagram (figure 7.1), which also represents the concepts within this category. After the case study, which seeks to provide an overall report on this category, I will report on how people perceived they were informed, if at all, about future treatments or care available. This will include what, if any, discussions about the future they reported having with their health professionals, consultations with their doctors and their prior experience of others' cancer or death.

The final section will report on how people, if they chose to, talked about making their decisions. It includes people with cancer and their family members' views about future treatment and describes who they said influenced their decision-making. For the most part, people with cancer did not report information sharing or discussions with health professionals about choices or options for treatment.

Figure 7.1 Diagram representing the category: clinical discussions about the future

| | |
|---|---|
| Doctors don't explain | |

Doctors don't explain ↔ Doctor explained ↔ Health professional's explanations

'Doctor knows best' or Doctor is wrong

'Won't refuse treatment'/refusing treatment

'Not close enough to death to decide' ↔ 'Not qualified to make decisions'

Doctor's consultation

No options

Options

**Clinicians informing practices**

**Clinical discussions about the future**

**Patients' decision-making**

Influence of others on decision-making

Doctors don't discuss future options

Health professionals don't have deep discussions

Past experience of others' cancer/dying

'Decided together' ↔ Involving family in decisions

Case study

Bob was a 68 year old man who lived with his wife Susan. He had been diagnosed with lung cancer two years previously and had recently received a diagnosis of brain metastases. Bob and Susan had both experienced the deaths of their daughter and Susan's mother; both died of cancer.

> *Susan: "We've already gone through quite a few deaths.  Especially our daughter; thirty-nine, that was a shock."*
>
> *Bob:  "We went to Swansea to look after our daughter-in-law because she had breast cancer, had an operation for breast cancer."*
>
> *Susan:  "This year.  So we've been going down there to look after her children and to run their house because of her treatment."*
>
> *Interviewer: "And you lost your own daughter?"*
>
> *Susan: "And we lost our own, six years ago."* (joint interview, p.11, L4)

The death of Bob's daughter influenced both his and his wife's joint decision about whether to be cremated or buried, as his wife explains:

> *Susan: "…he, we was going to be buried and we decided not to because nobody goes down to our daughter's grave, it was only us that keep it going.  We thought well if one of us goes, we're not going to be able to sort of, or that when we've both gone, they won't want to be bothered."*
>
> *Bob: "All they want is your money."*
>
> *Susan:  "He wants to be cremated."*
>
> *Bob: "Cremated. Cremated and thrown on the dust heap, you know."*  (p.10, L12)

Bob and Susan commented on their daughter's attitude of not wanting to know how much time she had left to live, although she had been told it was 'terminal'. Susan reported a similar attitude with Bob:

> Susan: "If he gets a bit low and depressed, I shake him out of it and tell him to get on with it. Don't give him any sympathy."
>
> Bob: "You don't want sympathy, no. You feel sorry for yourself, don't you?"
>
> Susan: "My daughter was the same. She didn't want to know. She didn't want to know if she was going to die. She had three children…"
>
> Bob: "They told her she was terminally ill."
>
> Susan: "Yes, but they didn't tell her how long she'd got. She didn't want to know." (p.11, L6)

Bob later admitted he didn't like to talk to others about his cancer or the future and he also found it difficult to talk anyone about his deceased daughter.

In response to questions about his experience at clinic appointments and consultations with his doctors, Bob and Susan both talked about the content of these. Bob explained the focus was on his general condition. He was sometimes asked to fill in a form about his condition. Bob denied that there had been any discussion about options, information or plans for future treatment.

> Bob: "We haven't been given any options really. You know, we just went to the doctors. She sent me to the hospital. Didn't, wasn't given a choice. I had to go and see the heart people, and then I had to go and see the other consultant at Town, but other than that, and then Dr H phoned me up here. Since then, that's it, been it." (p.9, L8)

He also reported that doctors didn't discuss anything during the clinic appointment:

*Bob: "No, nothing, no. I just go and see Dr H every three months."*

*Susan: "Nothing's discussed at all."*

*Bob: "I just have an x-ray normally on the day I go to a clinic."*
(p.7, L9)

Bob and Susan reported that they had initially wanted to talk to a Macmillan nurse following diagnosis but had struggled to get in contact with one, subsequently deciding to manage on their own. This experience and their experience prior to their daughter's death was the context for the following:

*Susan: "They don't discuss anything do they? Only your condition. That's about it, goodbye, and that's what we like."*
( p.9, L20)

Bob and Susan appeared to accept the lack of discussion and explanations offered them. Likewise, when I asked Bob about his views on who should initiate conversations about future treatment, he said his preference was for the oncologist to tell him what treatment was required, he would then agree to it. He explained he would not seek out information about treatment for himself because he didn't feel as though he needed treating:

*Bob: "If I needed treatment in the future, I would sooner it come from somebody like Dr H (oncologist). Well I go on a three-monthly period. On the end of a three month he might say we need to do this or that. And I'd sooner him say come and do it, come and get the information, have the treatment and done with, not sit there worrying about it, you know. You know, I'd sooner, say someone like Dr H say you need this treatment and this is what I propose to do."*

*Interviewer: "So sort of for him to lead the way with regards to that…?"*

Bob: *"Because if it's up to me, I won't go and ask him for treatment, because I don't think I'm that bad. I don't go to the doctor's that often."* (p.14, L2)

Bob further explained that he had worked hard all his life and was always '*pretty fit*' prior to this illness. Before his diagnosis he had not visited a doctor for over 20 years. This was a new experience for him personally, although as already mentioned he had the experience of witnessing and supporting his daughter and her family through her cancer and her death.

The key issues in this case study are that Bob reported that health professionals involved in his treatment and care did not discuss the future and provided little if any explanations, other than those related to current diagnostic information for staging the disease. He reported expectations of the oncologist to inform him of any future treatments that would be required because he would not seek this out for himself. Bob and Susan's experience of their relatives' illnesses and subsequent deaths affected their decisions about funeral arrangements and their negative attitude towards discussions about the future. There appeared to be a reliance on the doctor to provide the direction for future treatment.

## Informing practices

There are several categories and codes within this property that will now be reported on (figure 7.1). Table 7.1 shows those people with cancer who reported on each category and the similarities and differences between those reports.

Table 7.1 Participants reports on clinicians' informing practices

| Person with cancer | 'Doctor knows best' or put trust in them | Doctor/Health Professional's explained | Doctor perceived as wrong | 'No faith' or trust in doctor | 'Doctors don't explain' | No options/ Doctors don't discuss options | Clinicians don't have 'deep discussion' or don't discuss the future | Past experience of others cancer/dying |
|---|---|---|---|---|---|---|---|---|
| Barney | ✓ | ✓ Nurse, but Dr contradictory | ✗ | ✗ | ✗ | ✗ | ✓ | ✗ |
| Andy | ✗ | ✗ | ✗ | ✗ | ✗ | ✓ | ✓ | ✓ |
| Candy | ✗ | ✗ | ✗ | ✗ | ✗ | ✓ | ✓ | ✓ |
| Simon | ✓ | ✓ | ✗ | ✗ | ✗ | ✓ | ✗ | ✓ |
| Bernard | ✓ | ✓ | ✗ | ✗ | ✓ | ✗ | ✓ | ✓ |
| Dennis | ✓ | ✗ | ✗ | ✗ | ✓ unless ask | ✓ | ✓ | ✗ |
| Henry | ✓ | ✗ | ✗ | ✗ | ✗ | ✗ | ✗ | ✗ |
| Clive | ✗ | ✗ | ✗ | ✗ | ✗ | ✗ | ✗ | ✓ |
| Jim | ✗ | ✓ DN | ✓ re- prognosis | ✗ | ✓ unless ask | ✗ | ✓ | ✗ |
| Ruby | ✗ | ✓ | ✗ | ✗ | ✗ | ✓ | ✗ | ✗ |
| Dan | ✗ | ✓ Cancer nurse | ✗ | ✗ | ✗ | ✗ | ✓ | ✗ |

| Person with cancer | 'Doctor knows best', put trust in them' | Doctor/Health Professional's explained | Doctor perceived as wrong | 'No faith'/trust in doctor | 'Doctors don't' explain | No options/ Doctors don't discuss options | Clinicians 'don't have deep discussions', Don't discuss future | Past experience of others cancer/dying |
|---|---|---|---|---|---|---|---|---|
| Stewart | ✗ | ✗ | ✗ | ✗ | ✗ | ✓ | ✗ | ✓ |
| Burt | ✓ | ✗ | ✗ | ✗ | ✗ | ✗ | ✗ | ✓ |
| Mabel | ✗ | ✓ | ✗ | ✗ | ✗ | ✓ | ✗ | ✓ |
| Paul | ✗ | ✓ cancer nurse | ✗ | ✓ | ✓ | ✗ | ✗ | ✓ |
| Mary | ✗ | ✗ | ✗ | ✗ | ✗ | ✗ | ✓ because not asked | ✓ |
| George | ✗ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Bob | ✗ | ✗ | ✗ | ✗ | ✓ | ✓ | ✓ | ✓ |
| Vicky | ✗ | ✗ | ✗ | ✗ | ✗ | ✗ | ✗ | ✓ |
| Colin | ✓ | ✓ cancer nurse/GP | ✓ | ✓ | ✓ | ✗ | ✓ | ✗ |
| Doris | ✗ | ✓ cancer nurse/chest physician | ✓ | ✓ | ✓ | ✓ | ✗ | ✓ |
| Shelley | ✗ | ✗ | ✗ | ✗ | ✗ | ✗ | ✓ | ✓ |

| Person with cancer | 'Doctor knows best', put trust 'in them' | Doctor/Health Professional's explanation | Doctor perceived as wrong | 'No faith'/trust in doctor | 'Doctors don't' explain' | No options/ Doctors don't discuss options | Clinicians 'don't have deep discussions'/Don't discuss future | Past experience of others cancer/dying |
|---|---|---|---|---|---|---|---|---|
| Edward | ✗ | ✗ | ✗ | ✗ | ✗ | ✓ | ✗ | ✓ |
| Morris | ✓ | ✗ | ✗ | ✗ | ✗ | ✗ | ✓ | ✗ |
| Bernie | ✗ | ✓ but more confused | ✗ | ✗ | ✓ | ✗ | ✗ | ✓ |
| Total reported | 8 | 12 | 4 | 4 | 9 | 11 | 13 | 17 |

'Doctor knows best'

Eight people with cancer talked about the doctor knowing what was best for them. They mentioned their trust in the doctor because the doctor had knowledge of cancer and this was greater than their own. Sometimes this apparent trust in the doctor was talked about in terms of implicit acceptance of treatment or advice as figure 7.2:1 describes. Some people also talked about it being pointless to go against the doctor and that there was a need to trust them (figure 7.2:2). Others talked about trusting the doctor's knowledge of what was best for them. This related to following instructions or agreeing with the doctor who was treating them.

A few people expressed the view that doctors do not always know about the future (figure 7.2:3) or they reported that the doctor had said he did not know how long treatment would continue to work (figure 7.2:4). In relation to family members' reports, there was only Simon's wife who discussed leaving her husband's future in the doctor's hands. She talked about this within the context of there being little else she could do.

Figure 7.2 'Doctor knows best'

1. *"Well, I always this; they, they know what they're talking about, so I listen and I try whatever they wanted."* (Dennis, joint interview, p.3, L6)

2. *"And I just asked him, I said what's that going to do?  He says well, that will shrink it down so that we can operate, blah, blah, blah.  Is it necessary?  He says yes, so I said right, we'll do it.  And I left it in, in his capable hands because it's pointless going against, uh, the top notch isn't it, you know, you need to put your trust in these people." (*Henry, joint interview, p.4, L9).

3. *Jane: "They can't sometimes give you answers because they don't know.  It's like over the lung, suspicious, they might or they might not know."* (Bernie's wife Jane, joint interview, p.25, L26).

4. *Doris: "You said to him, how long is this treatment, like radiotherapy, chemotherapy?  Well I do, to be working."*

> *Ted: "Inside her, do you know what I mean?"*
>
> *Doris: "But they say it keeps working a bit, don't it? He said I don't know."*
>
> *Ted: "But we was all, well if you don't know how am I supposed to know?" (Doris and Ted, joint interview, p.4, L6)*
>
> 5. *Interviewer: "What discussions have you had, um, with Simon and the family about any medical decisions for the future?"*
>
> *Kath: "Um. We haven't really. Um. We've just left that in the doctor's hands, you know. Um. Um. I mean the medical, we're just going along with what, you know, the doctors, you know, the lifeline, you know, the doctors have thrown to us, and just going through the chemo. Um. I mean we don't know of any other, um, anything else that, I mean I've searched the web, you know, looking for things, you know, sort of thing that might help him, but. So, I don't know of any miracle cure or anything. Um. I think we're all just going along with, you know, what the doctors tell us really."* (Kath, single interview, p.3, L1)

'No faith in', or trust in the doctor.

Four people, several of whom we mentioned in the previous chapter, talked about experiencing a doctor being 'wrong' within the context of predicting how much time they had left to live (figure 7.3:1), and how this affected their acceptance of their prognosis. Some talked about the doctor giving wrong information and advice (figure 7.3:2) in respect of being able to cure their cancer, and they questioned the accuracy of the doctor's prediction. Additionally, three participants talked about a loss of trust or 'faith' in the doctor treating them as a result of being wrongly informed, or not having been given information about possible treatments available to them (figure 7.3:3). One person expressed a lack of faith in a doctor but did not say that they believed the doctor was wrong. Yet another person commented that the doctor had more knowledge than most, and was therefore better able offer a judgement about which treatments were appropriate for people with cancer, but this person did not personally profess faith in his own oncologist.

Furthermore, some people talked about the aloof attitude of a doctor or that they had experienced language barriers, which might have contributed to the complaint that they did not trust the doctor (figure 7.3:4) or that the doctor did not explain things. For all four of these people their reported lack of faith was restricted to one or two doctors, but all had found another health professional whom they could trust, either a GP, lung cancer nurse or district nurse.

Mavis, one of Iris's daughters, stated that she and her sisters did not have faith in the doctor caring for Iris and talked about the doctor having neglected her mother. This was discussed within the context of her experience of their father's 'horrible' death and her subsequent experience of the medical professions involvement with her mother. Mavis and her sisters also questioned whether the doctors were wrong in their diagnosis and prognosis because their mother had outlived her anticipated survival time. No other family members talked specifically about not having faith or trust in the doctor.

Figure 7.3 'No faith' or trust in the doctor

1. *"They gave me two months to live and I'm still plodding about, so. What they tell you don't always work out."* (Jim, joint interview p.13, L13)

2. *Paul: "One of the first things Dr (physician) said was there's no tablets and no surgery. That was one of the first things he said. Now both are wrong, there are tablets and, according to Dr (surgeon), surgery was possible, but I don't want it, I don't want surgery."* (Paul, joint interview, p.4, L13).

3. *Interviewer: "Right and how did it go at clinic? Doris: Truthfully, you want me truthful answers don't you? I'm not happy with them; I've no faith in them. Interviewer: Have you not? Doris: That's my truthful experience. Interviewer: Right, what, what's? Doris… "Well I've been trying to get to know about this other drug what I've been after and, I don't know, since I've mentioned that, it's as though Doctor is avoiding me. Ted: Run away. Doris: Run away. Ted: Best if he don't come and see her."* (Doris and Ted, p.2, L20)

> 4.  Colin: *"I won't have any faith in him. Teresa: It ain't affected that - just him. Colin: Not at all, because to me he's arrogant.  He's like a politician, that's what I call him. You know, he thinks he knows everything..."* (Colin and Teresa, joint interview, p.9, L13)

## 'Doctors don't explain'

Some of the above examples of lack of trust or faith in the doctor were discussed in relation to the lack of explanation about treatment, the disease, and alternative options or future plans. Nine people reported that the doctor had not explained anything, and two added that their doctor did not offer explanations unless asked to do so.

Lack of explanation was reported in relation to receiving only partial information, 'skating over' information or difficulty accessing information as figure 7.4:1 suggests. People also commented that they had not received full information about what treatments were available, including those only available privately. Others reported difficulties accessing information because it was couched in medical jargon rather in words they could understand. Lack of explanation about disease progression was also reported, although these observations came more from family members than from people with cancer. Seven of the nine people who reported that the doctor had did not offered an explanation also commented that they had received explanations from another doctor from a different hospital or department, their own general practitioner or a district nurse or lung cancer nurse.

Some family members also reported a lack of explanation about the future. Debbie, another of Iris's daughters, was interviewed within a group of family members. Debbie said that she still had unanswered questions about her mother's condition and that she had tried unsuccessfully to gain access to the doctor to receive an explanation.

Figure 7.4 'Doctors don't explain'

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1.  *Paul: "Not just what he said, it does a whole range of things, and he said taking it out, especially if it's not necessary, is stupid."*

2.  *Sheila: "And nobody told us when it was being discussed whether he'd have to have any treatment because of the removal of his gland. Now I asked N (lung cancer nurse) and straightaway she said yes he would, he'd be on steroids for the rest of his life. So, to me, they're only telling you part of it. And I think they should tell you all that it entails, the upsides of it and the downsides of it, because that's when you can make a decision when you know both sides, not just the one, not the one that they want you to hear, that you know them both."* (Paul and Sheila, joint interview, p.6, L19-25)

3.  *George: "And the actual consultant in M (city) that we saw, a Dr B, he did it in a professional way, he spent an hour and a half with me, going right through my case taking time out to explain the in and outs of things."* (George, joint interview, p3, L26)

4.  *Ted: "But when she had some doubts over different things, Dr A fitted her in."*

    *Doris: "And explained to me because I worked with him."*

    *Ted: "Do you know what I mean?"*

    *Doris: "They put it all up, he really explained things and you come out and you feel better for it."* (Doris and Ted, joint interview, p.7, L17)

5.  *Jane: "I would say, the only thing that I would say is that yes they do tell you what's what, but sometimes we have come away thinking."*

    *Bernie: "More confused."*

    *Jane: "Yeah, a bit confused."*

    *Bernie: "It's like the suspicious."*

    *Jane: "I think that was because, it's like in a hospital the doctors come and tell you what's what, like Dr B said firstly there's three things, firstly there's your fibrosis then secondly*

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Doctors and other health professionals' explanations

Twelve people reported that either a doctor or another health professional had explained to them about one or more of the following: their diagnosis, types of cancer treatments, side effects of treatment, the stages of the disease or the possible outcomes of treatment. For the most part people talked about explanations being focused on medical issues. People reported that other health professionals who had provided explanations were: district nurses, research nurses and lung cancer nurses. The types of explanations received from these health professionals included dietary advice, not calling for an ambulance in the event of death, written cancer information as well as further supporting information about cancer and its treatments.

People talked about how explanations were provided. George for example, had reported that a previous oncologist had showed a lack of respect and understanding. He considered that the consultant was being "driven by this trial agenda". By contrast, when he then met another consultant, he described how the explanation had been given in a professional manner (figure 7.4:3). Others reported how they felt when they received an explanation such as figure 7.4:4, where Doris said she felt better. Similarly, some people talked about feeling 'safe' having received a thorough explanation. Others commented that explanations related to the disease were delivered in stages or steps and that they did not offer possible options about future treatment or care. Others reported they were more confused by the doctor's explanation (figure 7.4:5) or overwhelmed. People also discussed how some explanations appeared to contradict those previously received.

## Doctor's discussion of future options

Eleven people reported that doctors had not presented them with different options for future treatment or care. This was talked about in response to questions about what discussions had taken place at their clinic appointments and whether any health professionals had talked about future treatment or care. Some explained that they understood why they had not been offered any options, that they had to get worse before they would be offered any further treatment (figure 7.5:1), and several reported they had been advised that there were no options and were told nothing more could be done (figure 7.5:2). Others reported being told that they were to have a particular course of treatment. Most of them had no further comments about this, but for some the issue of not being informed of options for treatment, combined with a lack of explanation and a view that the doctor was wrong, appeared to relate to a lack of faith or trust in a doctor.

Shelley, who we met in chapter 7, did report that she had been offered a choice between two adjuvant treatments (figure 7.5:3), and George, who we met above, asked if there were any more options and sought out private treatment, but these appeared to be the exceptions within this study (figure 7.5:4).

Some family members talked together in the first group interview about their lack of understanding of why treatment was not an option for their husbands. They also described the difficulties of explaining this to their grandchildren when they did not fully understand the reasoning behind the doctors' decisions themselves. They appeared to rationalize the lack of treatment (amongst themselves) when discussing the possible alternative approaches to different types of cancers and also the doctors' desire not to make their husbands 'feel poorly'.

Figure 7.5 Doctor's discussion of future options

1.  *Doris: "And now his words are his, the word, the feeling I got, and you did say, is I've got to wait while the cancer gets worse before I can have it.  Is it?"* (Doris, joint interview, p.6, L 3)

2.  *"But when I got the breathing, when Dr M got the breathing and he says I'm afraid there's nothing much we can do with regards that, as regards doing anything with regards the lungs."* (Edward, single interview, p.1, L13).

3.   *"And to be honest because I haven't felt ill or anything what's going to happen next hasn't really come up except in November when I went back and she said we need to think what we're going to do next because obviously it's grown slightly.  And because, she gave me the choice of Docetaxel or Tarceva and she'd be willing to go up the Tarceva way and we need to start applying now, because if they reject it you've got to appeal and it can take a while - which it has done, from the 14th November to starting it today.  So that was about the only thing we've ever discussed on what will happen, you know, what we're going to do next."* (Shelley, single interview, p.5, L11)

4.  *"But halfway through the treatment I had a scan, and it showed no effect, so we pulled the plug on that.  So I asked the question then, what other options have we got?   And the only other option that we were able to get at the time was, B… (tertiary cancer centre) were doing a trial."* (George, p.4, L8)

## Clinicians don't have deep discussions or discuss the future

Thirteen people with cancer reported that health professionals did not have deep discussions with them or initiate discussions about the future. People stated this within the context of questions related to whether health professionals initiated discussions about the future with them. Their comments related to questions about their experience in clinic appointments. People talked about health professionals not approaching them about the future, or said that discussions did not include broaching the topic of the future or their

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wishes. As previously mentioned, people reported that clinic appointments focused on their condition or the next procedure.

Some people talked about health professionals not having discussions about the future because they themselves had not asked to talk about this or had not felt the need to discuss the future. For example, when I asked Mary about whether there was anything health professionals had said to help her think about the future, she responded that she had not asked and also preferred not to worry about the future (figure 7.6:1). This links back to chapter six and the reported desire not to talk about the future because of not being close enough to death. There were indications from a few people that if their lung cancer nurse continued to visit and she initiated a discussion about the future, they would be receptive to this. Several others talked about the prospect of discussing the future with their general practitioner.

In addition, there were a number of reasons that people gave for health professionals not opening up discussions about the future. Some talked about insufficient time for discussion in the NHS compared to private clinics (figure 7.6:2), long times in the waiting room or the doctor having his own fixed agenda. Others gave examples of health professionals thinking they were not ready to talk about the future yet or they had difficulty in accessing someone to talk to. Others simply said that the future did not come up in conversation because no one knows what the future will bring.

People talked about the lack of depth in discussions. They said there were no 'real deep discussions' or there was a lack of detail in the discussions with their health professionals as figure 7.6:3 shows. The exception to these experiences can be found in the few people, such as George, who initiated their own discussions about the future with a health professional (figure 7.6:4) and Jim, who talked with his district nurse about his wishes for the future.

Some family members also reported that doctors did not discuss the future. Kath reported that the doctor had talked with her and her husband about the next chemotherapy treatment, but nothing else. When Kath was asked about her information needs she talked about wanting to know more, to have more 'in-depth knowledge' about Simon's condition and what to expect in the future (figure 7.6:5). Kath talked about the difficulty she had in speaking to a doctor on her own about her husband's future.

Figure 7.6 Clinicians don't discuss the future

1. *"No, not really because I haven't asked them anything. You see, and my own doctor at Town, I had to go and redo my tablets, and he didn't know anything about it until he put his thing (computer) on, you know. And he said oh my goodness you are in a bad way, aren't you? I suppose they knew but they don't bother to look while you're going to see them do they? And he told me that he's there if I want to go and talk to him about anything at all, he's there…But you see, up to now I haven't had, touch wood, I haven't needed to do that, and I don't feel I want to worry them for nothing. Mind you, I've always been like that, I don't like worrying anybody. But I suppose when the time comes, yes, I will do it, but I don't want to do it because I feel as if I don't want to do it yet, and there hasn't been any need really. So I don't mention it, so I don't get myself upset. And I think that's the best way for me to handle it."* (Mary, single interview, p.7, L4)

2. *George: "The problem with consultants they are under so much pressure and GPs are. It's amazing the difference if you're talking to somebody privately you don't feel under the same pressure do you love?"*

   *Winnie:" No there's a different atmosphere all together."*
   *Interviewer: "Is about the time that's available for your appointment or that there isn't that opportunity to talk?"*

   *George: "Well when you walk into an NHS consultancy area, you see twenty or thirty people there you know the consultants are under pressure. If you go into a private clinic and there's only one or two of there, there isn't the same problem, you know. And that tends to, some people maybe don't, and I probably should be the same, push it to the back of your mind, but having been in a professional job like that, I know the sort of pressure that they're under, and I can recognise it, because I've been under the same*

*pressure myself."* (George and Winnie, joint interview, p9, L8)

*Interviewer: "Since your diagnosis, have any health professionals talked to you about, what your wishes are, either of you or, for future?"*

*Eve: "Erm, not really but Barney has said that you don't want to go into hospital anymore."*

*Barney: "Uh huh." (acknowledging)*

*Eve: "So if anything, you know if he becomes really ill he wants to be nursed at home don't you?"*

*Barney: "Uh huh." (acknowledging)*

*Interviewer: "And is that something that one of your health professionals talked to you about?"*

*Eve: "Not, not, in real depth. But, I think it was M (district nurse)."*

*Barney: "Uh huh."*

*Eve: "She sort of mentioned briefly, like hospice at home, they have this kind of thing, she never went into any detail, did she, but erm, she did say it was an option."* (Barney and Eve, joint interview, p.10, L13)

3. *George:* "*I just said to her, I said we need to talk about things.  And so we had started to think about the future."*

*Interviewer: "And that's something that you've initiated, talked about?"*

*George:  "I initiated that, yeah."*

*Interviewer: "Did the doctor say anything to you last Tuesday?"*

*George: "No, I've got a meeting with her in a fortnight.  I was going to talk in a bit more detail."* (George, joint interview, p.6, L2)

4. *"I'd want to know what, how his illness was going to progress, how I could best help him. What signs to look for, um, what drugs are on offer to make his life more comfortable? Um. Um, just, I'd like to know more about the disease and what it's actually doing to him, etc. You know, that sort of thing. I'd like a more in-depth knowledge of what's going on. Um, you know, whether something's, you know, how it will affect him and what stages it'll go through etc, you know, just know more about it, you know, yeah. But you don't actually get that opportunity to ask them all these things."* (Kath, single interview, p.4, L1)

## Doctor's advice about the future.

Nine people reported that their doctor offered them advice about the future. The advice people talked about varied. Some said the doctor told them to "go home and enjoy life". Others reported how the advice given was often about the type of attitude they should have towards the future such as keeping their "spirits up", being strong or having the right frame of mind. Some talked about advice that was directive, for example, not to go out of the house until told or simply to enjoy themselves (figure 7.7:1). One person talked about the doctor offering moral advice such as making peace with God or putting their house in order (figure 7.7:2). For the most part, people thought it was acceptable to be given advice about attitudes or the ideal frame of mind and enjoying life. On the other hand, moral advice and directive advice was not viewed so positively.

Figure 7.7 Doctor's advice about the future

1. *"And he said well, all I can say to you is go and enjoy yourself. You're fine as far as I'm concerned. So Yvonne said does that mean he can do long haul? He said well, you won't know until you try it will you? So that was it, we were away off to the Caribbean". (*Clive, joint interview, p.6, L14)

2. *Dr A (physician) said, "Make your peace with man and God." Well, God's the last person, to be quite honest, because I'm totally irreligious in that respect."* (Patient 2, p.5, L6)

## Patients' decision-making

Many people did not want to talk about the future or to answer questions about what wishes they had for future treatment or care. Some of those who did talk about the future described their decision-making (figure 7.1). People reported on some of the influences on their decision-making, the contribution or involvement of others in their decisions, their knowledge about making decisions and their views on refusing treatment. People also commented on their reasons for not making decisions about the future.

## Past experience of others' cancer or death

People described their previous experiences of other people who had had cancer or who had died. Seventeen of the 25 people with cancer who were interviewed talked about other people's cancer experience or death. They talked about friends or family members 'still dying' despite surgery and chemotherapy. Some had nursed a parent or child with cancer. In addition, some of these had also experienced the death of a sibling, parent or child either from cancer or another life-threatening disease (figure 7.8:1). Others had witnessed friends' or fellow patients' deterioration from cancer and talked about the impact of this on them and their resolve to make the most of life.

Within all the accounts of these earlier experiences people described their own views on a variety of issues. For example, previous negative experiences of someone else's death encouraged some of them to make a will (figure 7.8:2) or to decide not to be buried. Others talked about not wanting to be a burden on their family, having witnessed the illness and death of another family member (figure 7.8:3). Some reported foregoing treatment, a decision they linked to the unfortunate experiences of others (figure 7.8:4). Statements about knowing "what it's like to die" were made by some people when asked about discussing the future.

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People also compared what others had been told when they had cancer with what they themselves had been told, and this related to prognossis or decisions to refuse treatment. Seven people did not report any previous experience of anyone else's cancer, and one person said that he had had no previous experience of cancer and he used this to explain why he did not know what to expect in the future. People's reports of others' past experiences of cancer appeared either to support the information given them by health professionals or to refute it, demonstrating an additional influence on discussions and decisions about the future.

Figure 7.8 Past experience of others' cancer or death

1. *"I think it was hard for us because I nursed my mum with cancer. Right 'til, 'cos she lived with us, and then, uh, my brother, about three years ago, he was only 56, he died of cancer. So there's not, we know quite a bit, you know, but they was both terminal and said they've only got a certain amount."* (Candy, joint interview, p.6, L20).

2. *"My son when his wife's mother died she hadn't got a will and it made him, he got a terrible job trying to get money from here there and everywhere. It took ages. And he advised mum and I to make a will. So we did. We made an appointment to make this will and when the wife died well it was no problem."* (Edward, p.6, L8)

3. *"…my mother-in-law died of lung cancer so…So, unfortunately, I do know how bad it will be for everybody else at the end because I can remember going to visit her and my husband having to leave the room with me in it. Thinking oh great everyone's left me with her. We didn't exactly see eye to eye. But it was oh you work in a hospital you'll be fine, you can stop down there, I'll have a cup of tea and read the paper. And I thought thanks. So I know how bad it is which makes me feel quite awful for them because obviously she didn't know what was going on."* (Shelley, single interview, p.2, L16)

4. *Paul: "You look round at people that's had cancer, Herman Norton for one, chemo, he went for it and he still died - it didn't save him."*

> *Sheila: "Young Philip."*
>
> *Paul: "Young Philip, Paul's son."*
>
> *Sheila: "Paul's son, yeah."*
>
> *Paul: "He suffered hell in hospital."*
>
> *Sheila: "He did."*
>
> *Paul: "Through chemotherapy. He was only twenty-one year old."*
>
> *Sheila: "Angela."*
>
> *Paul: "That was chemo. Angela, another one, spent the last few months didn't she?"*
>
> *Sheila: "In bed."*
>
> *Paul: "In bed, completely in bed."*
>
> *Sheila: "Yeah."*
>
> *Paul: "Finished, chemo. I don't want that. There's no way I'll have that, no."*
>
> *Sheila: "Unfortunately, we've not met anybody who's said well chemo did this for me, and chemo it's just that in our own circle …"* (Paul and Sheila, joint interview, p.8,L17)
>
> 5. *Angela: "You see I know, I know from my sister, she got so she had to be pushed around in a wheelchair, and they got her a wheelchair and it didn't have a cushion and that in it, and it used to bounce her about and it used to put her in such a lot of pain, and all those kind of things that we've witnessed, we've seen.."* (Angela, joint interview with Andy, p.17, L21)

Some partners of people with cancer and their family members talked about their husband's appearance in compared with that of their parents whom they had nursed prior to death. They reported witnessing other people's suffering in the process (figure 7.8:5) and this influenced their views about wanting to be prepared for the death of their partner or family member. This links back to reports about discussing dying in chapter six.

"Won't refuse treatment"

Seven people talked about not refusing treatment and related this to a number of different factors. For some, these reports were based on their own experiences of accepting treatment. Others expressed hypothetical views in response to a question about what advice they would give a friend who was faced with a decision whether to forgo chemotherapy or not.

Five people talked about not refusing treatment in terms of grasping hope (figure 7.9:1) and not refusing treatment if life depended on it. These five people talked about the importance of 'accepting' treatment and that those who did not accept treatment were 'silly' (figure 7.9:2). One person described their willingness to take the risk of treatment, being prepared to take any course of action required, and others reported leaving the decision to the doctor. When comparing these seven reports with other properties in this category (Table 7.1), it was noticeable that none of these participants reported having lost faith or trust in their doctor or felt them to be wrong. Five participants reported that doctors did not discuss future options with them.

There were four people who reported that they had refused or would refuse treatment and they described the rationale for this choice. This appears to be closely related to other views reported previously such as a loss of faith in their doctor or their view that the doctor had been wrong. Two people had refused surgery and said the rationale for their decision was their age, believing the cancer to be inoperable or not wanting to extend their suffering (figure 7.9:3). Another person talked about refusing surgery because of fears the cancer would spread and the effect surgery would have on their ability to work and get on with life. This person also refused chemotherapy because chemotherapy was like 'a lottery'. Another refused radiotherapy. This refusal was related to their having other cancer sites for which they had received treatment, their experiences of suffering the side-effects of radiotherapy,

and their perceptions that it would be futile having further treatment when there was no hope of cure (figure 7.9:4).

Figure 7.9 'Won't refuse treatment'

1. "It depends how serious it is in some respects. I mean if it is an absolute last hope, I would say don't, uh, don't suffer. But if there is a hope at the end of the tunnel then I would say go ahead. I mean my next door neighbour, I've been and sat with her a couple of times for about 20 minutes, and she's asking me questions. I mean I've only known a few months longer than she has…Now they've offered her, I think it's two courses of something, and she said I don't know whether to have them or not. And I said well, there's only you can make your mind up, I said and if there's hope then you must grasp it. I said but if they say they can't be sure, I said well, then it's your question is don't put up with the inconvenience, the pain or whatever it has."
(Andy, single interview, p.6, L19)

2. "Oh, I would tell them, uh, to, to, to have all the treatment they could have. Because that, that chemotherapy, it's not nice, but it didn't bother me, but it does, it, it does prolong you a bit, you know what I mean, it. Yeah. Oh I would advise anybody to take, to have it. I wouldn't, I, I think they'd be silly to refuse treatment. I really do. Yeah. Because, as I say, I took it all and if they told me I had to have some more I'd go, Yeah." (Ruby, single interview, p.10, L15)

3. Eddy: "You were told at first that you could have treatment but it was … radiotherapy and chemotherapy. And we decided, or you decided yourself and I backed her, that whilst she's in no pain she'll be having nothing done. At her age she didn't want to go through all that and extend the pain for nothing…"

   Vicky: "That's what I told him, I told him straight.." (Vicky and Eddy, joint interview, p.7, L12)

4. Jim: "It's pointless having radiotherapy on that if they can't do nowt with the other…So you just take what, whatever's gonna happen's gonna happen. You see I had radiotherapy seven years ago and that, so.."
   Interviewer: "Right, so you know what it's like?"

> *Jim: "Yes, I know what it's like, so I know what side effects you can get and that, and when you balance it out for an extra couple of months' life, it's not worth it is it?...[slight pause] You just let nature take its own course."* (Jim, joint interview, p.7, L13).

## Not qualified to make decisions or not close enough to death to decide

Five people talked about not having the knowledge to make decisions about future treatment. This was reported within the context of discussions with health professionals in clinic or in answer to a question about how they would make decisions about future treatment and care. The rationale for this was that professionals knew what they were doing (figure 7.10:1) and had the knowledge about cancer and its treatments. They reported that they would go along with the doctors' decisions (figure 7.10:2). There was one exception to these reports. Dan said that he had decided to stop treatment because he was interested in quality of life and that to continue chemotherapy would inhibit his ability to go on a cruise with his wife (figure 7.10:3). He subsequently commented that his doctor supported his decision.

Six people, four of whom were those who reported not being qualified to make decisions about future treatment, also talked about not being close enough to death to decide about treatment or care towards the end of life. Three of these people reported how what they had felt influenced their decision-making. They said their wishes would depend on how they would feel at the time a decision was needed (figure 7.10:4) or when they were told treatment had not worked. A lack of knowledge about what the "*ends' going to be like*" (Dan, p.5, L14) or a desire not to look into the future were also reported. This links back to chapter 6 and a desire to face death when it comes, not before.

Figure 7.10 Not qualified to make decisions

1. "*Too much information, you know, can drive you round the twist. [laughs, rubs hands together]. So I'm quite happy. Uh, they know, they're professionals, they know what they're doing, just let 'em get on with it, that's it.*" (Stewart, single interview, p.3, L14)

2. Interviewer: "*With regards to sort of the future and past ways of making decisions, if you had sort of decisions to make about the future how would you go about making those decisions? What's your sort of preference for …Simon: Decisions concerning?*"

3. Interviewer: *"Treatment or type of care, or?"*

   Simon: *"Um. [slight pause]. If, [slight pause], I don't know really. I mean I, well as far as treatment's concerned, um, I don't, I don't look upon myself as in a position to make them decisions, you know, the doctors, you know, the consultants would do that. Um. You know, they advise you need this treatment or that treatment and I'd just say fine, you know, I'd just go along with that." (Simon, single interview, p.6, L4)*

4. "*Well, when I went and arranged with lung cancer nurse, I said look, I said I'm not, I don't know I said but I think that my benefit to me now is to forget about this chemo, I said because he's started telling me that if my blood count didn't go back up, I couldn't go on this cruise because of infection. And being on cruises, you know what they're like, you know. So I thought, well I'm determined I'm going on this bloody cruise, you know, because we'd booked it a year before.*" (Dan, single interview, p.3, L19)

5. Interviewer: *"Have you made your wishes and preferences known to anyone, like you said?"*

   Andy: *"I've made a will."*

   Interviewer: *"About your care and your treatment?"*

   Andy: *"No. As I say, my family said they want to take care of it, so I've just left it in their hands at the moment. I mean it depends how I feel in, say, six months, twelve months' time and then I feel that then my wishes will be, that will be it. Because I'm*

## Involving family in discussions and other influences on decision-making

Seven people talked about whether or not to involve their family in decisions about their future treatment or care. This was reported in discussions about when and how they talked about decisions. Five of these people reported positively and two negatively about some family members' involvement.

Involvement was talked about in terms of wanting their children to know everything (figure 7.11:1), or not wanting to make decisions on their own (figure 7.11:2). Some reported being a close family, without which they would give up. One person, Bernard, had kept his diagnosis a secret from his children for fear of upsetting them. Following his and his wife's subsequent disclosure to the children of Bernard's diagnosis they had promised not keep anything from them again. Two people talked about not involving some of their family in decisions. For one person, this report related to grandchildren not having a say in his life (figure 7.11:3) although his fiancé and two children were involved. The other person did not want his wife to know about his prognosis or be involved in discussions about the future.

Figure 7.11 Involving family in discussions

1.  "*I'd want my son and daughter to be involved.  They, they want to, you know, I want them because they've been with me all the time, gone to the hospital.  Me daughter, me son's working this morning but he'll be here after, he'll come straight from work. Hmm.  Oh, I'd want them to know everything."* (Ruby, single interview, p.13, L 9).

2.  Interviewer: "*When it comes to making decisions about your treatment, you know, in the past how have you tended to make decisions?*"

    *Edward: "Well I normally wherever I go daughters come with me or my son comes with me.  And we make the decision between us.  I don't make them on my own.  I mean when I go to see Mr. M my son will be at work but the two daughters will be*

> *there. And they'll both come. Oh they'll both come. Oh they both want to know what's happening. And whatever Mr. M. suggests or doesn't suggest the two daughters will talk it over between us. We'll come to that decision."* (Edward, single interview, p.4, L8)
>
> 3. "*There's not many people who I have to account to anyway. Only me son and me daughter, me fiancée, that's it. I don't count me grandchildren as having a say in my life anyway, they've got their own life to get on with. And they're too young anyway, so. But there's that, there's only three people really who, who are – well, and like I say, that's it, me son, me daughter, me fiancée, that's it, there's nobody else."* (Stewart, single interview, p.6, L8).
>
> 4. "*I mean at the same time I was actually working with a solicitor on, you know putting a formal, you know, claim in, and this solicitor was marvellous because he gave me a lot of background information about some of the treatments that were available. Now some of the treatments were only available privately. Now none of this was explained to us. And there was an article in the paper the other week about this, that even if it's not available on the NHS, the consultant should tell people what could be available to them and not prejudge it.*" (George, joint interview, p.2, L 18)

Three people talked about other influences on their decision-making. These included a GP (who was a personal friend) and a physician, who were reported as supporting people's decisions. A solicitor, newspapers (figure 7.11:4) and information found on the World-Wide-Web were other reported influences on decision-making as they provided knowledge about different treatments.

Three wives of people with cancer talked about some of the difficulties they and their husbands faced in deciding whether to share information with other family members, but this was not reported within the context of decision-making.

'Decided together'

Eight men and two women discussed how they would make decisions with their partners about future care and treatment. This was in the context of questions about how they made decisions or what discussions, if any they had with their partners about future care and treatment. Several of these people talked about decisions being made just between the two of them, without the engagement of 'external' others (figure 7.12:1) or they said that the first discussion would be with their partner. After the initial discussion between themselves, some couples then included other family members as the previous exemplar shows, which in this case also led to involvement of the family doctor.

Some people reported that they did not hold back discussing the future together or talk about what was going to happen. Some people said that they had initiated a discussion themselves, but others reported that it was their partner who had done this (figure 7.12:2). They also talked about asking each other for their ideas or opinions (figure 7.12:3) before making joint decisions. Others described how they did not need to discuss things with each other, because decisions would be automatically made by the other person if they, as individuals, could not make a decision for themselves (figure 7.12:4). In addition, other people reported knowing their partner's wishes.

People talked about how they came to a joint decision. Some would come to a compromise (figure 7.12:5), whilst others reported that if a decision 'made sense' they would do it, if not, they would debate it. One man, who talked openly in response to questions about future care, said that his wife knew what his wishes were for the future and would know what was best for him in the event that he could not make a decision for himself. He talked about his wife knowing how he felt, and knowing what he would want because they had talked together. He reported his wife made his health care decisions for him (figure 7.12:6).

There were comments about the possible triggers to making decisions or expressing wishes. Some of these were related to previous illness, such as Barney's stroke, which prompted discussions about writing a will. Jim's wife worked as a health support worker and Jim described how she had come home and told him about the challenges of caring for people in hospital at the end of life. This may have led to their discussions about his future. In addition, people's experiences of other family members' cancer or deaths (for example: Andy or Bob), may have provoked discussion and decision-making about some aspects of future care.

As already mentioned in chapter six, some family members reported difficulty in initiating conversations to discuss decisions about the future with their partner who had cancer. This was in the context of not wanting to be disloyal to their husbands and their knowledge that their husband did not want to discuss the future. This may help explain the absence of the other 15 people's reports about joint decision-making.

Although some people had discussed with their partners some decisions about the future, most did not report having shared these decisions with clinicians. Even George, who talked about his life-long planning and who usually recorded details of his symptoms to share with his doctor, reported that he had not thought about recording wishes for the future because he pushed 'it' (dying) to the back of his mind (figure 7.12:7). This links back to 'facing death when it comes' and 'planning for death, but not dying'. In addition, although Jim and Colin had shared their preferred place of care with their lung cancer nurse, this was not stated in their hospital records. Iris's daughters discussed within a group interview how their mother's records included a 'do not resuscitate' doctors' order. They talked about being unaware whether any of their mother's wishes had been recorded in her medical notes.

I reviewed the records of those people who died during the two year data collection period, and the wishes or decisions of participants reported in this study were not recorded in

hospital records. It is possible that people's wishes or decisions may have been recorded in

other patient records such as those kept by GPs, lung cancer nurses or district nurses

records that I did not have access to during the course of this study.

Figure 7.12 'Decided together'

1.  Interviewer: "*So when you had these thoughts about not having surgery and what you've just discussed now, is it something that you've decided on your own or as a couple or did you involve anybody else in those decisions?*"

    Paul: "*No, we didn't.  It was just ourselves wasn't it, we talked ourselves.  Mind you, You mentioned it to our Jean and our Jean went to and had a word with Dr R (GP) didn't she?*"

    Sheila:  "*Yeah.*"

    Paul:  "*You know, he's retired now but he's all right.*"

    Sheila: "*But he was our doctor.*"

    Paul: "*He was our doctor and a friend.*"

    Sheila: "*A very close friend.  He's Godfather to one of our grandchildren.  So he's Been part of our lives ever since we moved down to B (town), which is twenty-nine years, and he agrees with what Paul's doing now." (*Paul and Sheila, joint interview, p.5, L22)

2.  Interviewer: "*You know you mentioned that you'd sort of sorted out your wills and that, was that something that you decided to do between you, or did somebody sort of …*"

    Angela:  "*We'd been going to do it and going to do it for months and we'd never, well for years actually, like we …*"

    Andy:  "*Most things.*"

    Angela: "*We never got round to it, and he said, "I think it's time that we did it.*"

*Andy: "Most things, Gill, we do together in that respect."*

*Interviewer: "Right, I was going to say, how do you sort of normally make decisions about things?"*

*Andy: "Well, I mean if Angela says something if I agree with it we go ahead. If I don't …"*

*Angela: "He tells me and we don't go ahead."*

*Andy: "You know, it's as straightforward as that. I mean there's no point in [pause]."*

*Angela: "He's a very strong, determined man, aren't you?"*

*Andy: "Well, I don't know about that, but I mean I just don't, uh."*

*Angela: "If it makes sense we do it, if it doesn't make sense we debate and …"*

*Andy: "We don't."*

*Angela: "And whichever reasoning happens that happens." (Andy and Angela, p.6, L21)*

3.  *Eve: "Talk about what's going to happen. And then we ask each other, their idea, or opinion of what's going to happen."*

    *Barney: (looking at wife) "Really."*

    *Eve: (nodding confirmation).* (Barney and Eve, joint interview, p.9, L5)

4.  *Interviewer: "The last thing really is have you ever as a couple discussed whether, related to this illness or not, have you ever discussed if one of you weren't capable of making decisions for yourselves who would be the person that would make those decisions for you? Is that something you've ever thought about?"*

    *Candy: "No, because automatically either one of us would make the decisions. If it was me, it would be him. If it was him, it would be me. There would be no hesitation about it at all, it would just automatic, there'd be no need to discuss that you see, so…You know. Everything's in joint names, everything, you know, so no, it's*

*something that, I've never really thought about because it would; it would automatically happen wouldn't it?"*

*Kevin: "Yeah, it would just follow on. It'd just follow on, you know. There'd be no qualms about anything…" (*Candy and Kevin, p.7, L27)

5. *Jim: "The wife don't want me to die at home, and I don't want to die at hospital so we come to a compromise, if possible, and go to the hospice when the time comes."* (Jim, joint interview, p.5, L4)

6. Interviewer: "*Have you ever thought about, um, if you ever became sort of unconscious and you couldn't make your own health decisions, have you ever thought about who might make those decisions for you?"*

    *Jim: "My wife, Yvette. She's made them all for me the last six years."*

    *Interviewer: "Has she?"*

    *Jim: "I couldn't even tell you what medication I take. I've heard the names, but if anything happened to her I'd be buggered. I wouldn't be able to, I mean I've got one of them pill boxes that she fills up weekly. I wouldn't know what's what."* (Jim, single interview, p.7, L15)

7. *Interviewer: "If you had any particular preferences or wishes, have you ever thought about recording them, is that something that you would think be important or not?"*

    *George: "What recording them?"*

    *Interviewer: "Writing them down."*

    *George: "We've started writing things down, family issues, haven't we, because that's what I mean, we started to looking at funeral arrangements the other day, and discussing that. You see that was a starter for ten, so there are some issues like that, and yes I would write them down."*

    *Interviewer: "Is that something you'd share with your health professionals, if it was related to treatment and care?"*

    *George: "If it was related to my treatment and care, yeah. Well having said that, I mean we've written most things haven't we?"*

> *Winnie: "We keep a record of everything we do."*
>
> *George: "I've given the consultants a written report every time I've seen them. You know, it's how I've been and how I am today, and most of them have found that helpful. At least somebody has actually taken the time out to do that.*
>
> *Because it does take pressure off them, if they've got a record it means, they're reasonably happy with it, they don't have to write it down themselves do they. So we have tried to do it that way, but. You know, sort of the end game type thing, we haven't really got round to it have we?"*
>
> *Winnie: "No."* (George, joint interview, p.9, L21)

## Summary

The main findings in this chapter are that people recall little, if any, discussion about the future with their clinicians. Where there was discussion, some people said that doctors did not explain about treatments or offer choices or options for future treatment and care. However, this was not necessarily reported as a concern, as people said the 'doctor knows best', they would not refuse treatment and some did not feel 'qualified' to make decisions about treatment. Conversely, other people reported a lack of trust or faith in their clinician because they recalled the doctor being wrong in his decision-making. Some people talked about how unsolicited moral advice from a doctor or a clinician's aloof or negative attitude towards them affected their ability to trust the clinician. People with cancer reported that family members or other people they knew who had been affected by cancer influenced their decision making about what they would, and would not want, in the future. Participants talked about joint decision making or involving their family in the process. Where people with cancer had discussed their decisions about the future with their spouse, few had shared these decisions with their clinician. Others said they would rely on their family member to know what decision they would want in the future, or to make decisions on their behalf.

Finally, participants reported a lack of 'deep discussions' about the future, which they related to lack of time during the clinic appointment, or because the focus was primarily on their condition or because they themselves had not asked for them. This was a particular concern reported by family members, as they wanted information for themselves so they would know what to expect and how to plan for the future when the person they cared for was dying.

# CHAPTER 8 : INTRODUCING THE THEORY: 'MAINTAINING INTEGRITY IN THE FACE OF DEATH' AND DISCUSSION

## Introduction

This chapter will offer a critique of the theoretical interpretation of the findings in the context of the available literature. I will also suggest how this study adds to current knowledge about patients' experiences of facing death from advanced lung cancer, and I propose recommendations for future policy, practice, education and research.

The primary focus of this research was to gain the views and perceptions of people with advanced lung cancer about discussing end of life issues, with particular reference to their preferences and wishes for future care and treatment. What people talked most about, were their perceptions and experiences in facing death. The context for this study was that most people were from working-class backgrounds, male and living in an ex-mining town or post-industrial city in the north of England. All 25 people had received care or treatment from a secondary or tertiary cancer centre.

What I found was that people spoke about how they managed a diagnosis of advanced lung cancer or how they experienced their partner's illness. They described the huge emotional effects of a poor prognosis on them and their families' lives. Following disclosure of a prognosis they engaged in a daily balancing act of living in the present, whilst knowing that death was imminent. Emerging from this study were the categories of 'facing death when it comes', 'planning for death not dying', 'only months to live' and 'clinical discussions about the future'.

The key findings in chapter four were that people with cancer preferred for the most part not to think about or discuss the future. They talked about not feeling ill or close enough to death to make decisions about their care and treatment. Discussing dying was viewed as 'morbid', not necessary or unhelpful, although some family members wanted to discuss

preparations for dying. People stated they wanted to 'carry on as normal' and to live 'day by day' or 'one day at a time' and family members supported this. They portrayed attitudes of soldiering on, stoicism, fate and positivity. In chapter five people reported that when they did discuss the future it was out of concern for family, in order to make practical plans for after their death, such as a will or funeral arrangements. Some did make plans for the short-term future, but this was focused on plans for living such as holidays. Others made preparations for death secretly or when they felt unwell. There were reports about fears of dying and this led to wishes for a quick death or a preference for home or hospice care.

Chapter six focussed on participants' reports of the huge emotional effect of being given a prognosis of a short time left to live and the impact this had on them and their families. People reported that the knowledge of how much time they had left to live was harmful and impacted on their relationship with the person who disclosed this information, sometimes causing an unwillingness to ask for further information or lack of trust in their doctor. The findings reported in chapter seven were that participants recalled that doctors (mainly oncologists) gave them information about future treatment in steps, but that they did not enter into deep discussions about the future and overall did not offer options. People described their knowledge of cancer and dying learnt from others' experiences. Family members' need for information was different to those of people living with lung cancer.

Some of the components of care necessary to support discussion about preferences for the future became apparent in these research findings, but this was not the main concern of the study participants. The following discussion synthesizes the findings by offering an interpretation of people's primary concerns and their meanings based on my proposed theory of *maintaining integrity in the face of death* (Figure 8.1).

Figure 8.1 Maintaining Integrity in the Face of Death
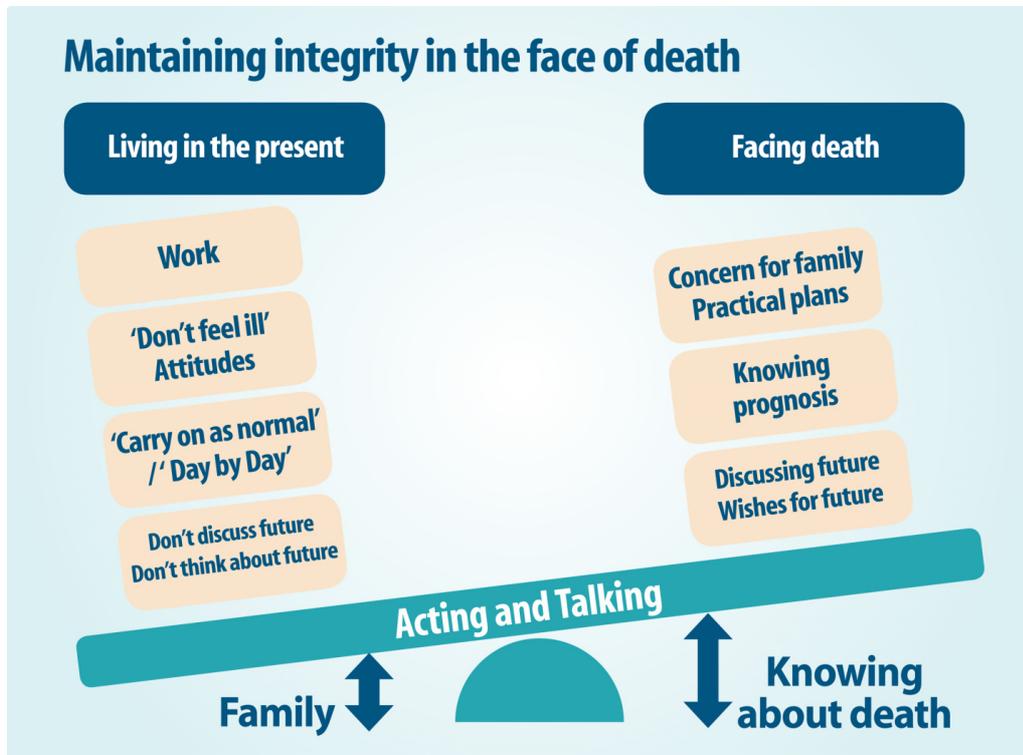


## Maintaining Integrity in the face of death

Maintaining integrity in the face of death is defined here as the work of balancing the opposing forces of living in the present and facing and preparing for death. This balancing work requires people to act and talk with integrity. Acting and talking in ways that allow a person facing death to remain 'real' or 'normal' are important in maintaining integrity. By 'carrying on as normal' and focusing on the present people can maintain a sense of purpose and hope for themselves and close family members.

There are various conceptions of integrity available in the literature. Widang et al (2007), describe integrity as being "wholeness in the sense of being an integrated whole person" (p.541). Integrity appears to relate to other concepts such as: 'self' (Widang et al., 2007), 'person-hood' (Egnew, 2009), dignity and identity (Wadensten and Ahlstrom, 2009; Isaksson

et al., 2007) autonomy and self-determination (Widang et al, 2007, Isaksson et al, 2007). Integrity has different meanings, with illness (Widang, Isaksson), disability (Wadensten and Ahlstrom, 2009), dependence (Widang et al, 2007), loss of control (Wadensten and Ahlstrom, 2009) and suffering (Egnew, 2009) viewed as threats to maintaining the integrity of a person.

*Maintaining integrity* in the face of death is concerned with maintaining one's integrity as part of 'being in the world' (Heidegger, 1973) and being an 'active agent' in other people's lives (Larkin, 2007). Heidegger (1973) suggests death brings with it the possibility of the non-existence of self. The need to balance the internal and external forces that move someone towards their death is normal, if facing death is interpreted as denying the existence of self. This view of death was supported in this study by people not wanting to discuss the future or engage in 'morbid talk', not wanting to play the 'end game', expressing the view that discussing dying was 'bringing things too close'. For these people death means a social separation, a separation from the life known, all that is or was, from a life as part of a family and social community and ultimately of self.

The theory proposed here suggests that *balancing living and dying* is the process of attempting to manage the dilemma of living in the present whilst preparing for death. *Acting and talking with integrity* are ways of 'doing' this balancing work. This work requires physical and huge psychological effort to focus on wellness. *Knowing about death* includes the internal and external sources of knowledge acquired about death and dying that influences people's ability to maintain their own and their family's integrity. *Family integrity* explains how the concern for family well-being causes people to place importance on protecting family and friends by exhibiting 'normal' social behaviours themselves. It also explains how preparing for death and leaving a legacy sometimes risks or strengthens personal integrity. These properties are highly relational and interdependent. In addition, the social context, relationships, culture and the beliefs of people with lung cancer support their integrity. I will now offer a theoretical explanation of these key properties.

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Balancing living and dying

*Maintaining integrity* in the face of death is about 'balance'. A balance or control is required to manage what is perceived as the opposing forces of not facing death and yet planning for it; managing the dilemma of living in the present and not worrying about the future. It is about 'being' and 'not being', 'hope' versus 'despair' and 'knowing' and 'not knowing' about death.

For the most part the findings identified that people's concerns were not about the physicality of their disease and its impact on their lives, but about managing their social lives. People's reports of 'not feeling ill' support this notion. Their focus was on attempting to balance facing death whilst living in the present. The way people acted, talked about and attempted to make sense of their future was centred on their social functioning and relationships and the desire to keep these 'normal'.

I examined the wider literature for resonance with these findings. In a study exploring the quality of life of people diagnosed with lung cancer Bertero et al (2008), described how being treated as normal was important for providing meaning and quality of life and further suggested that this supported integrity as a "guiding star". The (2002) ethnographic study of 30 lung cancer patients in The Netherlands also describes people's attempts to live as normal a life as possible to the end.  Maintaining integrity, 'carrying on as normal' and being treated 'as normal' within their social relationships appeared important to people with cancer and their families in this study. Not having this was viewed as 'horrendous' or 'terrible'.

The ability to balance the dilemma of living in the present whilst facing death required a type of work or labour that was often highly emotional, affecting both the people engaged in it and those close to them. This activity was used as a strategy or a process for managing a social death. The notion of work in facing death has been raised in the literature; Byock (1996), for example, describes 'task work' in relation to facing one's mortality. Similarly, Bury

(1982), who studied people living lives disrupted by rheumatoid arthritis, hints at the notion of work and describes the struggles of people living with a chronic illness as an

"*uneasy balance which is struck between seeing the condition as an outside force and yet feeling its invasion of all aspects of life*" (p.173).

Bury (1982) highlights the effect of illness on meaning, relationships, material and practical affairs. He also suggests there are powerful forces or tensions that people face and hints at the notion of work to balance these forces as a prerequisite for living.  The findings in this study support the premise that there is emotional work involved in managing one's social relationships whilst anticipating death, and this requires a careful balance of living in the present while yet dying.

Robinson (1993) proposed that to normalize life a person with a chronic condition attempts this as 'a *balancing act*' between deficits and abilities and what can or cannot be done. The findings from this study suggest that rather than focusing on deficits and abilities in themselves, the 'balancing act' involved people acting and talking in ways that enabled them to 'carry on as normal'. This was demonstrated by professing to 'not feeling ill', whilst at the same time having an awareness of facing death. Where there are factors pushing them towards having to face death, people appear to counterbalance this with acts or words to enable living in the present and integrity to be maintained.  In a narrative study of 31 adults with a chronic condition and 9 parents of a child with a chronic condition, Robinson (1993) reported that participants reconstructed their story of what was normal over a period of time. Seamark et al (2007), in a review of palliative care for patients with chronic obstructive pulmonary disease, suggest that patients make a 'response shift', changing their previously held perspectives or values about preferences and wishes for the future in response to the impact of facing severe disease or death. Because of the advanced nature of their disease,

most of the people who offered their views and experiences in this study had little, if any, time to reconstruct their stories or shift their responses towards 'being in the world'.

## Acting and talking with integrity

### Acting

As people are social beings, maintaining integrity requires actions and words. In this section I summarise how the type of work needed to maintain one's integrity and contribute to the integrity of the family requires diligence and determination. Maintaining life as 'normal' often required people to maintain routines such as: planning for and taking holidays, fixing the car, continuing with their paid employment, cleaning, babysitting, volunteering or cooking. 'Doing' enabled people to carry on 'as normal' and contribute to being in a family and thus maintain this wider relational integrity. 'Work' was involved in balancing living in the present and facing death

In Robinson's study (1993) of people seeking to live normally with a chronic condition, maintaining normal routines, working and taking holidays were important for maintaining normality. Similarly, Kagawa-Singer (1993) identified that keeping busy and being mobile supported normality for patients living with cancer and contributed to a sense of self integrity. In addition, Byock (1996) suggests that doing things and involvement in activities, whether these are mundane or not, are central to personhood and identity. If, as Heidegger (1973) suggests, "one is what one does" (p.284), then 'doing' demonstrates living and 'not doing' may represent death of self. In this study, doing things was described as "keeping it real", which was often put into practice by working to maintain existing routines or adapting them so people could continue living normally. Some people rewarded themselves for working; for others, 'doing work' overrode any concerns about whether the activity would be detrimental to their health. Volunteering at a local grocery store, babysitting for the family or fetching their own cup of tea, were examples where work, in addition to occupational work, provided a means to 'carry on as normal'. Work was especially important in this study and may also

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relate to participants' occupational backgrounds as ex-miners or industrial workers. In addition, loss of work and occupational roles, which are linked to social and self-esteem, cause people to suffer.

Findings in this study suggest that emotional labour is required to maintain integrity in the face of death. The emotional effort required is highlighted in reports of how people struggled when family members offered sympathy, which was deemed counterproductive to doing and 'carrying on as normal'. Grandey (2000) suggests that emotional labour is the modification or suppression of expressions or feelings as part of the work role, and in response to the rules of the job or organisation. It is also described as something learned in order to relate to the world (Hochschild, 2004). Although generally described in the literature in the context of paid employment, the concept of emotional labour is also reported in relation to managing one's illness. The importance of emotional labour in illness is reported by Exley and Letherly (2001), who identified in their parallel life history study of mainly women with either infertility or terminal illness that skills and effort were required by people to control their feelings and the feelings of others. In this study, people appeared to modify or suppress their emotions to maintain their roles within their social relationships and support a sense of 'normality'.

Another type of work, 'protecting the family', was especially important for the men in this study. Protecting the family was considered as always being part of their work and their role, and was work that needed to be continued, even though for the most part they no longer engaged in paid work to bring money into the home. Their role as protector was viewed as an important part of their lives and part of 'carrying on as normal'. Therefore, this type of work was crucial to maintaining integrity. Men have been stereo-typed as the strong hard-working gender (Lee and Owens, 2002), which could explain the importance of work here, with eighteen participants being men, many of whom had previously engaged in manual labour. The seven female patients also placed importance on working to carry on with their social roles such as preparing a spouse to do tasks previously done by them. This required women

to teach tasks, leave instructions, pull in others to support the spouse, for example in engaging a paid cleaner. Cassel et al (1991) proposes in a discussion paper that people are their roles and are diminished by lack of function or routine. This supports the argument in this study that people needed to 'work', sometimes substituting other work for previous occupational work, to help them 'carry on as normal'. This was at times emotionally demanding for people and required significant effort, planning and determination. This emotional labour was also about not giving in and was supported by another type of work – 'moral work'.

Moral work or values were demonstrated by attitudes of stoicism, 'fighting', hoping or positive talk. Blaxter (1990) proposes that hard work or behaviour is valued in a community with a predominantly working-class culture and brings with it a moral well-being. Furthermore, Lee and Owen (2002) suggest that men's identity, often found in occupational work, and their social relationships are closely intertwined, and this affects their well-being. The findings from this study suggest that not working at staying alive or not focusing on keeping things normal was regarded as immoral. Historically the UK has experienced a significant Christian influence and still upholds a protestant work ethic (Weber, 2003) whereby hard work is rewarded, which may have influenced the views of people in this study and their views about discussing the future. Under this premise the importance of maintaining integrity in the face of death as moral work is an important consideration in providing care for people at the end of life.

Living 'day by day' appeared to provide people with an element of control or protection within their social relationships. Living 'day by day' or 'one day at a time' appeared less emotionally difficult work than planning ahead for the future, and appeared to be an important strategy for maintaining integrity. Charmaz (1991) identified that people living with chronic diseases manage to control their situation by living in the present. She suggested that living one day at a time helped people to manage their fears and feelings of depression which they

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talked about, putting their illness in abeyance. Similarly, Copp (1999) described how individuals with cancer who were dying in a hospice took each day as it came, and sought to carry on as normal. She identified how people adopted this coping mechanism as a means of protecting their family from burden and themselves from disintegration. In addition, Copp suggested that taking each day as it came allowed the person to have some control of their lives, which is achieved either through choosing to talk about their illness and dying or choosing not to. The findings from the study reported here build on the descriptions and explanations in both Charmaz's (1991) and Copp's (1999) research by suggesting that people with cancer still seek to live one day at a time even when there is no hope of recovery and that this strategy helps people to maintain their integrity and that of their family.

If, as proposed here, maintaining integrity is about 'carrying on as normal' and living in the present despite facing death, it is worth considering how this relates to the argument by Carnevale (2005) who suggests in an interpretation of Heidegger's philosophy of being that 'authentic dying' requires people to contemplate and understand the meaning of death. If people do not want to think about or discuss death, or fail to demonstrate they are facing death by discussing and planning for it, are they to be judged as being inauthentic or untruthful in their dying? Truthfulness or 'keeping it real' was considered by people in this study as preserving family integrity and self integrity. An alternative interpretation could be that they were concealing the truth about their dying because it was too painful to bear. The following section will seek to explain the importance of talking, as well as acting, in relation to dying and the impact of talk or silence on shaping meaning.

*Talking*

Maintaining integrity in this study involved matching talk or words with actions. There may be both risks and benefits from people's ability to maintain their integrity by talking about the future or dying. Talking about death, described by people in this study as 'morbid talk', could tip the *balance* of control and threaten self or family integrity.  As mentioned in chapter two, 5

of the 17 people with cancer who were invited to take part in this study but who did not participate, chose not to because they did not want to talk about the topic. Furthermore, some interviews I conducted could not be steered towards people's views on future care and treatment because the participants gave cues or stated that they were not prepared to talk about the future in terms of their potential demise. Similarly, some people used the word 'it' in relation to describing death or dying. There appears to be a cultural theme in speaking about death, perhaps derived from a Christian influence, whereby talking about death can present a moral dilemma[6] and the spoken word is perceived to have a power that unspoken words do not have (Simon et al., 2008; Exley and Letherby, 2001). However, I did not collect data on people's beliefs; therefore I cannot draw any conclusions about this.

It is worth recognising at this point, before further discussion that in talking to me as a researcher about the future or to their health professionals as opposed to family or friends, people may have used a different language. Copp (1999) suggests that people juggle their private and public faces, and this could offer an explanation as to why people told me they did not want to discuss the future. People in this study may have created different meanings about discussing the future with different people based on their social context and relationships. What meaning they may have created in talking with those close to them, such as family members, may have been different to the meaning apparent when talking with their doctor or nurse and different again with me as a researcher.

Nevertheless, in this study discussing the future was usually viewed as putting people in a 'place' they did not want to go to. Carrese et al (2002) reported reluctance in people to think about the future because it made them feel miserable or depressed, causing them not to sleep at night or to worry. Discussing dying may threaten loss of integrity. People in this study reported similar views and related this both to thinking and talking about dying. In a

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[6] The influence of Christianity could impact on the acceptability or not of speaking about death or dying. The Bible states that it is "*not what enters the mouth defiles the man, but what proceeds out of the mouth, this defiles the man*" (The Holy Bible, Matthew 15, verse 11). This reference suggests that what is spoken has more power than what is heard.

study about people's experience of living with chronic illness, Charmaz (1991), described how they tried not to encapsulate illness into their lives, but rather push it to the side, as though 'accepting' illness would determine their future condition. For people in this study, talking about the future in relation to preferences and wishes for end of life care was something they did not want to engage in nor thought was necessary, as though talking about dying would make it happen.

From an interpretive and hermeneutical stance, talking and the use of language is viewed as creating meaning or significance (Outhwaite, 2005). For the most part, people in this study reported that they did not want to discuss death or dying because it brought death as an entity too close, making it too real for them. This supports the notion of talking about things which support balancing living in the present with facing death and not talking about things which threaten this balance. Nelson's (2000) suggestion that we construct meanings we can live with further underlines the importance of talking or not talking about end of life care. People faced with death may *only* talk about what they can live with, or are able to make sense of. When people in this study described talking about end of life wishes and preferences it was about the practical arrangements for their death or in response to concerns about their family managing their dying and death. They did not draw attention to death as an end of themselves.

Discussing the future, which in this study was mainly perceived as discussing dying, may lead people to define their own dying, making it seem real. They then had to live with the consequences of this knowledge. Nelson (2000) cites Campbell's idea that "the person fully explained could easily be the person lost" (p.5). To fully discuss one's wishes about end of life care could potentially result in a loss of this sense of mystery. Death can be perceived as profoundly mysterious, as are people's individual experiences of both life and death. Seeking to explain 'death' through anticipating it and planning for it perhaps takes away this mystery and the mystery of the person experiencing its approach.

The model of discussion proposed in chapter four (figure 4.18) suggests there are different levels of thinking and discussing dying, with some people having an awareness of dying but choosing not to openly discuss this with others. The proposed model provides further explanations about the complexity of the issues people face when choosing whether or not to talk about end of life care. Glaser and Strauss (1966) proposed that there are different levels of awareness, from closed to open awareness. Rather than viewing 'closed awareness' as the patient not knowing about their death and staff knowing, perhaps there is an alternative construction, one that instead views 'closed awareness' as silence or a choice not to discuss their awareness with others. This study found that patients thought about dying but for the most part reported they did not discuss their thoughts with others. The majority of people with cancer in this study were men. Chochinov et al (2000), reporting on a study measuring the prognostic awareness of 200 patients who were dying, suggested that, although some patients are open about their prognosis, there are others whose denial of their prognosis may offer protection, allowing them to manage their own reality in their own time. Chochinov et al (2000) also suggested that men were more likely than women to 'show' a lack of awareness of their prognosis. The 'mutual pretence' level of awareness proposed in Glaser and Strauss's (1966) theory describes both patient and staff having the knowledge of approaching death but both pretending otherwise. I propose that another explanation for this level could be that people with cancer and their family members have a mutual fear and understanding of the power of talking and its effect on shaping attitudes and behaviours, which risks destabilizing the integrity of those engaged in the discussion.

The discussion model (figure 4.18) acknowledges that people may think about, and be aware of, their approaching death, but choose not to verbalise these thoughts or to do so only under certain circumstances. Sanders et al (2008) described people's distress at the introduction of 'living wills' at a self-management training programme for people with chronic illness, which participants viewed as forcing them to discuss what they did not want to. The theoretical model (figure 8.1) explains how forcing conversations about the future when

people are struggling to live in the present can be a possible tipping point that disturbs their balance towards facing death too far, causing emotional distress and making it more difficult to maintain their integrity.

In this study, people with cancer reported that they did not want to talk about dying as it brought things too close and it was morbid. Many did not discuss dying with their family out of concern for their emotional well-being. Likewise, family members discussed how they did not want to be disloyal by opening up a conversation about dying for fear of upsetting their partner. In a study exploring the views of 72 people aged over 75, Howarth (1998) identified that, despite the popular myth that older people are more comfortable than younger people talking about dying, they were no more likely to feel at ease. Similarly, people in this small sample, aged between 48 and 85, showed no differences in the ease with which they discussed dying.

Some people talked about funeral plans in the same way as they would talk about a holiday, or the practicalities of planning an event, but they did not talk in the same way about other aspects of death or dying. Perhaps an 'open awareness' state in which people talk openly about death and dying with their families would threaten their ability to maintain integrity. Glaser and Strauss seem to propose that closed awareness is not a desired state of awareness and open awareness is viewed as the preferred state to have towards death. Charmaz (1995) suggests 'denial' is a label used by professionals to describe people's way of being towards illness, and identifies this is only one interpretation. The findings from this study suggest that professionals need to seek to understand that what they may interpret as 'denial', 'closed awareness' or 'mutual pretence' stances towards dying may have an alternative interpretation. Similarly, these stances towards dying may be more beneficial to a person in maintaining their integrity and that of their family than 'acceptance' or 'open awareness'. This argument therefore challenges the current trend in specialist palliative care and hospice care of moving people from closed to open awareness.

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People in this study talked about 'not feeling ill' even though many had complained of symptoms of breathlessness and fatigue and were observed to be close to death. There appeared to be a mismatch between people's psychological and physical experiences. Cieza et al (2008) suggest 'well-being' comprises non-health related components such as autonomy and integrity in addition to health-related domains. Findings from this study suggest that talking about feeling unwell may threaten a person's conception of well-being and therefore their integrity. It is important to acknowledge the relevance of maintaining integrity to support 'being' alive in the face of death. Furthermore, Robinson (1993) suggests a wellness orientation, focusing on abilities rather than deficits, promotes hope and helps keep grief and depression at bay. The theory of maintaining integrity in the face of death suggests that reporting 'not feeling ill' or focussing on wellness as part of 'being' supports a sense of integrity, offsetting fears about dying, depression and anxiety for themselves and their families.

## Knowing about death

The knowledge of approaching death gained through external or internal factors may impact on people's ability to maintain integrity. External factors affecting people's knowledge of dying and death included knowledge gained from discussion with health professionals, the disclosure of the predicted time they had left to live, the experience of others' deaths and information from the media. Internal factors included individuals' own awareness and thoughts of dying, the physical impact of their disease on their bodies and the internal thoughts resulting from offers of sympathy or the way family and friends looked at them. These factors were used to make sense of the future and dying. As well as carrying on as normal and generally not talking about dying, people balanced their knowledge of dying with hoping for the best and portraying a stoical and positive attitude towards the future which families also colluded with.

*External factors*

Being given an estimate of how much time you have left to live can remove the uncertainty of dying, which may have been used to support a hopeful stance and a life 'as normal' attitude. Christakis (1999) suggests that foretelling a patient's death is a physician's duty and can be used to guide the choice of therapy and a patient's compliance with this treatment. This poses the question of who benefits from the disclosure of a prognosis, clinicians or patients? Moreover, where there is no therapeutic intervention on offer, is foretelling the timing of death a physician's duty? In a study about information preferences, Barnett (2006) suggested that participants with cancer preferred not to discuss the timing of death although they welcomed other information about their disease. In addition, Barnett (2006) highlighted that people who had knowledge of their prognosis but not a realistic awareness of time were less likely to suffer distress. This is also reported elsewhere (Chochinov et al, 2000).

Christakis (1999) argues that there is a moral obligation on physicians to make a prognosis, and yet, as discussed earlier, we have heard how people facing death experience difficulties in talking about death. This presents another dilemma. The prediction of the time left before death may threaten the integrity of the individual and their family members by potentially impeding the maintenance 'work' of living as normal, and this in turn may cause suffering. Egnew (2009) suggests that suffering stems from a person's knowledge of their impending death and threatens the integrity of a person. Despite some arguments that foretelling death helps patients to prepare for death (Christakis, 1999) and is in the 'best interests' of patients and their families (Glare and Christakis, 2008), predicting the date of death may provide knowledge that some people would prefer not to have and may remove any control the person may have believed they had over their life. In a study about communication in the cancer clinic The (2002), described how in the Netherlands, doctors tended not to discuss a prognosis with patients because their stance was that it is wrong to deprive people of hope. People in this study still wanted to have hope. They hoped the doctor

was wrong and wished for more time, gaining hope from people they knew of personally and other people reported in the media. At the same time, they also hoped for a quick and pain free death.

The disclosure of a prognosis was often unwelcomed by people in this study; this knowledge was reported as harmful and emotionally distressing. A small study of Bosnian immigrants' views (Searight and Gafford, 2005) about the disclosure of prognosis identified similar views, such as concern about the emotional impact on self and family members. Glare and Christakis (2008) recognise the potential for harm and advocate that physicians improve their communication skills in disclosing a prognosis. Christakis (1999) has identified a lack of literature about how patients cope with a poor prognosis. In this study some people viewed unequivocal information as bringing things too close for comfort. Similarly, receiving an unsolicited disclosure of a predicted time they had left to live caused some people to express feelings of anger, and this resulted in a breakdown of trust in the clinician who made the disclosure. Bury (1982) suggests that individuals may access medical knowledge to help them conceptualise the disease as separate to their self. Although people reported wanting to know about their disease trajectory and its response to treatment, most did not want to know their prognosis. Acquiring knowledge of the predicted time left to live did not appear to promote the separation of disease or dying from self in this study. The opposite appeared to occur. Knowledge of one's expected time of death appeared to give disease more 'power'. There were a few exceptions where, despite being distressed by the disclosure, people said they still wanted the knowledge. Bury (1982) suggests that the strict separation of disease and self is precarious.

Robinson (1993) reported that medical information sometimes went against attempts to minimise the disruption to living life as normal. Although participants in this study wanted information about the disease and the effects of treatment, findings in relation to the disclosure of a prognosis suggest that this knowledge can disrupt attempts to carry on as

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'normal' and that rebalancing then needs to occur. Glaser and Strauss (1966) suggest that if patients are unaware of their terminal status they carry on as normal. Findings from this study indicate that irrespective of whether people with lung cancer were aware of their terminal state, they still wanted to carry on as normal. Therefore this knowledge does not change the desire to live in the present. The (2002) reported that people did not always want to know everything or want the truth to be made so explicit, so questioning the rationale for truth-telling and suggesting that not knowing can have positive benefits. People in this study employed strategies such as not discussing their future with others, seeking to preserve 'normality' perhaps as a means of fleeing from or minimizing the 'truth'.

The foretelling of death was often the threat that compelled a person to 'work at' maintaining integrity. People expressed feelings of fear and reported that 'knowing' what might happen was worse than 'not knowing'. Knowing brings a greater certainty to the possibility of death. Heidegger (1973) suggests that to be certain of something we need to hold it as true. In this study, knowing death was imminent forced people to engage in the work of maintaining integrity. 'Not knowing' allowed them to avoid thinking about death and reduced the threat of loss of integrity. Foretelling death leads us to questions about who this knowledge is for and what is the purpose of its disclosure. Whom does it benefit, the receiver or the giver?

Although Glare and Christakis (2008) argue that patients as well as doctors need this information and want to know, findings suggest that this may not be so for all people and that the information can be inaccurate. Carnevale (2005) suggests that things no longer concealed can sometimes overwhelm, and some people's experiences in this study gave a sense of being overwhelmed. Does a prognosis reveal what was previously only a possibility of death of self? Furthermore, the fact that few people proactively sought information about the future suggests they may have a *need* to conceal death, at least to the extent that they can maintain their integrity. Alternatively, it could be a need to conceal the emotions which

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result from this knowledge (Byrne et al., 2002) rather than the knowledge itself. What is apparent in this study is that the period from the disclosure of a prognosis of the predicted time of death until the actual death is laden with emotion and hard work, with individuals striving to maintain the balance between carrying on as normal and facing death.

Robinson (1993) suggests the medical model of health delivery provides information which opposes normalisation and instead "*services illness" (p20).* If health professionals view death avoidance as undesirable, this creates another dilemma. Participants in Robinson's study and in this study viewed 'normal' as living in the present, rather than focusing on their illness. Information about predicted illness trajectories was often very unwelcome because of the negative impact on people's lives. This was demonstrated by the profound distress experienced by people in this study. This knowledge interrupted their normal lives, threatened their integrity and caused despair.

*Internal factors*

As discussed earlier, people reported having thoughts about dying and an awareness of their deterioration, but were unwilling for the most part to entertain these thoughts for any period of time. People appeared to have beliefs about dying and death which were influenced by the experiences of others. Findings from this study suggest the importance of people's monitoring their own physiological and psychological well-being in relation to their future. As mentioned previously, people talked about 'not feeling ill'; in relation to knowing about death they monitored how they felt as a measure of whether or not they were dying. If they woke up in the morning, or if they woke up feeling well, they did not anticipate dying that day. Two of the three people who acknowledged symptoms such as fatigue, loss of appetite or nausea did not report feeling ill, nor did they report feeling well. Not feeling ill further supported people's reasoning for not needing to discuss plans for end of life care.

Moreover, offers of sympathy from distant relatives or friends were not welcomed because this detracted from a focus on wellness, which they needed to carry on as normal. The way family members regarded people with cancer supplied knowledge about how others perceived them, which may have made it more emotionally difficult to maintain the balance of living in the present and avoiding death, and was therefore not welcomed. This study highlighted the fact that family members recognised the effects they could have on the person with cancer by offering sympathy or changing routines, and they sought not to be disloyal to their partners by avoiding talking or gestures that portrayed anything other than normality. Schon (1963) suggests that people learn that if they act in certain ways they can expect certain other sense experiences. Here family members learnt that offering sympathy or changing routines changed the person's concept of themselves 'as normal'. They therefore resolved this problem by avoiding this behaviour.

## Family integrity

All those who took part in the study had some family or people they regarded as family. As social beings an individual's sense of integrity is closely linked to those around them. Byock (1996) suggests that a person's family is integral to who a person is. Furthermore, Marzano (2009) suggests that the death of a family member is a risk to social stability. Findings from this study showed that people with cancer expressed huge 'concern for family' when they were asked about the future. The concern for their families was often the trigger point to planning for, a time when the hope of a future no longer existed. Conversely, sometimes people with cancer avoided talking about dying to protect family members from emotional distress. Bertero (2008) in a Swedish study exploring the views of 23 people with lung cancer, reported that patients kept bad news to themselves to protect their relatives and they masked their own feelings with courage. Byrne et al (2002) also identified that people hide their own distress out of concern not to upset their families and to protect them. Similarly, The (2002) reported that some patients cushioned their wives from worrying about

them, for example by not speaking about dying. People also protect families from the burden of caring for them (Vandrevala et al., 2006; Schickedanz et al., 2008).

Family members reported not wanting to distress the person with cancer or indeed their children by talking about the future. People expressed views that considered others and did not wholly focus on their own needs. They appeared in some cases to place more emphasis on maintaining 'family integrity' than 'self integrity', showing selflessness and considering the preservation of their family unit to be of greater value than self-preservation. Moreover, people make sense of unfamiliar situations and an uncertain future through relationships rather than as individuals. Perhaps, as Black (2007) suggests, advance care planning is a social activity and not an autonomous act of decision-making, but rather as Simon and Murray (2008) suggest, a "product of relational autonomy" (p.262). Certainly self integrity and family integrity appeared to be interdependent in this study.

The ongoing support people with cancer provide for their family by getting them ready for their death through organising practical activities, tidying, employing a cleaner, creating memories and teaching tasks seems to support the notion of seeking to maintain family integrity. Hunter (2007) suggests that leaving a legacy is a way of passing on one's beliefs or values and helps people make meaning at the end of life.  The person with cancer seeks to fill the gap left in the family from the loss of their roles and responsibilities in the family unit, and leaves this legacy to sustain their identity as part of the family unit. In an in-depth interview study with seven patients with advanced cancer,  Coyle (2006), described people's struggle to find meaning through leaving a legacy for their family.  King and Wynne (2004) proposed that it is normal to belong to a family system and that this brings meaning and value to older people's lives. They use the term 'family integrity' to refer to "the positive outcome of this ongoing, developmental process" (p.9) and suggest that for the family system to develop there is a need for resolution or acceptance of past losses, conflicts and disappointments with the living and the dead. In the face of death it is the anticipation of

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future losses that may override any developmental processes.  People in this study focused on 'maintaining' the integrity of their family.

This study resonates with a study by Simon (2008), who sought to explore the barriers to advance care planning; people claimed that anticipation of death was emotionally harder for their family members than for themselves. As mentioned previously, the family members interviewed in this study did not want to upset their husbands, partners or parents by asking what wishes they had for the future, despite their own need for information, because of fear that the person with cancer might become distressed or they might be perceived as being disloyal to the individual. Family integrity was also important for partners and other family carers of people with cancer. An alternative rationale for not talking about wishes for the future could have been their own anxiety about their family member who had advanced cancer (Hodgson et al., 1997). The issue of collusion has been discussed elsewhere in the literature (Chaturvedi et al., 2009; Low et al., 2009), and palliative care professionals often seek to intervene by mediating discussion between family members. However, intervening by promoting discussion about preferences for end of life care could place a greater burden on the person with cancer and compromise the family's ability to 'carry on as normal'. Findings from this study support the notion that people seek to protect their families out of concern for them. The findings also demonstrate how concern for one's family shapes people's conversations and actions about making meaning of the present and not necessarily of the future. Promoting family integrity is related to maintaining a sense of hope (Kautz and Van Horn, 2009), which in turn supports the integrity of 'self'. Ways of doing this include the preservation of family routines and rituals (such as planning annual holidays), holding family celebrations and working, all efforts to maintain normality.

If health professionals insist that patients discuss and plan for their death through ACP, this could be viewed by some people as an 'immoral' suggestion that might threaten an individual's ability to maintain their integrity. Lending support to this, Carrese et al (2002), in

an interview study with elderly housebound people, identified people's resistance to planning; they preferred to leave the matter in God's hands. In relation to morality, Robinson (1993) suggests that people's belief in living a 'good' life is the impetus for striving towards 'normality'. Alternatively, for the people in this study it was also about the fear that the opposite of 'normal' was unconceivable or unbearable, threatening their life's existence, their integrity and the integrity of their family system.

## Summary

This discussion has offered a critique of the theory of maintaining integrity in the face of death, showing the importance of maintaining integrity over preferences and wishes for end of life care. The difficult work of balancing living in the present and preparing for the future is necessary, otherwise people may give up hope or lose their sense of control and die, or alternatively disregard their integrity by giving no recognition to their fears and thoughts of dying. The power of language, work and moral issues have been explored in relation to how people with cancer and their families act and talk in the face of death. Indeed, what people talked about most was the need to live in the present as opposed to facing their impending 'social death', the death of themselves as an "active agent in other lives" (Larkin, 2007).

This theory also offers an appraisal of some of the existing views and rhetoric in palliative care literature about promoting awareness of dying through open disclosure of prognosis to enable the planning of preferences and wishes for end of life care and treatment. In addition, the concern for family integrity has been highlighted as overriding the 'need' for individual autonomy and choice, the premise on which current UK policy on ACP and end of life choices is framed.

## Implications of the theory of maintaining integrity in the face of death

In this section I will discuss how the theory of maintaining integrity in the face of death contributes to new knowledge of the experiences and views of people living with lung cancer and their families. In addition, I will discuss the implications for policy, clinical practice, education and research, and appraise the limitations of this study and my chosen research design.

## Contribution to new knowledge

Most current literature on advance care planning and the discussion of preferences for the future is based on the views of healthy or fit older people, whereas this study looked at the views of people who had advanced disease and were facing death. This study offers the views of an underrepresented group of cancer patients from lower socioeconomic classes whose voices are not often heard.  This thesis argues that the views of those people actually facing their death may differ from those who are well, because the views of the former are no longer based on hypothetical scenarios but on actual circumstances within a particular social and cultural context.

The findings from this study capture the views of a sample composed mainly of men and their families from national socio-economic classes 3 to 5 (HMSO, 2005) living in northern England. Much research in the field of cancer is derived from samples of patients with breast cancer or from patients whose cancer is less advanced, and from people in higher educational and socio-economic classes. This study provides new knowledge of people's experiences and views of managing thoughts about dying whilst living with lung cancer. It also provides family members' views within the context of living with someone facing death.  Findings from this study built on the work of other researchers (Copp, 1999; The, 2002; Clayson, 2007).

Whereas current policy rhetoric promotes choice and the opportunity to state preferences and wishes for care and treatment as a means of exerting control over decisions at the end of life (Department of Health, 2008; Department of Health, 2009), this evidence suggests that some people facing the end of their life place little importance on choice. They focus instead on living in the present and carrying on as normal, not wanting to verbally acknowledge their demise because this would threaten their integrity and that of their family.

Lastly, for those who are well or in the early stages of a life-limiting illness and who are not currently 'facing death', they may want to plan for the preferences or wishes they want at end of life, but this study suggests that wishes may be different once a person is faced with a real rather than a perceived threat to their integrity and that of their family.

## Implications for policy, practice, education and future research

### *Policy*

This study argues that current policy on advance care planning does not meet the needs of working class people with lung cancer, but that it focuses instead on the needs of educated healthy people. Current policy makes assumptions about how people conceptualise and express beliefs about dying, assumptions that are not congruent with the evidence from older people from lower social classes who are living with cancer. People in this study were experiencing the approach of death and facing the subsequent separation from what had previously brought meaning to their lives. Their focus was on living in the present rather than planning for the future. Therefore, the development of supportive strategies for people and their families trying to maintain integrity in the face of death are indicated, with greater emphasis on preparing for a 'social' rather than a physical or 'medicalised' death.

Supportive strategies such as facilitating conversations with patients and their families within their own home environment about what gives their life meaning, helping them plan holidays and special celebrations, providing information about practical issues such as finding a cleaner, arranging a funeral or learning new skills (for partners) may be more helpful than discussing preferences for end of life care and treatment. In addition, it is important to further develop the role and provision of funding for occupational therapy in palliative care to support 'normal' activities. There is some recent research that suggests that the benefits of engaging in ACP include the ability of people to manage their affairs and reduce the burden on their family (Fried et al., 2009), improved communication with significant others (Song et al, 2009), additional emotional and practical support and enhanced relationships through work and roles within their family (Davison and Simpson, 2006). This underline the need for a greater emphasis on developing policy directed at socially constructed ACP. Future end of life care quality markers (Department of Health, 2009) could include a requirement to report on people's experiences of being able to maintain their integrity, rather than producing evidence of documented advance care plans. Patient and family experiences may be more important than written documentation as an indicator of quality of care.

Promoting greater discussion about death, which is current policy (Department of Health, 2008), may risk depersonalising people's experiences of dying. It may even do harm and increase suffering if people, like many in this study, are not ready to accept or acknowledge verbally that they are dying. Information given to prepare people for death using a medical framework may not be welcomed. Information can be interpreted in different ways, and misunderstandings about advance care planning and debates surrounding euthanasia could, if not understood and framed within their own social context compound people's feelings of being a burden to others.

Current policy (Department of Health, 2008) aims to demystify death, but this may be harmful to people who are themselves facing death. Recent government policy suggests we

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need as a society to demystify death, to take the 'sting' out of it, to make the public talk about death. The 'Dying Matters' coalition (The National Council For Palliative Care, 2010) was launched following the publication of the national End of Life Care Strategy (2008). It aims to raise public awareness of issues related to dying and promote discussion of wishes for end of life care. However, is it really possible or appropriate to demystify death? Will this in turn devalue life? Is it not a mystery for a purpose? No one can fully prepare us for dying because it is such an individual event. If we attempt to remove the mystery, to investigate all its parts (if that were possible), will that allay the fears people have or increase them? Will it promote planning for end of life care or increase the need to avoid it even further? An alternative focus could be to celebrate 'living' at the end of life and to provide opportunities to witness the contributions people can make to their families and society, even in the last weeks of life. Providing more opportunities for people to stay engaged with society through occupational activities, and helping them to contribute to future generations by leaving legacies, may have a more positive impact on how the public perceive dying, death and bereavement.

Policy makers need to consider the views of working class people when developing future policies for end of life care, as these views may be different to the views of people usually sought or from the views of healthy older people.

*Research*

This study focused on one small sample of people diagnosed with lung cancer in northern England. Further research is required in different patient populations into people's experiences of discussing preferences and wishes for end of life care and to test out the theoretical explanations provided in this study. This study explored family members' views, but in relation to the person with cancer. It would be beneficial to have further research which specifically explores the views and experiences of family members caring for someone facing death, and their needs in relation to maintaining their integrity and future planning.

The impact of the disclosure of a prognosis on people from lower socio-economic classes with different cancers may provide comparative data, which may help determine if the findings offered here provide a better understanding of the views and perceptions of working class people with cancer in facing death or whether they are limited to this patient sample. Further research is also required to explore and understand clinicians' communication skills in relation to foretelling death. Listening to clinicians' views about prognostication and ACP may help to determine best practice in ascertaining people's desire and readiness to receive a prognosis and discuss dying and death.

There is a need for research that develops and tests culturally acceptable interventions that support people affected by lung cancer to maintain their integrity through their work, their roles in the family and leaving of a legacy. The development of ACP interventions specifically for people from lower socioeconomic classes may benefit from building on the concepts from this study. In addition, research that further explores the triggers to initiating conversations about end of life care could test the discussion continuum (figure 4.18) for its usefulness as a barometer in relation to willingness to discuss the future.

Finally, using as a basis people's reported concerns about their family, and family members' desires not to distress the person with cancer, future research which explores the use of family discussions to elicit preferences and wishes for future care and treatment may support a more integrated approach to advance care planning.

*Practice and education*

The following implications for practice and education can be drawn from this study's findings and may support further work to develop components of care that help nurses and other health and social care professionals to care for terminally ill patients and their families.

Understanding people's efforts to maintain integrity in the face of death, in preference to studying choices or wishes for future care, may enable health professionals to seek ways to support people with lung cancer following the disclosure of a poor prognosis. Helping people acknowledge threats to their integrity and to that of their families, may enable them to understand and explain to others the impact that facing death has on their feelings of well-being. Training for doctors and other health professionals in the social aspects of death and dying may promote a better understanding of patients' and families' needs in relation to facilitating conversations about future medical treatment and care. Health and social care professionals can help people with lung cancer find ways to sustain social relationships by: providing information and practical support to enable people to retain employment or find other means of work – through for example volunteering, planning holidays and special occasions, creating legacies and other ways of 'being' that support 'normality'. For health professionals, efforts to support people at the end of life should be framed around preventing suffering by fostering hope and supporting social inclusion. As health and social care professionals we cannot maintain the integrity of someone else, but we can support them in the process.

The continuum model of discussing the future (figure 4.18) may provide an educational framework to explain what triggers people to consider their future and to help them start, if they wish, to plan for death and become prepared to engage in conversations about their end of life. Health and social care professionals are often charged with providing opportunities to discuss people's preferences for care, but in this context these findings suggest the professionals need to be wary of insisting on conversations about dying. Using the categories developed in this study, such as 'don't feel ill', 'discussing future', 'concern for family', 'carry on as normal', 'not thinking about the future', could be useful as a means of eliciting a person's preparedness to take part in conversations about facing death.

Raising an awareness in health and social care professionals that some people may not be willing to visualize a time of not 'being' will help ensure that patients are not forced to voice their

own thoughts about death and dying, which could take away control and hope, cause emotional distress and make it 'harder' to do the balancing work required in maintaining integrity. Palliative care education should include communication training that teaches health and social care professionals to faciliate conversations with people with advanced disease and their families in ways that support people to live in the present, whilst gently introducing issues about facing death, checking with the person that they are providing balance and recognising that integrity is paramount. Asking open-ended questions when communicating about the future, testing people's reactions and being led by their responses may help professionals ascertain people's information needs in relation to ACP.

Providing opportunities for family conversations about planning for the future by offering 'family clinic appointments', and including information about access to these, may be more beneficial than focusing on ACP for the individual. Conversely, health professionals also need to develop strategies to enable people to signal if they need a personal conversation about the future, when their families routinely accompany them to clinic appointments.

Finally, there is a need for readily available public information about how to access practical and financial support, where to obtain equipment for caring in the home and how to access end of life support services for family and informal carers.

## Strengths and limitations of the theory and design

In chapter two I discussed the use of Spencer et al's assessment framework (Spencer et al., 2003) to evaluate this study. A full appraisal using this framework is available in a table at appendix 4. I will now outline the key limitations of this study drawn from this appraisal.

One strength of the design of this study was the flexibility of the grounded theory approach to respond to the views of those it sought. By listening and analysing the early interview transcripts I was able to let the views and perceptions of people I interviewed influence the direction of the study. Their views supported the need for further data collection to gain a better understanding of the meaning of discussing end of life care. An alternative design might have limited the ability to redirect the study and risked not supporting the very views of those I sought, or caused me to develop an intervention that might not have met the needs of those it was designed for.

The cross-sectional design in which only one interview was conducted with each person with lung cancer was a limitation. More interviews earlier in the person's illness which were then followed up longitudinally might have captured different perceptions or changing attitudes about future care and treatment over time. Murray et al (2009) suggest serial interviews can be beneficial in eliciting patients' experiences and changing needs, but where prognosis is uncertain the timing of subsequent interviews can be difficult. With this target population it would have been problematic because of the diagnosis for most lung cancer patients, and predicting which, if any, would be alive for follow up was inherently difficult. The potential for intrusion or disruption to people's lives through revisiting a topic that many found difficult to discuss and asking to interview them again might also have been unethical.

There was a limitation in the sampling of family members. It was mainly female family members who agreed to participate because the majority of patient participants were male. No

male family members attended the group interviews and only three men engaged as family members in a joint interview. The views of more men as family carers might have influenced the findings. Another possible limitation in recruitment was introducing the topic area and providing sample questions in the study information letter (appendix 1). However, this is defendable from an ethical standpoint. A convenience sample was used and an unequal number of men and women were recruited.  As mentioned earlier, the lung cancer incidence ratio by gender is four men to three women (Cancer Research UK, 2010b). We therefore expected more men than women would be recruited, but the total sample was still lower for women. In 2007 mortality in the UK was higher for men than women, with 65.6 per 100,000 men to 47.9 per 100,000 for women (Cancer Research UK, 2010b).

As shown in chapter two, interviews were used to collect data from people with cancer and some of their family members, and were mostly conducted in people's homes. I have argued that this was the most ethical and appropriate means of gathering data from people who were living with advanced disease. Use of observational data, especially where a prognosis was disclosed to patients in clinic, may have enhanced the data collected. Interviews with the health professionals involved in the participants' care and treatment might have provided additional data to inform the findings.

A limitation in interviewing people with a partner present was the influence that the family member may have had on the story the person chose to report to me. It is not known how the comments might have been different if individuals had been on their own. Morris (2001) highlighted the fact that a carer's voice may sometimes be the dominant one, but that this may also be reversed within the interview. In the interviews I conducted the people with cancer usually had the dominant voice, except for the first interview with Barney and Eve. Eve, (Barney's wife), contributed more than Barney because of his memory difficulties related to brain metastases. Morris (2001) also suggests a couple will check their responses with each other and their relationship becomes a voice in the data as well as the individuals. The relationship

voice in this study was a strength because it helped to explain the meaning spousal relationships had on people with cancer who were facing death.

Another limitation I became aware of in relation to me as a researcher is my health care training and my experience being based on the medical model. Looking through the 'medical model' lens, I risked missing the social constructs emerging in the findings. Through reading and supervision I was made aware of the lens I was using and I was able to adapt and refocus my 'lens' to consider different interpretations.

As discussed in chapter two, careful attention was paid to the ethical design of this study. There were some limitations imposed on data collection because of this. The word 'future', instead of the word 'dying' was deemed to be a useful word to use to inform people about the topic for this study, and to include in the questions used in the interviews. The difficulty in using this more general word arose from people's different interpretations of the word. Most people appeared to interpret the questions about the 'future' as questions about dying, and a few people interpreted this as a period of time yet to come. Some of those who quickly interpreted questions about the future as dying, found it difficult to discuss the topic or they became emotional. For example, when Mabel was asked about what thoughts she had about the future she became tearful. Mabel said she worried that this would be her last Christmas. Where a few people interpreted the term 'future' differently, the interview was able to proceed with relative ease, building up to more specific questions, but not always reaching a conversation about wishes for end of life care because of their interpretation or unwillingness to discuss the future. A bereaved family member within the research advisory group has since suggested the use of an alternate term: 'day to day living'. This may be useful to consider as a preliminary general question in future research, however for the purpose of this study a reference to the future prompted most people to share their experiences. Similarly, difficulties in answering questions about the future were useful data in themselves.

Another ethical limitation, which had an impact on the subsequent findings, was my lack of awareness that some people might associate living wills with euthanasia. In one instance this appeared to cause distress to a person I was interviewing when I introduced these terms in an information card. To avoid causing distress to other people, this information card was not used with the remaining participants.

Limitations of theory development

One of the advantages of the methodological approach I chose was that it allowed people to express, if they wished, their own views about the future. As mentioned earlier, I recognise these accounts were limited by how people may have chosen to frame their accounts to me both as a stranger and a nurse. People may have chosen to give only the view they were willing to have made public and to have held different views privately. In addition, what they chose to discuss may have been uppermost in their mind at that window in time.

The theory developed is also influenced by my knowledge and experience as a nurse researcher and by that of my academic supervisors who supported the process. It is one interpretation of the data influenced by the researcher's construction and reading (Banister et al, 1994). A limitation of this new knowledge and proposed theory is that it could not be checked by those whose experiences have informed its development. Having others involved in the analysis, or engaging the participants themselves, if that had been possible, might have offered different interpretations of reality.

The findings and the theory have been compared to existing theories in the literature and appear to 'fit' within these. Health professionals involved in the advisory group and others who have since listened to a presentation of the findings have commented that the findings 'ring true' and enhance their understanding of patients' experiences. This adds credibility to the findings proposed by Glaser (1978), whereby people using the theory can apply it in their practice.

However, the theory presented here is only one interpretation of the findings, and therefore requires further testing for its usefulness to others wishing to understand and care for people affected by lung cancer.

## Summary

This study set out to explore the experiences and perceptions of people living with lung cancer and their families about their discussion about preferences and wishes for future care and treatment. What the interview findings showed is that people facing death prefer to live in the present and face death when it comes. Preferences and wishes for future care and treatment were not their main concern; rather, any concerns about the future related to the social aspects of death. The implications for policy and clinical practice have been highlighted as a need to focus on supportive strategies that do not force people into discussions about the future, recognising that discussing death and dying could threaten their integrity and cause suffering for some people. Further research in advance care planning is required to determine the attitudes of people living with different advanced diseases. In addition, the theory proposed in this chapter should be tested for its usefulness in understanding other patient group's attitudes towards planning for end of life care.

Lastly, this doctoral study has been both a personal and professional journey for me. I have learnt about research methodologies, about designing and conducting a qualitative interview study. My assumptions about life and death, nursing, medicine and palliative care have been challenged through critical reflection from academic study and discussions with colleagues and my supervisors. Most importantly, I have learnt from the patients and their families who generously reported their experiences and whose views have supported the design, findings and the theoretical interpretation of this research.

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# APPENDICES

**Patient information sheet.**

Study title: **Lung cancer patients, families and staff experiences of discussing and planning for future care and treatment**

You are invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it involves. Please take time to read the following information carefully and discuss it with others if you wish. Ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

**What is the purpose of the study?**
This study aims to find out what patients' views are about discussing their wishes for their future care and treatment to help health care professionals to support future patients and their families to talk, if they wish, about their preferences for their future.

Patient, family members and staff views will be collected over a period of approximately eight months. Gill Horne, a cancer nurse and a researcher at the University of Nottingham will be conducting the research, supported by Jane Seymour, Professor at the University of Nottingham, and Sheila Payne, Professor at the University of Lancaster.

**Why have I been chosen?**
You have been chosen to take part in this study because your views are important to help understand the care required for patients like yourself. This study hopes to gain the views of approximately 20 patients like you.

**Do I have to take part?**
It is up to you whether you decide whether or not to take part. Your participation is entirely voluntary. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any point and without having to give a reason. A decision to withdraw will not affect the standard of the care you receive.

**What will happen if I take part?**
We are seeking your permission to ask you some questions at one or possibly two interviews with the researcher (Gill Horne). The first meeting will be an opportunity for you and the researcher to get to know each other and begin to introduce some of the following potential topic areas and questions:

**How you make plans or not, for the future.**

- What discussions you may have had about your future care and treatment.
- Who initiated these discussions?
- Who you would want to involve in discussions about future care and treatment?
- What care, if any has helped you plan ahead and express your preferences for future care and treatment?

An interview within two weeks of the first meeting will provide an opportunity to discuss the above types of questions in more depth and offer a time to reflect on what was discussed at the first meeting.

Interviews will last approximately 30-45 minutes each. Each interview may be taped with your permission or, if you prefer, the researcher may take notes. The information gained at the interviews will be gathered with those from others selected for this study. You may be invited to attend a further interview to check out the researcher's understanding of your answers.

Any travel expenses incurred will be covered if the interview venue is not in your home.

**What are the possible benefits of taking part?**
We hope that the information you provide during the study interview will be used to help health care professionals support future patients and their families to talk, if they wish, about their preferences for their future care and treatment. The interview may also help you to crystallise your own ideas about future care.

**Will my taking part in this study be kept confidential?**
All information, which is collected, about you during the course of the research will be kept strictly confidential.  Any information about you, which leaves the hospital/surgery, will have your name and address removed so that you cannot be recognised from it.

Your GP will be notified of your participation in this study after first obtaining your permission.

**What will happen to the results of the research study?**
The results of this research study will be written up in a report to Macmillan Cancer Support and possibly published to help inform local and national service development. With your permission, anonymous quotes may be used to give examples of the results from the study. You will not be identified in any report or publication.

**Who is funding this study?**
This research study is funded through Macmillan Cancer Support and sponsored by the University of Nottingham.

**Contact for further information**
Please feel free to contact the principal researcher at any point in the study for further information


**Principal Researcher's name**:  Gillian Horne (principal researcher)
Address:

Tel No:

You will be given a copy of this document and the consent form to keep for future reference.

**Thank you for taking the time to take part in this research study.**


Gillian Horne/Professor Jane Seymour/Professor Sheila Payne

Appendix 2.Patient interview schedule (version 1)

**Introductory narrative questions (which may form the basis of the first meeting)**

> Q. Could you tell me about how you knew you had something wrong with you?

> Q. What, if any thoughts have you had about the future?

**General topic areas which would be explored during the interview**

- Who they have discussed the future with

- How they make decisions

- Who talked to about future care and treatment and whether health professionals initiated a discussion about the future

- Who did they include in this discussion, or would want to.

- Whether discussion was welcomed, or not

**More focussed topic areas**

- What topics discussed or would have liked to discuss

- Options or choices offered or would want for future care and treatment

- Recording of future wishes for care and treatment

- Affect of future planning on family relationships

**If patients are openly talking about dying or preparing for death I will proceed to discuss the following topic areas**

Whether discussed with health professionals about whom they would want to make decisions for them in future if no longer able to

What things may have helped in planning end of life care and whether anything that health professionals have said or done, has been helpful or hindered discussion about end of life

Whether they have an advance directive or have they thought about writing one

**General probes**
    …Could you tell me what happened next? Can you tell me more about that? And then?

**Introductory narrative questions (which may form the basis of the first meeting)**

- Could you tell me about your illness?

- Could you tell me about what happened in clinic or at your GP practice?

- What do you think about the future?

**General topic areas which would be explored during the interview**

- With whom discussed these thoughts, if anyone.

- Initiation of conversations/discussion about options for future medical treatment or care

- Recording of these discussions

- Preferred decision-making style/s – in relation to health care in past, present and future

**More focussed topic areas:** (*If patients are talking openly about dying or preparing for death I will proceed to discuss the following topics*).

Experiences of discussions relating to prognosis – (feelings, meanings, impact of knowing).

Views relating to importance or not of 'carrying on as normal' and living 'day by day'

Views about doctor-patient/doctor-health professional relationship in considering future care

Doctors and nurses communication in relation to the future – things that have helped or hindered.

Concerns relating to family members or influence of family in thinking/planning ahead

Any aspects of future care have planned for or would want to plan

Impact of previous knowledge and experience on thoughts about the future.

Opportunities, timing, and involvement of others in discussions about wishes or preferences for future medical treatment & care

**General probes**
…Could you tell me what happened next? Can you tell me more about that? And then?

Appendix 4.Completed Framework for Assessing Qualitative Evaluations (Adapted from Spencer et al, 2003, pages 22-28)[7]

| | Appraisal question | Quality indicators | Appraisal of this study |
|---|---|---|---|
| **Findings** | How credible are the findings? | Findings/conclusion are supported by data/study evidence | Findings have been supported by direct quotes from patient and family member interview transcripts and research field diary. Most codes were derived from participants own words. |
| | | Findings/conclusion makes sense/have coherent logic | The findings and proposed theory are derived from the themes which emerged directly from peoples reports. Findings from the first phase of interviews influenced the revision of the semi-structured interview guide to participants in the second phase to gain further data. |
| | | Findings/conclusions are resonant with other knowledge and experience (peer/member review)

Use of corroborating evidence to refine findings | It was not possible to return to 'members' to share findings because most patient participants have died. Findings have been discussed with members of the research advisory group (16/03/09) and other groups of staff and users through presentations (February 9th, 2010, to Lung Cancer MDT & Research advisory group). Their views have been captured in my research field diary and have helped refine the proposed theory. Following a presentation by Jane Seymour at the Inaugural International Conference on Advance Care Planning held in Australia (April, 2010) a number of clinicians reported confirmation of the findings from this study in their own practice/experience. |
| | How has the knowledge/understanding been extended by the research? | Literature review summarising knowledge to date/key issues raised by previous research | Chapter eight draws on previous research in relation to the proposed theory and applies this to test the theory. |
| | | Aims and design of study set in context of existing knowledge/understanding: identified new areas for investigation | Chapter eight examines issues raised by the findings and proposes implications for policy, practice, education and future research. |
| | | Credible/clear discussion of how findings have | Chapter eight offers a discussion of how the findings |

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| | | contributed to knowledge and understanding | and theory contribute new knowledge to this field of research. A discussion about how the findings may increase health professionals understanding of patients' and their families experiences' of living with and dying from lung cancer is provided. |
|---|---|---|---|
| | | Findings presented or conceptualised in a way that offers new insights/alternative ways of thinking | A new theory is proposed to offer conceptions about how patients and their families perceive discussions about the future and their focus on living in the present, rather than planning for dying. |
| | | Discussion of limitations of evidence and what remains unknown or unclear or what further information/research is needed. | Chapter eight describes the limitations in relation to evidence collated, detailing what is still unknown and where further research is needed. |
| | How well does the evaluation address its original aims and purpose? | Clear statement of study aims and objectives: reasons for any changes in objectives | Chapter two clearly states the aims and objectives of the study and how these changed in relation to the views expressed by people in phase one. Ethical and moral reasons were also stated for a change in objectives. |
| | | Findings clearly linked to the purposes of the study and to the initiative or policy studied | Findings demonstrated people's perceptions and experiences of discussing, or not discussing the future. From the findings inferences have been made about current and future policy. |
| | | Summary or conclusion directed towards aims of study | Chapter eight returns to the aim of the study by concluding that peoples' conceptions found in this study are incongruent with current assumptions presented in UK policy on advance care planning. |
| | | Discussion of limitations of study in meeting aims | Issues of gate-keeping by staff recruiting to the study were discussed in Chapter two. Limitations in design have been discussed in chapter eight. There were no identified gaps in the analysis, although challenges around this were described. |
| | Scope for drawing wider inference – how well is this explained? | Discussion of what can be generalised to wider population from which sample is drawn/case selection made. | Some inferences were made to a wider population from perspective of research with people from lower socio-economic groups living with advanced disease and within the wider context of literature on theories of dying or living with lung cancer. |

| | | Detailed description of the contexts in which the study was conducted to allow applicability to other settings/contextual generalities to be assessed | Study context and populations demographics are provided including details of peoples' stage of disease and socioeconomic status. |
|---|---|---|---|
| | | Discussion of how hypotheses/propositions/findings may relate to wider theory: consideration of rival explanations. Evidence supplied to support claims for wider inference | Existing theories of dying and managing 'normality' were explored and related to discussion of the proposed theory. |
| | | Discussion of limitations on drawing wider inference. | Chapter eight offers a discussion of the remaining questions and limitations of the findings from this study |
| | How clear is the basis of evaluative appraisal? | Discussion of how assessments of effectiveness/evaluative judgements have been reached. | This framework has been used as a basis of assessing the credibility of this study. Questions from this framework have been used by members of the research advisory group and colleagues in the Local Lung Cancer MDT to help evaluate the study. |
| | | Description of any formalised appraisal criteria used, when generated and how and by whom they have been applied | As above |
| | | Discussion of the nature and source of any divergence in evaluative process | In addition to using this framework, I have met regularly with my research supervisors to continually evaluate the progress of this study. I have kept a reflective research diary to note my thoughts about the study design, analysis, theoretical memos and development of the theory. A section in chapter two provides a section on my key reflections on this study to offer transparency in the processes used. |
| | | Discussion of any unintended consequences of intervention, their impact and why they arose. | The impact of discussing the topic area and my impact as a 'stranger' within the interview setting has been discussed in the reflexivity section, chapter two. |
| **Design** | How defensible is the research design? | Discussion of how overall research strategy was designed to meet aims of study, including rationale | Chapter two presents the philosophical and ontological underpinnings. Although the original design was revised, reasons for this were presented. |

|  |  | Convincing argument for different features of research design (diff stages, components, purpose of methods, time frames, data sources etc) | The different phases of the research study, methods chosen (interviewing) and time frames with their rationale are outlined. The choice to triangulate with different types of participants provides evidence of congruence between findings from people with cancer and their family members. |
|---|---|---|---|
|  |  | Use of different features of design/data sources evident in findings presented | Data sources included: people with cancer with/without their partner/family member and group interviews with family members on their own. Research field diary notes and observations were also used. Observations of observers of the group interviews were also taken in account. Research advisory group members and recruiters were also data sources. |
|  |  | Discussion of limitations of research design and their implications for the study evidence. | Chapter eight discusses the limitation and implications on the evidence. |
| **Sample** | How well defended is the sample design/target selection of cases/documents? | Description of study locations/areas and how and why chosen | Chapter two outlines the rationale for location as convenient sample in two local areas of my clinical practice, with access to recruiters. |
|  |  | Description of population of interest and how sample selection relates to it. | The population of interest described in chapter one. Sample selection described in chapter two and relates to predictable trajectory of disease, ease of recruitment and my area of interest. |
|  |  | Rationale for basis of selection of target sample/settings/documents. | Inclusion and exclusion criteria stated clearly. Aim of proposed sample size and aims of different peoples' views were described. |
|  |  | Discussion of how sample/selections allowed required comparisons to be made. | Chapter two and three provides examples of how the sample recruited allowed comparisons between and across individual, joint and group interviews to develop emerging theory. |
|  | Sample composition/case inclusion – how well is the eventual coverage described? | Detailed profile of achieved sample/case coverage. | Profile of people with cancer and where possible profile of family members has been provided within chapter three. Case study illustrations used in findings chapters. Both demographic and socioeconomic details are included. |

| | | Maximum inclusion (language matching/translation; specialised recruitment; organised transport for group attendance). | No person was excluded based on need for translation. However due to lower ethnic minority within study population no recruited people required translation. Transportation was offered to people within study information letter. One person took up offer of transport for group interviews. I travelled to peoples' homes. |
|---|---|---|---|
| | | Discussion of any missing coverage in achieved sample/cases and implications for study evidence. | Details of missing demographic details shared within sample tables. Discussion around more men than women within sample included in findings and discussion of theory. |
| | | Documentation of reasons for non-participation among sample approached/non-inclusion of selected cases. | Table detailing non-participation of invited people and non-inclusion presented in chapter two. This was important information to make inferences about findings. |
| | | Discussion of access and methods of approach and how these might have affected participation/coverage | Chapter two includes a discussion about issues of access and gate keeping. |
| **Data collection** | How well was the data collection carried out? | Discussion of: Who conducted data collection, procedures/documents used for collection/recording and checks on origin/status and authorship of documents? | Discussion included in reports on data collection methods within chapter two. Documents capturing data about patients created and completed by me |
| | | Audio/video recording of interviews/discussions/conversations | Chapter two describes audio-recording of all interviews (single, joint and group). Research advisory group minutes were typed and are available on request. |
| | | Description of how fieldwork methods or settings may have influenced data collected | Chapter two and three describe how fieldwork and setting influenced data collection in addition to influence of myself as researcher. |
| | | Demonstration, through portrayal and use of data, that depth, detail and richness were achieved in collection | Direct quotes from interview transcripts have been used to illustrate the findings in detail. Pen portraits and case studies within findings chapters have provided rich detail to help evidence how the theory is grounded in the data. |

| Analysis | How well has the approach to and formulation of the analysis been conveyed? | Description of form or original data (verbatim transcripts, observations, interview notes etc) | Data analysis section details how transcripts were transcribed verbatim and my field notes of observations were also used. Process of coding was photographed to provide audit trail of the process of analysis. |
|---|---|---|---|
| | | Clear rationale for choice of data management method/tool/package | Rationale given for preferring to hand code in analysis section of chapter two, making it easier for conducting comparative analysis across transcripts. Use of qualitative data analysis software for family group interviews for learning purposes only. |
| | | Evidence of how descriptive analytic categories, classes, labels etc have been generated and used. | Discussion of how codes and categories derived described in chapter two. Diagrams of models showing relationship of codes also provided. |
| | | Discussion, with examples, of how any constructed analytic concepts/typologies etc have been devised and applied. | The proposed theory shows how it is constructed from codes, to categories and then substantive categories both in writing and through diagrammatic representations. The application of the theory is discussed in chapter eight. |
| | Context of data sources – how well are they retained and portrayed? | Description of background or historical developments and social/organisational characteristics of study sites or settings | Socio-economic background of people with cancer provided. Study setting described minimally to ensure confidentiality of participants but observations of peoples' homes/family life portrayed in pen portraits. |
| | | Participants perspectives/observations placed in personal context (use of case studies/vignettes/profiles etc) | Use of both case studies to introduce findings and pen portraits of all people with cancer who participated provides personal context. |
| | | Explanation of origin/history of written documents | Patient medical records reviewed within context of gaining demographic data |
| | | Use of data management methods that preserve context | Choice to code data by hand preserved integrity of whole transcripts and enabled comparisons of transcripts. Qualitative data analysis software used to store family group interviews, but these were still coded initially by hand. |

| | How well has diversity of perspective and content been explored? | Discussion of contribution of sample design/case selection in generating diversity | Men and women recruited. Discussion about sample obtained within chapter eight linking to construction of theory. |
| --- | --- | --- | --- |
| | | Description and illumination of diversity/multiple perspectives/alternative positions in the evidence displayed | Use of direct quotes showing different perspectives within each findings chapter. |
| | | Evidence of attention to negative cases, outliers or exceptions. | 'Negative' cases were explored in findings chapters to illustrate different perspectives. Where there were exceptions these were described in chapters: four to seven. |
| | | Examination of origins/influences and opposing or differing positions. | My Influences on methodology and in reflexivity are described. Different positions and questions for further consideration have been put forward in arguments within discussion. |
| | | Identification of patterns of associations/linkages with divergent positions/groups | Patterns and relationship between substantive categories are described within the theory proposed and detailed in the list of final codes. Family interview data used to confirm or refute developing theory from perceptions of people with cancer. Descriptions of differing views from family members also discussed in each finding chapter |
| | How well has detail, depth and complexity of the date been conveyed? | Use and exploration of contributor's terms, concepts and meanings. | Operational definitions provided at beginning of thesis. Concepts and meanings discussed within chapter eight. |
| | | Unpacking and portrayal of nuance/subtlety/intricacy within data | Findings chapters explain through use of examples, the nuances in individual perceptions. |
| | | Detection of underlying factors/influences. Identification and discussion of patterns of association/conceptual linkages within data. | Pen portraits seek to describe the influences of each case of the data on the analysis and how each interview contributed to the next. Use of a grounded theory approach to the analysis (chapter two) describes how the data analysis was an iterative process. Use of the constant comparative method involved identifying conceptual links to develop the theory in chapter eight. |

| | | Presentation of illuminating textual extracts and observations | Multiple direct extracts from transcripts and field-notes used to illuminate findings. |
|---|---|---|---|
| **Reporting** | How clear are the links between data, interpretation and conclusions – i.e. how well can the routes to any conclusions be seen? | Clear conceptual links between analytic commentary and presentations of original data. | Systematic analysis demonstrated through coding the original data using peoples own words, developing conceptual links between the findings and the proposed theory. |
| | | Discussion of how/why particular interpretation is assigned to specific aspects of data – with illustrative extracts of original data. | Use of diagrams/models in the findings chapters, coding table, and pen portraits show link between analytic concepts and proposed theory. |
| | | Discussion of how explanations/theories/conclusions were derived – and how they relate to interpretations and content of original data; whether alternative explanations explored | As above. Alternative explanations explored in limitations section, chapter eight. |
| | | Display of negative cases and how they lie outside main proposition/theory/hypothesis etc or how proposition etc revised to include them. | 'Negative cases' reported in the findings and discussed in chapter eight |
| | How clear and coherent is the reporting? | Demonstrates link to aims of study/research questions | Chapter eight revisits the aims of the study and links findings and proposed theory to these. |
| | | Provides a narrative/story or clearly constructed thematic account. | Pen portraits introduce 'actors' in the story. Findings chapters through case studies and extracts of transcripts provide thematic account. |
| | | Has structure and signposting that usefully guides the reader through the commentary. | The thesis has a content page, clearly structured chapters and signposting between chapters to support the reader. |
| | | Provides accessible information for intended target audience | Reporting is intended for academic audience and in the form of a thesis. |
| | | Key messages highlighted or summarised | The thesis abstract and the findings chapters introduce and summarises key concepts. The proposed theory highlights key messages. |

| Reflexivity & neutrality | How clear are the assumptions/theoretical perspectives/values that have shaped the form and output of the evaluation? | Discussion/evidence of the main assumptions/hypotheses/theoretical ideas on which the evaluation was based and how these affected the form, coverage or output of the evaluation. | This chosen framework for evaluating this doctoral study is discussed in chapter two. The issue of ensuring quality in the study influenced the systematic approach to using grounded theory, the sensitive and ethically focussed conduct of the study and the development of an explanatory theory to answer the research question. |
|---|---|---|---|
| | | Discussion/evidence of the ideological perspective/values/philosophies of research team and their impact on the methodological or substantive content of the evaluation | My underpinning philosophies and personal and professional influences as a researcher are discussed in chapter one. A constructivist and pragmatic approach was taken and reporting demonstrates how this influenced the findings and developing theory. |
| | | Evidence of openness to new/alternative ways of viewing subject/theories/assumptions | I have sought to be open about the assumptions I had and decisions I made throughout the thesis, especially in the sections on analysis, and reflexivity in chapter two. |
| | | Discussion of how error or bias may have arisen in design/data collection/analysis and how addressed, it al all | My original assumptions were challenged through: reviewing the literature in the topic, initial and subsequent data collection, supervision and in discussion with other researchers work in the topic area. Challenging of assumptions and asking questions of the data has helped address preconceived notions. |
| | | Reflections on the impact of the researcher on the research process | The pen portraits (chapter three) and the reflexivity section in chapter two detail my reflections on the research process. Where appropriate there are other references to my effect on the generation of data and the subsequent analysis. My recognition as a co-constructor of data is implicit within the chosen design. |
| Ethics | What evidence is there of attention to ethical issues? | Evidence of thoughtfulness/sensitivity about research contexts and participants | Discussion of design, data collection methods show consideration of people who are facing death. Specific examples include: how the research was presented to potential participants including topic and questions; information provided to participants; sensitivity of interviewer to the field from past experience and clinical role; supporting mechanisms for potentially |

| | | | distressed participants; sensitive interviewing using general to more specific questions and sensitive handling of individual and family members accounts. Use of users to inform design. |
|---|---|---|---|
| | | Documentation of how research was presented in study settings/to participants | The appendices include copies of participant information sheets showing presentation of study and topics to be discussed. |
| | | Documentation of consent procedures and information provided to participants | Sample information sheets (appendix 1) and consent forms are available on request. Consent procedures are explained in chapter two. Acknowledgement of participants' contribution was done through thanks following the interview and individual thank-you notes posted the following day. |
| | | Discussion of confidentiality of data and procedures for protecting/Discussion of how anonymity or participants and sources were protected. | Participants were informed of confidentiality and use of pseudonyms through the information letter. Use of unidentifiable codes for transcripts and storage of data are discussed within chapter two |
| | | Discussion of any measures to offer information/advice/services etc at end of study Discussion of potential harm or difficulty through participation and how avoided. | List of useful contact details were provided to all participants. This included access to counselling and other forms of psychosocial support. Examples of where I offered further information to support questions raised in interviews are reported. Discussion about potential risks found within methods and procedures in chapter two. Introduction of new information to research interview and the impact of me as interviewer as interventionist are discussed in the reflexivity section, chapter two. |
| **Auditability** | How adequately has the research process been documented? | Discussion of strengths and weaknesses of data sources and methods | Limitations of study data sources and methods discussed in chapter eight. |
| | | Documentation of changes made to design and reasons; implications for study coverage | Documentation of change in design to conduct grounded theory study and not continue to design and test an advance care plan are explained within footnotes. |

| | | Documentation and reasons for changes in sample coverage/data collection/analytic approach; implications | No change in sample coverage made. Theoretical saturation defined the completion of data collection though a grounded theory approach. |
|---|---|---|---|
| | | Reproduction of main study documents | Invitation letters, topic guides/interview schedules, conceptual labels, and ethical approval provided are available in appendices or researcher study file. |