

**The Carer's Initiation:
A qualitative study of the experience of family care of the dying**

Margaret Jenny Newbury

A thesis submitted for the degree of Professional Doctorate in Health

University of Bath

School for Health

July 2009

COPYRIGHT

Attention is drawn to the fact that copyright of this thesis rests with its author. A copy of this thesis has been supplied on condition that anyone who consults it is understood to recognise that its copyright rests with the author and they must not copy it or use material from it except as permitted by law or with the consent of the author.

This thesis may be made available for consultation within the University Library and may be photocopied or lent to other libraries for the purposes of consultation.

Table of Contents

List of Appendices	5
List of Tables and Figures.....	6
Acknowledgements	7
Abstract	8
Abbreviations	9
Glossary of terms	10
Chapter 1 Introduction	13
Structure of the thesis	14
Chapter 2 Literature review	15
1. Introduction.....	15
2. Background.....	17
3. Carers: who are they?	19
4. The stresses and strains of being a carer in palliative home care	21
5. Positive aspects of caring.....	24
6. Formal and informal support	26
7. Preparation for the final stages of the dying process.....	30
8. Statement of the problem.....	33
Chapter 3 Methods	35
Introduction.....	35
Research aims	35
Research design	36
Methods	38
Population and sample	40
Sample characteristics	42
Methodology and data analysis	44

Limitations of the methodology	45
Reflexivity	48
Ethical principles and issues	49
Summary	54
Chapter 4 Findings and analysis	55
Introduction.....	55
Dramaturgical perspective	55
The carer's initiation.....	60
Carers as performers	62
Setting and props	67
No rehearsals	69
No script.....	72
Direction	75
Supporting cast	80
Audience	83
Types of performance	85
The climax of the drama	87
The finale	89
Summary	91
Chapter 5 Discussion	92
Introduction.....	92
The carer's initiation.....	92
Uncertainty and information seeking.....	95
Interaction with professionals and paid carers.....	97
Social isolation.....	103
Emotional impacts	104
Helps and hindrances	105

Summary.....	106
Chapter 6 Conclusion.....	108
Thesis summary.....	108
Limitations of the study.....	109
Implications of the study for policy and practice	110
Suggestions for further research	116
References	118
Appendices.....	131

List of Appendices

Appendix 1 Interview guide – current carers.....	131
Appendix 2 Interview guide – bereaved carers.....	132
Appendix 3 Inclusion and exclusion criteria.....	133
Appendix 4 Example of coded current carer interview transcript.....	134
Appendix 5 Example of coded bereaved carer interview transcript.....	146
Appendix 6 A note on reflexivity.....	158
Appendix 7 Information sheet for participants 1.....	162
Appendix 8 Invitation letter – current carers.....	164
Appendix 9 Invitation letter – bereaved carers.....	165
Appendix 10 Information sheet for participants 2.....	166
Appendix 11 Consent form – current carers.....	168
Appendix 12 Consent form – bereaved carers.....	169
Appendix 13 Thank you letter to participants.....	170

List of Tables and Figures

Table 1 Carer characteristics.....	42
Table 2 Patient characteristics.....	43
Table 3 Most valued aspects of professional help.....	76
Table 4 Most criticised aspects of professional help.....	77
Table 5 Most valued aspects of paid carers.....	81
Table 6 Difficulties encountered with paid carers.....	83
Table 7 Types of carer performance.....	85
Table 8 The carer's initiation.....	93
Table 9 Factors that helped and did not help carers to perform their role.....	105
Figure 1 Dramaturgical concepts of the carer's initiation play.....	94

Acknowledgements

I would like to express my thanks to my supervisor, Professor Allan Kellehear for his patience and expert guidance throughout the process of the study and writing of this thesis.

I would also like to express my gratitude to my colleagues who have supported me in many ways and kept me going. My thanks also go to my peers in the first cohort of the Professional Doctorate in Health at the University of Bath who have also been immensely supportive.

But most of all, I wish to thank my participants, the carers who gave their time and shared their experiences with me at a very difficult time in their lives.

Abstract

The aim of this study was to explore the experience of carers of family members dying at home with particular reference to their expectations and preparedness for the dying process. It was a qualitative, longitudinal study which initially followed a grounded theory approach. However, as a theatrical metaphor became apparent from the data the approach changed to dramaturgical analysis. Face to face semi-structured interviews were conducted with fifteen carers before and after the death of their family member. Carers were found to be performing a leading role in home palliative care but they experienced a universal sense of uncertainty and of being unrehearsed for their role in the dying process. They were reluctant to seek information to give them a script for their performance because it was painful and difficult to contemplate their family member dying. They needed the direction of health professionals and the support of paid carers but had variable experiences of these services. Carers' performance types were also variable but tended to be towards the combative or the pragmatic end of a continuum. Their experience was illuminated through the dramaturgical metaphor of a play called the Carer's Initiation. The climax of the play was the death of the family member followed by the finale in which they watch over the body until it is removed and they finally face a future without their family member. The carer's initiation highlighted policy and practice implications for improving the preparation and support of carers for the dying process.

Abbreviations

ACP – Advance care planning

CAQDAS – Computer assisted qualitative data analysis software

CHC – Continuing health care

COREC – Central office for research ethics committees

DH – Department of Health

EOLC – End of life care

GP – General practitioner

GSF – Gold Standards Framework

LCP – Liverpool care pathway

LREC – Local research ethics committee

NCHSPCS – National Council for Hospices and Specialist Palliative Care Services

NCPC – National Council for Palliative Care

NICE – National Institute for Health and Clinical Excellence

PCT – Primary care trust

RCN – Royal College of Nursing

UKHCA – United Kingdom Homecare Association

Glossary of terms

Advance care planning: a voluntary process of discussion about future care between an individual and their care providers, irrespective of discipline, which may result in a statement of wishes, preferences, beliefs and values and/or an advance decision to refuse treatment and/or lasting power of attorney. The difference between ACP and planning more generally is that the process of ACP is to make clear a person's wishes and will usually take place in the context of anticipated deterioration in the individual's condition in the future, with attendant loss of capacity to make decisions and/or ability to communicate wishes to others (Henry and Seymour, 2008).

Carer: "A carer spends a significant proportion of their life providing unpaid support to family or potentially friends. This could be caring for a relative, partner or friend who is ill, disabled or has mental health or substance misuse problems" (DH, 2008:11). In the palliative care context I have borrowed the NICE (2004:155) definition - "carers, who may or may not be family members, are lay people in a close supportive role who share the illness experience of the patient and who undertake vital care work and emotional management". Thus, carers provide emotional as well as physical care. For the purposes of this thesis, carer refers to the patient's main carer. However, I recognise that other family members, friends or neighbours contribute to the emotional and physical care and well-being of the patient.

End of Life Care: a term that has superseded terminal care and refers to the care in any setting for any patient who is thought to be approaching the end of their life.

End of life care programme and strategy: government initiatives which aim to improve the quality of care at the end of life for all patients and enable more patients to live and die in the place of their choice. They incorporate ACP, LCP and GSF.
(www.endoflifecareforadults.nhs.org, 2009).

Gold Standards Framework: a systematic approach to optimising the care delivered by primary care teams for any patient nearing the end of life in the community
(www.goldstandandsframework.nhs.uk, 2006).

Health professional: any health care worker with a professional qualification. Health professionals working in primary health care and specialist palliative care are the most prominent in the context of home palliative care.

Liverpool Care Pathway: a clinical tool originally developed to transfer a hospice model of care into mainstream NHS care settings. It is used by all the multidisciplinary team and incorporates evidence based practice and guidelines related to the care of and support of the dying patient in the last days of life (www.mcpcil.org.uk/liverpool_care_pathway).

Paid care: personal care given to patients at home by health care assistants employed by domiciliary care agencies. The agencies are normally independent, but contract with health and social services or individual patients to provide a care package. Paid care is sometimes delivered directly by health and social services. In the study area it is also delivered by Hospice at Home. A care package may involve one or more visits a day and/or overnight attendance by care assistants, or a 24 hour live-in care assistant.

Palliative care: originally defined as - the active total care of patients and their families by a multi-professional team when the patient's disease is no longer responsive to curative treatment (WHO, 1990). More recently defined as - the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments (NICE, 2004)

Primary Health Care: the services provided in the community by statutory health and social care professionals. The primary health care team usually comprises GPs, practice nurses, district nurses, health visitors, community matrons, professions allied to medicine and attached social workers.

Specialist palliative care: the services provided for patients and their families who have complex palliative care needs. These services are provided by specialist multidisciplinary palliative care teams which should include palliative medicine consultants and palliative care

nurse specialists together with a range of expertise provided by physiotherapists, occupational therapists, dieticians, social workers and those able to give spiritual and psychological support. Specialist palliative care includes intensive co-ordinated home support for patients with complex needs who wish to stay at home (NCPC, 2009).

Terminal care: usually refers to the management of patients during their last few days or weeks from a point at which it becomes clear that the patient is in a progressive state of decline (NCHSPCS, 1995).

Terminally ill: those with active and progressive disease for which curative treatment is not possible and who have entered a progressive state of decline.
(NCHSPCS, 1995)

Chapter 1 Introduction

This thesis has its origins in my professional practice as a community palliative care nurse specialist. I am involved in supporting the carers of patients receiving home palliative care on a daily basis and I am aware that many carers have fears and anxieties about coping with the dying process at home. I was instrumental in developing a short course for carers which is run three times a year at the hospice where I am employed. Among other topics, the course aims to prepare carers for the final stages of the patient's life. The course is well attended and evaluated. Nevertheless I am aware that only the minority of carers within the specialist palliative care caseload of the hospice attend the carers' course and that it does not fully meet the information and preparation needs of those who do attend. I was concerned that the methods of preparing carers for the dying process were potentially haphazard. I conducted a literature search and discovered that there seemed to be little evidence on what is effective in supporting and preparing carers specifically for this final stage.

I therefore wished to investigate the process of preparing carers for the final stages of the patient's life. While I could have asked health professionals how they did this and what they thought was most effective, I decided that it was more appropriate to ask carers themselves what they found helpful and unhelpful. I therefore decided to explore from the carer's perspective what their expectations and preparation needs were for the dying process. In order to do this it was necessary to define and identify carers. NICE (2004:155) provided a succinct definition which encapsulates the physical and emotional role of carers - "carers, who may or may not be family members, are lay people in a close supportive role who share the illness experience of the patient and who undertake vital care work and emotional management". In many home palliative care situations there are several family members who attend to the emotional, social and physical needs of the dying patient, but there is usually a main carer who undertakes the principal responsibility for the day-to-day caring role. While I did not wish to underestimate the contribution of other family members and/or friends and neighbours, I decided to concentrate on the main carer because they carry the most responsibility and experience the full range of implications of caring. I then elected to undertake a qualitative study to explore carers' expectations and preparation for the dying process which I will present in this thesis.

Structure of the thesis

The thesis is divided into six chapters which describe the process of the study.

- In chapter two I present a review of the literature on carers in home palliative care. This review includes some background on carers in general but mostly emphasises the specific characteristics of caring for a dying relative or friend at home. It identifies that expectations and preparation of carers for the dying process is under-researched.
- In chapter three I describe the aims and design of the study. I explain how I selected the methods and I outline the sampling strategy and characteristics. I also explain how the analysis took shape and I critique the methodology. In this chapter I discuss the ethical issues of the study and the importance of reflexivity throughout the research process.
- Chapter four presents the findings using quotations from the data to support the analysis. In this chapter I seek to understand what carers have said before and after the death of their patient about caring through the dying process of their family member. I also seek to put the interpretation of their experiences into a theoretical framework.
- In chapter five I discuss the findings of the study in relation to existing literature on carers in home palliative care. I present new insights from the findings and analysis in relation to carers' expectations and preparation for the dying process.
- Chapter six includes a summary of the thesis and presents the limitations of the study. In this final chapter I also describe the implications for health and social policy and practice and I make recommendations for further research.

Chapter 2 Literature review

1. Introduction

The contribution of carers and their vital role in our communities have been recognised in recent policy initiatives such as the Carers and Disabled Children Act 2000, the Carers (Equal Opportunities) Act 2004 (DH, 2005) and the Carers' Strategy (DH, 2008). The Department of Health (1999) acknowledged that carers enable people to stay in their own homes and to remain independent, but it is also recognised that being a carer has effects on carers' own health and well being and that their needs are not adequately met.

The aim of this review is to examine the literature on carers, and in particular carers of people receiving palliative care, i.e. those patients with a life-threatening disease which is beyond the scope of cure. It will focus especially on the expectations and preparation of carers of the terminally ill, i.e. those in their last few weeks or months of life. It will include assessment of the quality and context of existing research and analyse and synthesise the findings to build a comprehensive overview of the issues and problems. Examining the literature in this way will demonstrate the need for further research in this area by identifying gaps and therefore avoiding repetition.

The literature demonstrates that caring for a relative or friend at home is a relentlessly onerous task and it is particularly demanding in home palliative care. Carers of people receiving palliative care face physical and emotional challenges as their patient deteriorates. They frequently feel a lack of professional understanding and support. They also experience unwelcome changes in their self identity and lifestyle. These changes often have financial implications for which there are inadequate state benefits.

Although these difficulties for carers during the palliative phase are reported in the literature, there is insufficient existing research on carers' experiences in the final stages of the dying process. We do not know how carers know how to care and to cope at the end of their family member's life and what helps and does not help them at this time. In particular there is very little research around carers' expectations and preparation for the last few days of life.

Organisation of the review

Following the introduction, the second section of the literature review will identify background issues for all carers. The third section presents some of the demographic data for carers in general and in palliative care. These sections set the scene for the examination of the specific issues for carers in palliative care in the following sections.

Section four identifies the particular stresses and strains of being a carer in home palliative care. It examines the literature on carer burden, the emotional aspects of caring and the social stress and lifestyle interference resulting from caring. This section presents a picture of the many difficulties associated with caring for someone who is going to die at home.

Section five, however, shows the other side of the coin by exploring the positive aspects of caring and the ways in which carers cope. Section six proceeds to present the literature on formal and informal support for carers. Access to, and effectiveness of, professional care services are evaluated. Specific interventions for carers in palliative care are also reviewed. Information giving and communication between health professionals and carers are then explored because they are fundamental to supporting carers but considerable barriers are reported which prevent effective communication.

The many issues for carers in palliative care at home and the extent to which current services meet their needs are reviewed in the above sections but the emphasis in existing research is on the long lead up to the dying phase rather than caring in the last days of life. Section seven looks at the preparation of carers for the final stages of the dying process and finds a lack of research studies in this area. The difficulties of identifying the dying phase and professionals' and carers' ambivalence about what they need or want to be told are discussed. But a gap is found in the literature about what carers expect during the dying process or on how they become prepared for this potentially difficult experience.

The final section eight presents the argument that more research is needed to explore carers' expectations and preparation for the final stages of the dying process.

2. Background

A number of terms are used to describe those who look after a relative or friend at home. Family carer, informal carer, lay carer or just carer as well as caregiver or family caregiver are all used, but there can be confusion as professional health and social care providers are also sometimes referred to as carers and caregivers. For this review of the literature and the thesis as a whole the term carer will be used as it is the label used by statutory and non-statutory organisations in the UK and is the term that carers themselves are most likely to identify with.

Before the 1970's, recognition of carers did not exist. The activity of caring was scarcely visible, regarded only as an obscure and taken-for-granted aspect of family relations. During the 1980's, however, the subject received much interest in both policy and research. With the introduction of community care policy, there was much attention on prevention of institutionalisation, the cost-effectiveness of community care and the central role of carers in both. However, the feminists at this time were quick to identify the uneven burden of caring borne by women and men (Twigg, 1992). The feminist critique of community care was the underlying assumption that it was synonymous with care within the family to be provided mainly by women. Women's role as carers was seen as part of their oppression (Stalker, 2003). Gendered assumptions about women being 'natural carers' and better able to cope with the demands of caregiving than men continue to influence service providers and can still disadvantage female carers. However, such assumptions are often held by carers themselves and different personal meaning may be ascribed to caring tasks by men and women accordingly (Twigg, 1992).

The feminist critique that emphasised the exploitative character of community care, the demands associated with caring and the negative impact on carers' lives laid the foundation for carers to voice their concerns and for official recognition of their needs. Carers became more organised on a broader based platform and in a more sophisticated manner, clearly articulating and publicising their needs. And more formal support, resources and legislative rights became available (Stalker, 2003).

However, at the same time, the mobilisation of carers did not go unchallenged. Disability and service user movements have argued that supporting carers, or treating them as resources, only perpetuates the dependency of disabled people, older people and users of mental health

services. Focusing exclusively on the carer is demeaning to the disabled person who is made an adjunct of somebody else. The very notion of care implies that people need looking after rather than having the right to exercise choice and control over the support they receive and thus over other aspects of their lives (Stalker, 2003). Although there may be arguments against the imbalance of gender roles and of power and dependency in caring relationships, caring is nevertheless an essential element of our society. Caring is embedded in relationships of obligation such as marriage, parenthood, or kinship. The relationship also includes the physical work of caring; emotion, frequently associated with and energised by love but also involving emotional labour; co-residence and the consequences of caring on the relationship; and being responsible for the cared for person (Twigg and Atkin, 1994). This analysis, however, ignores mutual obligation in caring relationships and the delicate and reciprocal dynamics that often exist between care receivers and carers. Indeed many care receivers become skilled in working collaboratively with their carers. They maintain reciprocities in relationships by such efforts as providing emotional support and love to the carer, showing appreciation and maintaining a sense of humour and fun (Nolan, 2001).

Although carers carry a huge responsibility for care in the community, caring does not exist purely within the family. Health and social care agencies also play a role. Addressing the different constituencies in community care, Twigg and Atkin (1994) identified four models of caring in relation to service provision. The first of the four models is *carers as resources*, whereby informal care in the broadest sense largely results from long-term social factors, such as demography and family obligation, is expected as a 'given' and carries no cost to the public purse. The second model, *carers as co-workers*, involves agencies working alongside carers, interweaving their support with that of the carers. It is based on the premise that carers want to care and that assisting them to do so is the most important way for agencies to relate to them. *Carers as clients* is the third model. Here carers are regarded as people in need of help in their own right. This model generally applies only to those who are heavily involved in caring where services are aimed at relieving their situation and enhancing their morale. Finally there is *the superseded carer*. In this model the aim is not to support the carer but to supersede their role. This may occur when there is a need to maximise the independence of the care receiver and agencies intervene in ways that result in the cared for person no longer having to rely on a carer. Or it may happen because of concern for the carer and may assist the carer in making the decision to give up caring. The models reveal that carers lie on the margins of the social

care system, partly as an area of concern and response and partly a taken-for-granted reality against which welfare services operate (Twigg and Atkin, 1994). This marginalisation is confirmed by Marriot (2003) writing from personal experience as a carer when he describes “the awareness that sneaks up on most of us in the early days of caring, that we’re on our own” (p39).

3. Carers: who are they?

The 2000 General Household Survey found that one in six people aged 16 or over (16%) was caring for a sick, disabled or elderly person and one in five households (21%) contained a carer. These figures represent around 6.8 million adult carers in 5 million households (Maher and Green, 2002). Carers UK estimate that one in eight adults is a carer (www.caretotakealook.com, 2009) and three out of five people will be carers at some point in their lives. Women are more likely to be carers (58%) than men (42%) and 1.3 million carers are over the age of 65 (www.carersuk.org.uk, 2007). Carers under the age of 18 remain a rather hidden entity but it is estimated that 175,000 young carers provide substantial and regular care (www.caretotakealook.com, 2009). There are other pockets of hidden carers including those from black and minority ethnic communities, older carers and those living in rural areas (Stalker, 2003)

There is very little demographic data available regarding carers in home palliative care. It is only possible to make assumptions about them based upon data on patients using palliative care services. The National Council for Palliative Care (NCPC, 2008) collect and publish annual statistics of patient activity in specialist palliative care in England, Wales and Northern Ireland. These reveal that in the year 2007-2008 for patients receiving home care there was an even distribution of male (51%) and female (49%) patients with the following age ranges – under 25 (0.4%), under 65 (29%), 65-84 (57%) and over 84 (14%). National life expectancy projections suggest that this is a population of patients who are dying prematurely. For instance, for those aged 65 in 2006 life expectancy is projected to be 20.6 years for males (85.6) and 23.1 years for females (88.1) (Office of National Statistics, 2009). Older patients are less likely to receive palliative care than younger patients but carer age may be as important a predictor of palliative home care use as patient age (Grande et al, 2006).

Only 44% of palliative care services provided data for NCPC on ethnicity. Of these, for all patients receiving specialist palliative care services, 94.5% were white, 2.13% were black, 1.62% were Chinese or other, 1.44% were Indian, Pakistani or Bangladeshi and 0.31% were mixed race. Koffman and Higginson (2001) found that few black Caribbean patients accessed specialist palliative care services and suggested this may be due to restricted knowledge among the black Caribbean community on how best to make use of local health services, some GPs being more likely to act as gatekeepers to services among ethnic minorities, and demand for services being influenced by the ethnocentric outlook of palliative care services and discouraging black and ethnic minority groups from making use of relevant provision.

An estimated 11% of all patients receiving specialist palliative care services had a non-cancer diagnosis, but no accurate figures can be given for an overall proportion of non-cancer patients. For place of death 30% are reported to have died at home, 28% in a palliative care unit, 36% in hospital and 6% other. These place of death figures should be treated with caution, however, as only 61% of services provided data and the responses do not necessarily mirror the proportion of the different types of palliative care services. 26% of all patients were reported to be living alone. The only data given for carers are their relationship to the patient. The majority were spouses (47%), then daughters (16%), sons (9%), other relative (9%), other (11%) and no main carer (7%). However, only 37% of services supplied data on carers (NCPC, 2008).

The NCPC recognises that the validity of the data may be questioned because of the low response rates and apparent double-counting of patients receiving more than one palliative care service. Nevertheless the data give a picture of a disproportionately white population of patients, with a relatively young age profile and mostly with a cancer diagnosis, who are cared for by their spouses or other family members. The NCPC do not report on the social class of patients using specialist palliative care services. Studies have shown that patients from more deprived areas were less likely to die at home (Higginson et al, 1999; Gatrell et al, 2003; Grundy et al, 2004). In a study in a mixed socio-economic city area in Britain cancer patients from social class V were less likely to die in the hospice but social inequality in access to or utilisation of other services for terminal care was not prominent (Kessler, et al 2005). Similarly, social class and ward of residence did not affect utilisation of specialist palliative care services in a population based study in northern Britain (Gray and Forster, 1997).

4. The stresses and strains of being a carer in palliative home care

The majority of terminally ill patients spend most of their last year of life at home and most patients, given a choice, say they want to die at home (Higginson and Sen-Gupta, 2000). The role of carers is paramount in achieving death at home. While all carers have common and individual needs, there are specific factors for carers of people with terminal illness at home which, although not exclusive to caring for the terminally ill, do set them apart.

For these carers it is a time-limited activity associated with progressive loss (Rhodes and Shaw, 1999), putting their lives on hold while the patient is ill knowing that it is temporary because the patient will die (Harding and Higginson, 2001). Among carers of cancer patients those caring for people in the palliative phase have more unmet psychosocial needs (Soothill et al 2001). Carers in palliative care are frequently in an ambiguous position, equivocal about their role, and many do not identify with the term 'carer' at all (Smith, 2000). They describe themselves as being invisible or just part of the patient and are highly ambivalent regarding their own needs (Harding and Higginson, 2001). Conversely, in a US study of carers of people with brain tumours, carers did not express ambiguous or unclear feelings regarding their role and had little trouble expressing their needs (Sherwood et al, 2004) which may suggest a cultural dimension to how carers perceive themselves or a disease specific factor.

Brown and Stetz (1999) describe four phases of caregiving during potentially fatal illness: becoming a caregiver; taking care; midwifing the death; and taking the next step. They found that the issues and tasks vary in each phase. The decision to become a carer for a dying relative comes naturally to some, driven by a sense of duty and responsibility (Perrealt et al, 2004), but Stajduhar (2003) describes three modes of decision making. Some made snap decisions with little consideration to the implications, some made indifferent decisions whereby they felt they had little choice and others made negotiated decisions whereby it was openly discussed and was a mutual agreement. In making the decision to care for the dying patient at home carers were influenced by three factors – fulfilling promise, desire to maintain 'normal family life' and previous negative encounters with institutional care.

These carers find themselves in a unique position of both providing and needing support (Aoun et al, 2005) and have the dual task of attending to their family member's need for

preparation and attending to their own preparation for the patient's death and their own future (Steinhauser et al, 2001). In addition to this they have the duality of role as a partner or next of kin and carer (Broback and Bertero, 2003) in which many find a change to self identity (McLoughlin, 2002). The carers face further conflict in not wanting to lose the ill person but not wanting them to suffer any longer (Harding et al, 2003).

Burden

There is considerable emphasis in the literature on the burden of caring for the terminally ill and this is seen in terms of time and logistics, physical tasks, emotional burdens, mental health risk and physical health risk (Rabow et al, 2004). Hence, burden is not merely associated with physical caring. It includes emotional, social and spiritual or existential elements.

Carers become highly involved in their family member's daily activities, providing an average 10.8 hours/day of direct care and 8.9 hours/day of companionship (Wyatt et al, 1999). It is exhausting, difficult to recover from and requires both financial and personal sacrifice (Stajduhar, 2003). Hudson (2004) found that 23.4% of carers suffered ill health themselves. About a half of carers report problems with sleeping and about a third report weight loss during the patient's last year of life (Ramirez et al, 1998).

The highest burden is felt by carers with limited social networks, those who experience more restrictions in their daily activities and younger carers. However, variations exist in burden due to subjective experience and social support rather than the amount of assistance provided (Goldstein et al 2004). Correlations are found between carer burden and pain, symptom distress and declining functional status of the patient (Grinfeld et al, 2004; Andrews, 2001; Harding et al, 2003). In a study of lung cancer patients the carers found the most difficult and time consuming aspects of caring were providing emotional support, coping with behavioural problems, such as irritability, confusion and moodiness, monitoring symptoms and transportation (Bakas et al, 2001). Carers are also emotionally affected when their loved one changes as a person and it is difficult to please and do the right thing (Broback and Bertero, 2002) but carers are often reluctant to share these concerns as they do not wish to be seen as complaining about the patient (Payne et al, 1999).

There is growing evidence to suggest that dying patients worry about creating burden to others. Patients feel concerned about the social and emotional consequences for their carers in coping with illness and impending death. This self-perceived burden is of clinical significance because it is distressing and has a negative impact on the quality of the patient's end of life and their sense of dignity and it can lead to suffering. It can also influence the treatment choices patients make, even to the extent of considering ending one's life (McPherson et al, 2007). Patients' concern for their carers goes beyond death to encompass concerns about how they will manage when they are gone and many find ways of preparing people for their absence (Kellehear, 1999; McPherson et al, 2007).

Emotional aspects

A range of emotional aspects of caring for the terminally ill is identified in the literature. It is an intense and emotional experience (Stajduhar and Davies, 1998) characterised by watching the deterioration and dying of a loved one, moving between acceptance and hope (McLoughlin, 2002). There is anger, disillusionment (Stajduhar and Davies, 1998) and anticipatory grief (Dawson and Kristjanson, 2003). Over a third of carers describe feelings of helplessness or powerlessness (Milberg et al, 2004) associated with witnessing deterioration, feeling isolated and waiting for the inevitable (Perreault, et al 2004). These feelings of helplessness were also associated with feelings of insufficiency and inability to relieve patient's suffering or stop the deterioration (Broback and Bertero, 2003; Milberg et al, 2004). Carers are also reported to feel that no-one understands their experience, that there is a lack of acknowledgement of their expertise and lack of recognition of their needs ((Stajduhar and Davies, 1998; Milberg et al, 2004; Scott et al, 2001).

It is perhaps not surprising that carers experience high levels of anxiety and depression. Payne et al, (1999) found that 84% of carers scored above the threshold of 5 for psychological distress using the general household questionnaire and Grunfeld et al (2004) found that more carers were anxious than patients. Female carers experience more psychological morbidity and carer strain than men (Payne, et al, 1999; Scott et al, 2001). Women carers are also more likely to report relationship difficulties with their dying relative, while male carers appear to be more affected by material and social consequences of caring (Scott, et al, 2001), but as Scott (2001) argues it may be that men manage to deny their problems to others more convincingly.

Lifestyle interference and social stress

Cameron et al (2002) found that lifestyle interference is a significant and unique correlate of emotional distress. The effects upon lifestyle of becoming a carer for a dying relative can be profound, involving changes to social identity and relationships (Soothill et al, 2001). Carers feel tied to the home (Broback and Bertero, 2003; Hudson, 2003) in constant need to watch the dying loved one (Perreault et al, 2004). 40.4% of carers stated they have no time for themselves (Hudson, 2004) and most have little time to devote to maintaining their core identities as wives, husbands etc and this produces changes in family relationships (Stajduhar, 2003). There can be significant impact upon working life and financial consequences for carers of working age (Grunfeld et al, 2004). Although the government recognised that two thirds of carers (not necessarily of the terminally ill) are in paid employment and said that it would keep financial support for working carers under review (DH, 1999) there is little financial compensation mentioned in recent legislation (DH, 2005).

Social stress is most frequently implied in terms of isolation and lack of emotional support (Payne et al, 1999; Stajduhar and Davies, 1998). Many carers feel a sense of isolation as their social networks tend to diminish as their patient's condition deteriorates (Perreault et al, 2004). Some feel isolated and alone with the full responsibility for the patient's care (Milberg and Strang, 2003). Rhodes and Shaw (1999) found that few, if any, had anticipated the level of care which would eventually become necessary and the need for intimate care caused embarrassment and humiliation (Rhodes and Shaw, 1999; Scott, 2001). Carers feel they lack the skills to manage patients' symptoms (Hudson, 2004) and feel concerned about how/whether they will cope with the patient's death (Payne et al, 1999).

5. Positive aspects of caring

As well as feeling the burden of caring, 60 % of carers in a study using semi-structured interviews with 47 carers of advanced cancer patients acknowledged positive or beneficial aspects (Hudson, 2004). They describe a sense of accomplishment and satisfaction (Perreault et al, 2004) and pride in doing a good job (Salmon et al, 2005). Some even describe considerable pleasure that death was a lengthy process as it allowed them to explore things they would not have had the opportunity to do had it been a sudden event (Grbich et al, 2001). Carers report personal growth and learning about themselves and the patient in new ways, and describe it as a life enriching experience and an opportunity for reciprocity, spending time

with the patient and gaining closer relationships (Stajduhar, 2003; Hudson, 2004). Indeed, Ingleton et al (2003) challenge the concept of caregiving as a burden and its wide use in the literature as there is no operational definition of burden and it casts the recipients of care as burdens with no recognition of reciprocity in the caring relationship or the potential rewards of caring. Strang and Koop (2003) also challenge the notion of the terminally ill person being the passive recipient of care. They found that carers drew strength from the emotional strength of the dying person and it was within this profound, reciprocal, emotional and interdependent relationship that the carers were able to continue to provide care despite overwhelming emotional and physical strain.

As well as patients supporting their carers, Vafiades (2001) found that the patient and family also support their doctors. The patient's and family's realisation that the medical task was difficult and that doctors themselves felt helpless created a mutual understanding that transformed the doctor's predicament into one of mutual appreciation. Similarly, Steinhauser et al (2000) found that terminally ill people contribute to the wellbeing of others, including their professional carers, and that this contribution was a major component of a good death.

Coping strategies

Carers use a variety of coping strategies. Antonovsky's (1987) theory of sense of coherence with its three components - comprehensibility, manageability and meaningfulness, has been used as a basis for understanding relatives' coping in palliative care (Andershed and Ternstedt 2001; Milberg and Strang, 2004) and these components are reflected in the literature. Carers appear to value self-reliance and independence (Payne et al, 1999), stoicism and maintaining control (Scott et al, 2001). A sense of regaining power through confidence in caring tasks, acceptance of patient's death, feeling calm or at peace contributed to carers' ability to cope (Milberg and Strang, 2004; Mok et al, 2002). Carers use positive interpretations of their experience as a meaning-based coping resource (Hudson, 2004; Strang and Koop, 2003). They use verbal and non-verbal symbols to interpret death and deterioration, such as weight loss, referral to palliative care services and talking about the funeral (Milberg and Strang, 2004), as well as euphemisms for death (Payne et al, 1999). Yates and Stetz (1999) found that carers were very resilient as they adopted specific strategies for managing the uncertainty and agony they were experiencing. They used hoping, pretending and preparing as means of adjusting to the awareness of dying.

6. Formal and informal support

Carers also need formal and informal support, including information, to help them to cope with the care of the terminally ill at home. However, carers' experiences of formal support are very mixed and their main source of support is usually other family members (Smith, 2000; Payne et al, 1999; Perreault et al, 2004). Kessler et al (2005) showed that carers from social classes IIIM, IV and V received more regular and reliable support from their families than those in social classes I, II and IIIN and this support appeared to be associated with reduced carer anxiety.

Carers find that support from the health professionals is marred by poor communication and inflexibility in service provision (King et al, 2004), lack of continuity due to compartmentalisation of services and separation into different specialisms (Rhodes and Shaw, 1999) and rigid, impersonal and demeaning systems that disregard and diminish their experience (Stajduhar and Davies, 1998). However, Soothill et al (2001) argue that satisfying the particular needs of some carers is beyond the remit of health professionals and it may be inappropriate to criticise the health care system in this respect. For a significant minority of carers their concerns will be just a further aspect of the general problems of living.

Accessibility to basic primary care is seen by carers as most important (Grande et al, 2004) with high levels of satisfaction reported with the district nursing service (Wilson, 1999). Access to specialist palliative care support is variable (Rhodes and Shaw, 1999) and is largely dependent on the diagnosis of the patient as seen in Murray et al's (2002) study of lung cancer and cardiac failure patients and their carers. This study showed that specialist palliative care services are rarely available to people with cardiac failure and their carers feel isolated and exhausted, whereas these services are often available for lung cancer patients, although their carers remain anxious. Access to specialist palliative care may also depend on ethnicity with black Caribbean and Bangladeshi families identified as needing more specialist support (Koffman and Higginson, 2001; Somerville, 2001). In general, however, when it is received, the support of specialist palliative care services is highly valued by carers (Lecouturier et al, 1999), in particular the security of regular visits from specialist palliative care nurses (Payne et al, 1999).

Once formal support is provided it often leads to medicalisation of the home (Rhodes and Shaw, 1999). Maintaining privacy, intimacy and self-determination – hallmarks of normal home life – become difficult when the home is taken over by equipment and visiting professionals (Dawson and Kristjanson, 2003). Although professional help is valued, it is hard to be constantly on show and to have a succession of professional visitors when carers need to have a bit of space and rest (Sheldon, 1997). Death at home may be seen as the gold standard but it does not come without significant challenges (Stajduhar and Davies, 1998; Hudson, 2003). Even when the patient did not die in their preferred location, the majority of carers felt in retrospect that they had died in the right place and for some patients and a greater number of carers the preference was for death to occur in an institution (Brazil et al, 2005; Grande and Ewing, 2009). Grande and Ewing (2009) found that the adequacy of formal support, particularly psychological, in the last month of the patient's life may be more important for carers' bereavement outcome than achievement of the preferred place of death for the patient.

For many carers this is the first time they have taken on a caring role for someone who they are close to and who is going to die (Brown and Stetz, 1999). In a systematic review of the literature on carers' needs in providing home-based end stage care, Bee et al (2009) found that carers typically adopt a 'trial and error' approach to palliative care because of inadequate practical support and insufficient information on acquiring practical nursing skills. It is suggested therefore that health professionals should provide carers with information on how to deliver care in the home and how symptoms may be relieved (Vachon, 1998). They need to provide anticipatory guidance and information about what to expect at the end of life (Strang and Koop, 2003; Sherwood et al, 2004). There should be guidance around realising the enormity of physical care requirements, securing effective support and coping with feelings, especially how to gain a sense of control and mastery of the notions of helplessness in the caring situation (Scott, 2001). Beyond just giving information health professionals need to ensure comprehensibility and carer's ability to integrate information into providing care (Sherwood et al, 2004; Milberg and Strang, 2004).

Interventions for carers

Although specific interventions for carers in palliative care have been developed, they are only likely to take up support services aimed at carers if they feel that these do not divert resources and attention away from patients (Soothill et al, 2001). In a systematic literature review of

interventions for adults caring for cancer and palliative care patients at home Harding and Higginson (2003) identified 22 interventions. These included home nursing care, respite services, social networks and activity enhancement, problem solving and education and group work. However, of these interventions only nine were solely for carers and only six of these had been evaluated. They concluded that interventions for carers should aim to be feasible, acceptable, accessible and effective and that feasible and robust evaluation methods are needed. It is also recognised that carers are not a homogenous group and may have different levels of needs and ways of processing information (Morris and Thomas, 2002) and that needs change over time (Brown and Stetz, 1999).

Respite

One of the most valuable forms of support for carers in relieving physical stress, especially tiredness, is the provision of respite and hospice at home (Scott, 2001). Some carers felt they would not have been able to manage without the help of a night sitting service (Rhodes and Shaw, 1999) and patients who would have been admitted to an institution were able to die at home with the support of a night respite service (Kristjanson et al, 2004). However, Ingleton et al (2003) found that there is no literature on the effects of respite on carers in palliative care and no evidence for the effects of palliative respite in reducing carers' distress.

Group interventions

Apart from respite services, most services for carers involve group interventions which range from educational programmes to support groups (Harding et al, 2002; Hearn, 2004; Milberg et al, 2005, Oldham and Kristjanson, 2004; Witkowski and Carlsson, 2004). Group interventions for carers in palliative care which focus on information giving and/or support are generally well received and evaluated by the participants, but uptake is relatively low and they do not tend to attract carers from ethnic minorities (Hearn, 2004; Milberg et al, 2005; Witkowski and Carlsson, 2004; Harding et al, 2002). As an adjunct to other support services, it appears that courses and/or support groups for carers offer a unique opportunity for them to receive and share information and gain some time-out for themselves. Carers value the opportunity to meet other carers in a similar situation which is rare because of their full time commitment to caring for the sick person (Milberg et al, 2005; Witkowski and Carlsson, 2004). Apart from acquiring knowledge and information, in the company of their peers, carers find that they can discuss topics that are perceived as taboo in relation to the patient, such as their own needs and having

conflicts with the dying person (Milberg et al, 2005). Bee et al (2009) suggest the involvement of carers in the design and testing of new educational interventions. Groups also provide an opportunity for death education for carers which may include social preparations for death, philosophical, existential or spiritual discussions about death and education about grief and loss (Kellehear, 1999). However, Hearn (2004) acknowledges that a support group cannot claim to meet all the support needs of palliative carers and only a minority of carers attend group interventions (Harding et al, 2002). Wong et al (2002) found that one-to-one interaction and short written material were carers' preferred sources of information. Carers, as well as patients, are not all the same and different groups have different needs (Soothill et al, 2001). It is necessary to recognise that a range of strategies may be needed to make a positive difference for carers because needs change over time and vary according to other factors including gender, age, and length of caring experience (Scott et al, 2001).

Prognosis and other end of life information

Information giving is deemed unsatisfactory by a large number of carers (Lecouturier et al, 1999). Ineffective communication about end of life issues often results from both doctors' lack of discussion and carers' difficulty hearing the news (Cherlin et al, 2005). Some carers feel angry at being given inaccurate prognoses (McLoughlin, 2002), but patients and carers also feel ambiguous about information on prognosis. They want to be told and they don't want to know (Kirk et al, 2004). The mixed feelings about receiving information may relate to timing and where carers are in relation to their coping strategies of hoping, pretending and preparing (Yates and Stetz, 1999). The ambivalence of carers regarding what they want to know and when reflects the complexity of communicating effectively and appropriately about all end of life issues, not just prognosis. Despite the principles of autonomy and informed decision making, uniform approaches to communication in this area are unlikely to be successful or appropriate, given the diversity of preferences and views of patients and their carers (Cherlin et al, 2005).

Different information and communication needs

Carers tend to reach a higher state of awareness and acceptance of dying than patients. Hinton (1999) argues that this is possibly because patients may not seek so much information and they have the option to continue denying or minimising the true prognosis right to the end, whereas relatives have a caring role and will have to cope with the realities of bereavement.

Kirk et al (2004) also found that the information needs of patient and family changed and diverged as illness progressed. They also found that communication between them became less verbally explicit as the patient deteriorated.

Carers frequently have more need of information than the patient (Bolmsjo and Hermeren, 2001; Clayton et al, 2005), but they have to ask for it (Broback and Bertero, 2003; Dawson and Kristjanson, 2003) and carers are often unwilling to express their information needs (Harding et al, 2003; Smith, 2000; Broback and Bertero, 2003). Carers from lower socio-economic groups may be more passive in seeking information and support than those in higher social groups (Kessler et al, 2005). There are also cultural differences in information seeking behaviour. For example, Somerville (2001) found that Bangladeshi women carers who did not speak English were sometimes kept in the dark by their relatives with the pretext of protecting them from upsetting information. Health care professionals also have differing attitudes, beliefs and experience in communicating with patients and families about end of life issues (Bruera, et al, 2000).

7. Preparation for the final stages of the dying process

Carers of terminally ill patients face universal uncertainties, including medical, practical, psychosocial and religious/spiritual dimensions (Hebert et al, 2009). The final stages of an illness can be difficult to identify in some conditions with protracted disease trajectories where each exacerbation could be a terminal phase, e.g. heart failure, chronic obstructive pulmonary disease. However, there is usually a combination of factors that indicate the patient is entering the last few days of life and the final stages of the dying process. The Liverpool Care Pathway for the dying person identifies four criteria for entering the dying phase as the patient i) being bedbound, ii) no longer able to take oral medication, iii) only able to take sips of fluid and iv) semi-comatose (www.mcpcil.org.uk/liverpool_care_pathway, 2007). Reimer et al (1991) describe the transition into the final stages as 'fading away'. They found that carers recognised this transition as associated with extreme weakness, inability to get around, loss of independence in personal care and loss of mental clarity. Carers' expectations and preparations for the final stages of the dying process have social, physical/practical, emotional and spiritual/existential components. These components are not distinct entities but overlapping aspects of the experience. Hebert et al (2009) suggest that carers' preparedness for death and bereavement is cognitive, affective and behavioural. However, there are few studies

about what carers expect during the process of their relative dying. And, apart from group interventions which are attended by a minority of carers, there is little reported on how they become prepared for this experience.

In one study of patients, carers and palliative care professionals, Clayton et al (2005) found distinct content areas emerged for discussing end of life issues - treatment decisions at the end of life; potential future symptoms; preferences for place of death; the process of dying; what needs to be done immediately after death; and existential issues. In general, carers wanted detail about what to expect during the terminal phase and practical information about looking after a very sick person. Some carers, however, did not want to know too many details as they thought it would be overwhelming, but they valued knowing they could discuss the dying process when they wanted. In Clayton et al's study the health professionals were all working in specialist palliative care and, unlike the findings of other studies, the doctors and nurses mostly felt confident and experienced in discussing the dying process with patients and their carers. However, many of the palliative care professionals identified the dilemma regarding whether to discuss potential complications around the time of death, such as haemorrhage or severe dyspnoea. However, a number of carers wanted to be warned about them so that they would not be surprised or left in a situation not knowing what to do. Clayton et al (2005) found that although patients and carers are often afraid to talk about the process of dying, they are relieved when the topic is finally discussed. However, there is minimal research to demonstrate how, when and whether such discussions, information and advice are helpful to carers.

In Yates and Stetz (1999) study of families' awareness of and response to dying, carers 'preparing' involved achieving wishes or goals, making wills and funeral arrangements and bringing closure by saying goodbye and preparing for life without the loved one. However, it did not include preparedness for what dying might be like and what to expect in the days leading up to death and death itself. Steinhauser et al (2000), on the other hand, found that family members needed to learn about the physical and psychosocial changes that would occur as death approached. They identified situations in which lack of preparation adversely affected patient care, such as families panicking at the very last stage and bringing the patient to the emergency department. Both of these studies found that health professionals appeared uncomfortable with and avoided dealing with the issue of dying. Suggested reasons for their

discomfort and avoidance included being too distressed themselves to discuss such issues, feeling unable to effectively intervene should the person become distressed, not having the necessary communication skills to effectively address death and dying and fear of removing hope (Yates and Stetz, 1999; Steinhauser et al, 2000). However, Steinhauser et al (2000) concluded that preparation does not preclude hope: it merely frames it in terms of such things as relief of symptoms and a peaceful death with the patient's preferences met.

Talking about end of life issues is very difficult for both health professionals and patients and carers. However, learning what to expect about physical changes as the patient declines helps carers to make appropriate choices about participation in home care and planning timing of when relatives may travel to make their final goodbyes. Because most people are unfamiliar with care of the dying, clinical benchmarks signalling impending death to professionals may not be obvious to family members (Steinhauser et al, 2001). The giving of information to carers about what to expect as the patient dies appears to be haphazard in health care. There is little guidance in the literature for health professionals on informing carers about such things as changes in breathing and consciousness, terminal restlessness and reduced desire and ability to eat and drink. Similarly there is little in the literature about advice for carers on practical issues, such as the inappropriateness of calling an ambulance in the last stages of life and that deaths from occupational diseases such as mesothelioma will be reported to the coroner.

Payne (2002), however, challenges the notion that information is held by health professionals and given to patients and their families. It is becoming more appropriate for patients and carers to produce their own information resources and to seek out information for themselves through the internet (Pereira et al, 2000). Secondary sources of information such as the internet, friends, support groups, books or second opinions from other health providers, conventional and alternative, expand information which decreases uncertainty, allows the search for hopeful alternatives, gives some sense of control and helps to make or confirm decisions about care, treatment or lifestyle choices (Kirk et al, 2004). Information about the dying process is available on websites such as www.macmillancancersupport.org.uk and in booklets such as those produced by Help the Hospices Time to Care project and Marie Curie. However, there appears to be little evidence that carers access this information themselves or are signposted to it or given it by health professionals, and whether they find it helpful if they do.

8. Statement of the problem

It is evident from this review of the literature that there is a considerable body of research on carers in home palliative care. Much of it confirms the physical, emotional and social burdens of caring and identifies carers' many unmet needs. This literature on the stresses and strains that carers face is relevant to health care systems and professionals in order to develop services and individual care to support carers in their vital role. One of the features that distinguishes these carers is the knowledge that their patient is approaching the end of their life and this awareness of impending death creates additional anxiety for them.

Not knowing what the dying phase will entail is one aspect of their anxiety. Because people in modern society are generally unfamiliar with the physical changes and practical needs associated with death and dying, most carers need some sort of preparation for what to expect and what to do in the final stages of the dying process. However, this review of current literature shows that there is minimal research on meeting this need. While group interventions for carers often include death education, the majority of carers do not attend these (Harding et al, 2002; Milberg et al, 2005). There is therefore an apparent need for researchers to engage in a more meaningful dialogue with carers if planned interventions are to be appropriate and sensitive (Ingleton et al, 2003; McLoughlin, 2002). There are resources, such as websites and booklets, which aim to give information to prepare carers for the dying phase, but studies have shown that carers are often ambivalent about such information (Cherlin et al, 2005) and therefore they may be reluctant to access and/or read these resources. Clayton et al (2005) found that there is a lack of research evidence to guide clinicians regarding discussing end of life issues with terminally ill patients and their carers. Health professionals frequently feel hesitant, uncomfortable and inadequately skilled about talking with patients and carers about death and dying. The question about how carers should, or would prefer to, be prepared for the final stages has not been adequately answered by current research. Hudson and Payne (2009) confirm that more studies are required to enhance the evidence base on carers in palliative care through rigorous research. They identify accounts of the psychosocial impact of caring and effective means of communication between carers and health professionals as two priority topics for research.

My study, therefore, will examine the expectations and preparedness of carers for the final stages of the dying process. Using a qualitative approach, it will involve semi-structured interviews with carers in the final weeks of their patient's life and again after the patient has died. In this way it will use the two perspectives of current carers in the midst of caring and the same carers when bereaved and able to reflect on the whole experience. It will explore carers' experiences and expectations around caring for a terminally ill relative or friend at home and it will ask carers what helps and does not help them to care and to cope through the final stages of the dying process.

The next chapter will outline the research design including the philosophical background and methodology of the study.

Chapter 3 Methods

Introduction

In the previous chapter I examined the literature on carers in home palliative care. The many stresses and strains, as well as rewards, experienced by these carers were identified. I also identified the need for further research into the needs and experiences of carers of patients in the final stages of the dying process. Carers frequently face the unknown when they take on the care of a terminally ill relative or friend at home. Little is known of carers' expectations of this final phase and of what helps and does not help them to care and to cope during this period. This study explored these end of life issues with carers and this chapter describes the methods used. In this chapter I will discuss the aims of the study and its context within community health care research. I will describe the research design and philosophical basis. Next I will describe the methods, data collection, sampling, including the access to and characteristics of the sample, and analysis within a dramaturgical framework. I will then discuss the limitations of the methodology and the role of reflexivity in the whole research process. Finally I will examine the ethics of this study.

Research aims

This study is derived from a health services research epistemology which aims to produce reliable and valid research data on which to base appropriate, effective, cost-effective, efficient and acceptable health services (Bowling, 2001). By exploring carers' experiences the study intended to bridge the gap between lay and professional perspectives on health and health care and the frequent failure of health professionals to recognise this gap (Heyman, 1995). The purpose of this study was to increase our understanding of what expectations carers have for the final stages of the dying process for the person they care for and what helps and does not help them to feel prepared and to cope at this time. The intended outcome of the study was to generate a theoretical basis on which services for carers in palliative care could be enhanced.

More specifically the study falls within community health care research. Heyman (1995) identifies three characteristics of community health care which underpin this study. The first characteristic is its orientation towards promotion of health, prevention of long term health problems and amelioration of the human consequences of such problems, rather than cure.

This study explored carers' experiences of a situation which is known to cause physical and emotional stress and to have adverse health consequences for them. It is the premise of this study that getting services right for carers is health promotion. Maintaining the physical and emotional health of carers is not only essential for them to be able to continue to provide care, it is also an end in itself. The study also aimed to find out what helped and did not help to ameliorate the human consequences of their role as carer for a terminally ill person, such as lifestyle interference, financial implications and social stresses.

The second characteristic of community health care is associated with a critical attitude towards institutional, bureaucratic delivery of care. Although the emphasis of the study was on the experience of caring for people dying at home, its philosophical basis is not anti-institutions. Home is not always the ideal place for death and for some patients and their carers death in an institution is acceptable or even preferable. However, as most patients, given the choice, say they want to die at home (Higginson and Sen-Gupta, 2000), the study aimed to seek carers' views on their preparation for and expectations of the final stages of the dying process in the home where they are the primary carers, not the professionals. Home care however does not escape a critical attitude from carers towards institutionalisation and bureaucracy and the study aimed to explore their views on this. The third characteristic of community health care is that it attempts to utilise and work with community resources, principally the family, which was the very essence of this piece of research.

To summarise, the research aims were:

- To study the experience of carers of terminally ill patients in relation to their expectations and preparedness and what helps and does not help them at this time.
- To explore current carers' experiences and expectations around caring for a relative/friend at home as s/he approaches the final stages of the dying process.
- To explore bereaved carers' reflections on their experience of caring and on what helped and did not help them to care and to cope through the dying process.
- The development of a theoretical framework to inform practice.

Research design

In planning the study a quantitative design was felt to be inappropriate. Quantitative methods are generally deductive and are designed to test theory. They require the use of standardised

measures so that the varying perspectives and experiences of people can be fitted into a limited number of predetermined response categories to which numbers are assigned (Patton, 2002). This approach would not have allowed a full, in-depth exploration of carers' individual and unique experiences which was required to fulfil the research aims. Instead, a qualitative approach initially using grounded theory methodology was taken because this approach facilitates study of issues in depth and detail (Patton, 2002). A qualitative design was also integral to the study's philosophical underpinning of interpretivism. Qualitative research from an interpretivist point of view seeks to understand the meanings in human action. To find meaning in an action or accounts of action, or to suggest that one understands what a particular action means, requires that one interpret in a particular way what the actors are doing (Schwandt, 2003).

Initially hermeneutic phenomenology was considered for this study because of its emphasis on lived experience and the meanings people derive from their experiences (Cohen et al, 2000). This approach however does not generate theory on which to guide practice which was the aim of the study so it was not used. Narrative analysis was another possible methodology. Although it can take a number of forms, narrative analysis usually deals with the ways that people organise and forge connections between events and make sense of those connections through the stories they tell of the past, present and future (Bryman, 2004). Although narrative analysis would be relevant to the stories carers told of their experiences, a more direct approach was needed in this study in order to probe the expectations and preparation of carers. An ethnographic approach was also considered because of its focus on understanding the culture of a particular group. However, carers cannot really be defined as a cultural group since they come from a diversity of social and cultural backgrounds and are therefore not necessarily a homogenous group.

Initially grounded theory was the chosen approach because it is inductive and aimed at generating theory which was a principal aim of the study. This approach entails developing increasingly abstract ideas about research participants' meanings, actions and worlds and seeking specific data to fill out, refine and check emerging conceptual categories (Charmaz, 2005). Hence, in this study there were several levels of interpretation including carers' own accounts and interpretations of their experiences. Then, as the researcher, I brought my own understanding, experience and culture to the research, provided an interpretation of the

participants' accounts and related them to emerging concepts and theories and to the literature on carers in palliative care (Bryman, 2004).

The aim of the research was to explore carers' expectations and preparation for the last few days of their family members' lives, but I could not be present during this intimate and emotion-charged period. Therefore, a longitudinal design was adopted in order to capture carers' perspectives at two points in time; firstly, in the weeks just before the final stages of the dying process and then again three months after the death when the carers had experienced the whole phenomenon. A third perspective was my own, through field notes and reflexivity throughout the research process. This triangulation of data collection gained interpretation of the experience of carers in the here and now of caring (current carers) and of carers later on with the benefit of hindsight and reflection on the whole process of caring for the dying (bereaved carers). Using triangulation of methods and sources allowed different perspectives to illuminate the meanings constructed by the researcher (Williamson, 2005).

Methods

The methods selected for the study were firstly in-depth semi-structured interviews with current and bereaved carers and secondly observation recorded as field notes. The advantages of semi-structured interviews are that they allow all participants to be asked the same questions within a flexible framework and the open nature of the questions encourages depth and vitality and allows new concepts to emerge (Dearnley, 2005). The researcher can probe fully for responses and clarify ambiguities, complex topics can be explored and inconsistencies and misinterpretations can be checked (Bowling, 2001). Observation is an important adjunct to studies that rely mainly on interviewing as a data collection technique. Observational methods to note body language and other behavioural cues lend meaning to the words of the person being interviewed (Angrosino, 2005). Observation of the physical settings, such as the home environment, can enlighten the interpretation of the participant's world.

The research topic was not suitable for a survey method either by questionnaire or interviews. In general, surveys try to measure facts, attitudes, knowledge and behaviour in a structured way (Bowling, 2002). They usually serve a quantitative purpose and for this reason a survey method was not used. Some qualitative methods were also rejected for pragmatic reasons. As

the phenomenon to be researched took place in the patients' homes at an intensely emotional and demanding time, participant observation was not feasible. Unobtrusive methods such as document analysis of case files would not have yielded much data on the carers' experience as this is rarely documented in any detail in the patients' records.

Solicited or researcher-driven diaries were considered as a method of collecting data from current carers. Although this is a suitable method for personally sensitive data and it might have engendered some very rich data (Bryman, 2004), it was felt to be too burdensome for these carers. Focus groups were considered for the data collection from bereaved carers. Although focus groups are a useful tool for understanding people's attitudes and opinions, they were not used because they are incompatible with the gaining an in-depth understanding of participants' experiences. This is because participants frequently feel constrained and uncomfortable about disclosing sensitive feelings and experiences in a group setting and even with skilled facilitation one group member can dominate the discussion (Webb and Kevern, 2001).

Hence in-depth semi-structured interviews were selected for data collection from both current and bereaved carers. Interview guides were drawn up to address the gaps in the research evidence identified in the literature review (see appendices 1 and 2). A small pilot study was undertaken with three current carers and one bereaved carer to test the data collection methods and to refine the interview guides. The pilot proved to be particularly useful for testing out the practicalities of conducting, audio-recording and transcribing semi-structured interviews (Dearnley, 2005).

The length of the current carer interviews ranged from 16 minutes to 60 minutes with an average of 38 minutes. The length of the bereaved interviews ranged from 16 minutes to 61 minutes with an average of 40 minutes. Each interview was followed by an unrecorded discussion of issues raised in the interview and/or issues concerning caring and bereavement in general. I recorded my own observations and reflections on each interview in field notes as soon as possible after each interview. I also recorded my reflections during transcribing and analysis. The field notes formed part of the primary data. I transcribed each interview myself. I found that this was a useful way to begin to understand the data as it took at least three runs

through each recording to complete the transcription. A colleague checked a random sample of my transcripts for accuracy.

Population and sample

The population for the study was made up of all carers of patients receiving specialist palliative care services at home in the United Kingdom. The sample was derived from the caseload of one specialist palliative care service in South West England which serves a general population of 500,000. I am employed within this service but carers of patients known to me were excluded. This convenience sample of carers was selected because I had easy access but also because I needed to be able to respond quickly when a current carer was referred to me, as the timing was crucial. Firstly, I had to wait for a positive response from the carer and then the interview had to be arranged within the last weeks of the patient's life and at the carer's convenience and when my normal workload permitted. To do this at a distance would not have been feasible. There was also the issue of trust. Because of the sensitivity of the research, it was vital that the nurses referring potential participants knew and trusted me. It was also important that I knew and trusted them and/or the bereavement service to provide on-going support to the participants where necessary. It was convenience sampling, but it was also purposive in that I sought information-rich participants. Purposive sampling is a deliberately non-random method of sampling which aims to sample a group of people with a particular characteristic (Bowling, 2001), in this case the characteristic was caring for a terminally ill relative or friend at home.

Carers were recruited from the caseloads of the community palliative care nurses. The nurses identified them to me according to inclusion and exclusion criteria (see appendix 3) and I made the initial contact by writing to them about the project. Steeves (2000) adopted a sampling strategy in which hospice workers identified carers as informants in a similar study and he found both advantages and dangers in this method. The advantage is that the nurses know the patients and families well and are likely to make fairly accurate prognoses. The danger is that the researcher could be sampling the prejudices of the nurses who may have fixed ideas about who is suitable or unsuitable for involvement in the research. Gate-keeping by health professionals is a recognised barrier to recruitment in palliative care research and it usually occurs out of desire to protect the patient and family (Hudson et al, 2005). However, gate-keeping threatens the representativeness of research samples and in this study could have

denied carers the opportunity to make up their own minds about contributing to research. In an attempt to overcome gate-keeping, the nurses were given a clear account of the research study, including the ethical issues and ethical approval. They were given repeated opportunities to discuss any concerns they had about the study and to explore possible solutions.

Strauss and Corbin (1998) advocate a process of theoretical sampling through three stages of open, relational and variation, and discriminate sampling. Open sampling is a wide sampling method which aims to include any persons or situations that will provide the greatest opportunity for discovery. Analysis began as soon as the interviews from open sampling were transcribed. Concepts were identified and their properties and dimensions were discovered. For instance, the concept of the patient/carer relationship emerged and one of its properties was communication between them. The dimensions of communication varied along a spectrum from talking openly about dying to avoidance of the subject to colluding in denial. Another emerging concept was helpful and unhelpful behaviour. As the analysis progresses and concepts and theories are identified and defined, relational and variation sampling seeks incidents which demonstrate dimensional range and variation of a concept and the relationships among concepts. For instance, I was therefore seeking to illustrate communication at different points along the spectrum from openness to collusion in order to relate whether they found their style of communication helpful or unhelpful. Discriminate sampling seeks to fill the gaps in the theoretical framework and maximise opportunities for comparative analysis, such as negative cases who did not appear to fit the emerging theories (Strauss and Corbin, 1998). The study focused on caring for someone dying at home. However, where the patient did not die at home, the bereaved carer was still invited for the second interview as these carers provided valuable insights and could be seen as one example of negative cases because of their alternative experience (Patton, 2002).

As I was initially following a grounded theory methodology, I aimed to follow the three stages of theoretical sampling, but this was not easy to achieve. The stages were not neatly defined, as sampling was frequently on the basis of carers who were available and willing to participate. However, sampling continued until there was data saturation. In other words, I continued to recruit participants until no new relevant data emerged and there were recurring

and confirming data from different sources (Morse, 1994). I had anticipated some attrition between the first and second interviews and two carers declined the second interview.

Sample characteristics

I set up a database on a secure computer at my workplace to record carer and patient characteristics and the various contact dates with potential and actual participants. A total of twenty seven carers were referred to me. Of these four declined involvement, one became sick herself and for seven the patient died before an interview could be arranged. The final sample was fifteen. The sample characteristics are detailed in tables 1 and 2.

Table 1 Carer characteristics n = 15

Age	Range 23 - 85	Mean 56 Median 55
Gender	Male 5	Female 10
Ethnicity	White 15	Other 0

Relationship to patient	Number	Percentage
Wife	7	47%
Husband	2	13%
Partner	2	13%
Daughter	3	20%
Son	1	7%

Work situation	Number	Percentage
Full-time	5 (2 working from home)	33%
Part-time	2	13%
Work suspended for caring	5	33%
Part-time voluntary	1	7%
Retired/unemployed	2	13%

Table 2 Patient characteristics n = 15

Age	Range 27 - 87	Mean 66 Median 71
Gender	Male 10	Female 5
Ethnicity	White 15	Other 0

Diagnosis	Number	Percentage
Bowel cancer	2	13.3%
Brain tumour	2	13.3%
Breast cancer	1	6.6%
Liver metastases (primary unknown)	1	6.6%
Lung cancer	1	6.6%
Lymphoma	1	6.6%
Malignant melanoma	1	6.6%
Motor neurone disease	1	6.6%
Oesophageal cancer	1	6.6%
Pancreatic cancer	1	6.6%
Prostate cancer	2	13.3%
Renal failure	1	6.6%

The sample of carers was made up of five men and ten women. They were all white. Their ages ranged from 23 to 85 with a median age of 55. Of the women, seven were the wife and three were the daughter of the patient. Of the men, two were partners, two were the husband and one was the son of the patient. Five of the participants worked full-time, of whom two were able to work from home, and three worked part-time, one of whom worked voluntarily. Five had given up work temporarily in order to provide care. Two participants did not work, one was retired and the other was unemployed.

Most of the patients had cancer, but one had motor neurone disease and another had end stage renal failure. There were ten male and five female patients. Their ages ranged from 27 to 87 with a median age of 71. They were all white.

Methodology and data analysis

Originally grounded theory was the methodology chosen for the study. This approach was selected because grounded theories are drawn from data and based on the reality of the topic under study (Benton, 1984). As such they are likely to offer insight, enhance understanding and provide a meaningful guide to action (Strauss and Corbin, 1998). Grounded theory methods consist of simultaneous data collection and analysis, with each informing and focusing the other throughout the research process (Charmaz, 2005) and leading to the generation of a theoretical framework that could be used to guide and improve professional practice to support carers (Patton, 2002).

Analysis begins with a process of coding. Coding is usually a mixture of data reduction and data complication. It is generally used to break up and segment data into simpler, general categories and is used to expand and tease out the data in order to formulate new questions and levels of interpretation (Coffey and Atkinson, 1996).

Computer software can be used to assist the coding process in qualitative research and it has certain advantages. Fielding and Lee (1998) argue that computer use in qualitative data analysis can facilitate data management and to a small extent I was assisted by use of 'Excel' for the study database. They suggest computer software can extend the capabilities of qualitative research, especially for team research. And they suggest that it can enhance the acceptability and credibility of qualitative research. However, there is a risk that use of computer assisted qualitative data analysis software (CAQDAS) will make qualitative research more acceptable and credible because it appears more 'scientific' which is not a valid rationale as it suggests that a positivist stance is superior. Another possible risk identified with the increasing use of computer assisted data analysis is convergence toward one dominant mode of analysis (Coffey and Atkinson, 1996). I was also aware that the computer does not do the analysis or build the theory and that I had to be responsible for the conceptual development of the project (Morse, 2006). As Weitzman (2000) stresses, using software cannot be a substitute for learning data analysis methods and as I was new to this methodology I decided to use traditional manual methods. The in-depth experience gained in this study through manual data coding will therefore provide a sound basis for use of computer software in future studies.

Coding aims to discover, name and categorise phenomena according to their properties and dimensions (Strauss and Corbin, 1998). This involved detailed annotation of each transcript identifying phenomena or concepts. Words, sentences and paragraphs which represented concepts and the properties which define them were highlighted in the text (see appendices 4 and 5 for an example). The concepts and their properties were recorded and referenced by transcript page and line numbers in box files in order to facilitate comparison within and between transcripts. Questions arising from the analysis were recorded as memos to be followed up in subsequent interviews and further analysis. I also re-read each transcript as a whole and asked myself what is the main theme of this interview and what is the sub-plot? I then cited the sections of interview text that supported the theme and the sub-plot (see appendices 4 and 5).

By cross referencing, comparing and questioning it was possible to begin to make inferences and explanations. As I completed coding the interviews, I returned to the transcripts, my diagrams of mini-frameworks, my field notes and box files and asked myself what seems to be going on here? Through this process a dramaturgical meaning emerged in the carers' accounts of their experiences. It was at this point that it became clear to me that carers were playing a leading role in a drama. I studied the literature on dramaturgical analysis and from then on I used a dramaturgical perspective to explore and explain the theoretical framework of the study based on the metaphor of the drama that carers found themselves in. The essence of metaphor is the experiencing and understanding of one thing in terms of another (Richardson, 1994). I found dramaturgical analysis enlightening because the language of theatre can be used metaphorically as a set of hypotheses to guide the investigation of social events and the theatre provides a good working set of concepts that move the analysis through from the overture until the last curtain call, including what is happening backstage, onstage and outside the theatre (Hare, 1985:46-47). The dramaturgical perspective will be explored in more detail in the next chapter.

Limitations of the methodology

Convenience sampling was used for a number of reasons but it limited the study to a sample of carers who were all receiving the support of a specialist palliative care team. Therefore one would expect these carers to have a good level to preparation for the dying process and therefore they may not have been representative of all carers of the terminally ill. They were

also all receiving support from the same palliative care team and were aware that I was a member of that team. The participants' responses may therefore have been biased by the gratitude factor which tends to make those receiving care reluctant to criticise the caregivers (Glickman, 1997).

As qualitative research is inherently subjective and interpretative it must be biased. Indeed Morse (2006) argues that bias is essential if qualitative inquiry is to be conducted well. However, in order to enhance investigator sensitivity, it was important for me to be aware of a number of ways in which the study was particularly subject to bias. There was the potential for interviewer bias and participants' deliberate social desirability bias. I tried to reduce these biases to a minimum by acting in a neutral, non-judgmental manner (Bowling, 2001). But as an experienced palliative care nurse, I automatically respond with empathy and encouragement in a face-to-face encounter with patients' carers. I found I could not change my approach for the research interviews and my demeanour may have reflected my own cultural and professional values and led participants to respond in a certain way.

Also, through my method of interviewing it was not possible to know how much of the participants' responses were affected by mood bias. People who are depressed may underestimate their health status, level of functioning and amount of social activity and support (Bowling, 2001). All the other emotional effects of caring and bereavement could also affect how participants described their experience.

Similarly, there was the potential, especially in the bereaved carers' interviews, for recall bias in which participants may have had selective memories in recalling events, experience and behaviour. However, memory is generally better for topics of high saliency to respondents, such as death (Bowling, 2001). Also, the philosophical basis of the study emphasised the importance of the participants' interpretations of their social world and it valued their constructions of events and experiences from memory.

One method of checking the accuracy of participants' accounts (respondent validation) is by returning transcripts to them for feedback. I did not think this method would be appropriate for the carers in this study as it makes considerable demands on participants' time and can be exploitative and distressing (Barbow, 2001; Dearnley, 2005). I felt there was a considerable

difference between disclosing personal and sensitive information in the contained environment of a one-to-one interview where distress could be recognised and support given and reading a transcript of such disclosures on your own. I therefore elected not to send copies of interview transcripts to the participants.

In the analysis there was the danger of making false assumptions based on my background in palliative care about the meaning of the data, and therefore a potential dichotomy between the participant's perspectives and my own (Morse, 2006). Another method of respondent validation involves confirming emerging theory with participants. However, this was also felt to be inappropriate since participants each have one perspective only and probably have none of the theoretical knowledge. It may be unrealistic therefore to expect them to be able to recognise their own experience within a theoretical framework or even to find the analysis meaningful (Morse, 2006; Bryman, 2004). Nevertheless, rejecting processes of respondent validation was another weakness in the methodology. It was therefore important to develop sensitivity to the meanings in the data through reflexivity, making comparisons with the literature and known concepts, asking questions and seeking negative data (Morse, 2006; Strauss and Corbin, 1998).

Another potential limitation in the analysis was undertaking the coding and theory building process on my own. There are arguments for and against using multiple coders and determining inter-rater reliability among these coders. Patton (2002) suggests that it can be helpful to have more than one person developing the coding scheme independently and then comparing and discussing similarities and differences. Important insights can emerge from the different ways in which two people look at the same set of data in a form of analytical triangulation. Morse (2006) on the other hand argues that trying to achieve agreement between multiple coders inhibits the analytical induction processes because most coding is an interpretive process which focuses on identifying what the data signify rather than sorting the face value of the text. As the process of coding in this study was protracted and inductive it was appropriate to do the analysis as a solo enterprise. However, I kept meticulous records of every stage in the research process to ensure that it was transparent and accessible and I discussed all aspects of the study with my research supervisor throughout the process.

Reflexivity

Reflexivity was an important element of the research process and I have included a note on my process of reflexivity in this study in appendix 6. Patton (2002) describes reflexivity in qualitative research as a way of emphasising the importance of self awareness, political/cultural consciousness and ownership of one's perspective. Willig (2001) suggests there are two types of reflexivity: epistemological and personal. Epistemological reflexivity requires one to question where does this study come from and how was the research question defined, as well as could it have been done differently? It also encourages us to reflect upon the assumptions that we make in the course of the research and to think about the implications of these assumptions for the research and its findings and conclusions. I have tried to question my motivations and my methodological decisions for the study and I am aware that my personal and professional philosophy influenced my leaning towards a qualitative approach and grounded theory in particular because of my desire to produce something of practical relevance.

Personal reflexivity involves reflecting upon ways in which one's own values, experiences, interests, beliefs, political stance and social identities shape the research. I was aware from the start that I could not deny or disregard my own background in palliative care nursing and the knowledge, culture and values that this work entails. My original motivation to study carers of terminally ill people at home was borne out of my perspective of their needs based on many years experience and my own political viewpoint. My personal experiences and feelings around death, dying and caring could not be discounted either. Therefore I did not come to the research value free and my perspective was part of the context for the findings (Patton, 2002). It was essential for me to remain aware and take note of the impact that I had on every stage of the research process. In particular, a reflexive approach was required during data collection and analysis. Equally I had to be aware of the effect of these processes on me and then how these effects might have impacted on my interpretation and analysis. I kept field notes to record my impressions and experiences of each interview. I noted my interviewing style and how it may have affected participants' responses. I found my role conflict between neutral research interviewer and empathetic palliative care nurse mirrored what other researchers in the caring professions had reported (Carolan, 2003; Valentine, 2007). A reflexive approach involving observation, field notes, personal reflection and awareness of my impact on

participants and vice versa was therefore essential. It also involved constant attention to the ethical issues raised within the research process.

Ethical principles and issues

The research protocol was approved by the Bath Local Research Ethics Committee (LREC) using the format prescribed by the Central Office for Research Ethics Committees (COREC). Annual progress reports using the COREC format were also submitted to the Bath LREC throughout the study. The protocol was approved by the School for Health Research Ethics Approval Panel at the University of Bath.

Research in the field of palliative care presents many ethical challenges and family members may find it hard to be involved in research because of the burden of caring, fatigue and the emotions associated with grief and loss (Lee and Kristjanson, 2003). However, adhering to ethical principles can overcome some of these problems. Hence the study was based upon the ethical principles of respect for every individual, autonomy, non-maleficence, beneficence and justice (Johnson et al, 2004; Mathers et al, 2002). Particular attention was paid to the following ethical issues.

Intrusion and burden

Sensitive topics present problems because research into them involves potential costs to those involved in the research (Lee, 1993). In this study physical and emotional intrusion were recognised as potential costs. For instance, the majority of interviews took place in the participant's home, an intrusion into their personal time and space. However this approach was aimed at reducing the burden of involvement in the study.

Carer burden is a recognised phenomenon and caring for a terminally ill person at home can be especially burdensome (Rabow et al, 2004; Stajduhar, 2003). I tried to minimise the extra burden of being interviewed by arranging to visit participants at their own home or place of choice and at a time convenient to them. I also aimed to complete each interview in one hour.

Distress

Research into sensitive areas like caring for the dying may be threatening because of the levels of stress which it may induce (Lee, 1993). One of the main ethical concerns when involving

family members in palliative care research is the risk of causing distress. Current carers are in the midst of the emotional effects of their family members's deteriorating condition and their own anticipatory grief, while bereaved carers are actively grieving. A participant may feel the added stress of maintaining an appropriate demeanour in face to face contact with the researcher (Lee, 1993).

Takesaka et al (2004) looked at whether carers believe that interviews about end-of-life care are distressing and found that data collection from family members does pose a small risk of distress. However, only a small minority of respondents reported any distress and those who did generally reported distress that was mild/moderate. Seemark et al (2000) also found a low incidence of distress causing problems in post-bereavement interviews with 80% of those interviewed showing only mild or no distress and the same number did not find the interview unhelpful. Indeed, 75% found the interview helpful or very helpful, which the authors feel implies that expressions of distress are likely to be therapeutic in this context. Hudson (2003) also found that very few carers cited negative aspects of participation in palliative care research but that issues such as bringing patient deterioration to the fore can arise. He found that 71.1% reported benefits of being involved in research and 88.9% cited no negative aspects associated with research participation.

Every effort was made in this study to reduce the risks of distress and to ameliorate harm when distress occurred. I have extensive experience as a palliative care nurse and was always ready to discontinue or postpone interviews in favour of responding sensitively and with compassion to emotional distress if it arose (Dean and McClement, 2002). Reference to the small risk of distress was included in the informed consent process (Takesaka et al, 2004). Participants were told in the information sheets that they should feedback any issues of concern and of their right to withdraw (Hudson, 2003). Current carers recruited to the study were known to a specialist palliative care service which was available to give additional support if it was required as a result of the interview. I could refer bereaved carers to the bereavement service if they needed and wished for on-going support.

Vulnerability

Because current and bereaved carers are dealing with end of life issues they are felt to be vulnerable. Carers involved in this research study may have been intrinsically vulnerable due

to factors such as age, cognitive ability and coping abilities. Their extrinsic vulnerability was associated with aspects of being a carer such as stress, fatigue, financial consequences, lifestyle changes and anticipatory loss or bereavement. There was also relational vulnerability stemming from interactions between carer and patient and between carer and professionals and from reduced social networks associated with caring and bereavement (Dean and McClement, 2002).

Although carers are vulnerable, Lee and Kristjanson (2003) challenge the persistent idea that dying patients and their families are so burdened by the dying process and so vulnerable to exploitation that they should not be approached to be involved in research. They feel that this is over-protectiveness and that limiting their involvement in studies may deny them the opportunity to fulfil a social role. Kellehear (1998) also cautions against the arrogance of assuming that comfort and safety are more important to vulnerable social groups than their desire to be heard, or their desire to contribute to our attempts to understand them. Hudson (2003) found that 31.3% of carers believed that their participation in research would assist future carers. Seamark et al (2000) also found that bereaved carers frequently viewed research involvement as an opportunity for altruism as well as providing the chance to talk through the process of dying and vent anger. I now feel it is my ethical responsibility to the people I chose to research to disseminate the findings through publication and participation in conferences in order to fulfil their desire to be heard, to be understood and to help others (Kellehear, 1998; Gysels et al, 2008).

Vulnerability can, however, lead to exploitation. Hudson et al (2005) suggest that families are in a “one-down” power relationship to the clinician and may feel less inclined to decline participation in research if they believe that their refusal may diminish quality of care. Because of the danger that carers may feel obliged, in gratitude or wanting to please their caregivers, it is essential that palliative care researchers take precautions to ensure that some distance is created in the research process between participants and their researchers and that participants are not dependent on care from them (Lee and Kristjanson, 2003). For this reason, sampling and recruitment of current and bereaved carers did not involve any carers of patients for whom I had any professional involvement. The participant information sheets assured them that their involvement and what they said in interviews or their refusal would not affect the care their patients or they received.

Confidentiality, data storage, disclosure and anonymity

It is essential to safeguard participants' dignity and privacy and this means ensuring that personal information given as part of the study is kept confidential (Johnson et al, 2004). All data was stored in locked cabinets either at my place of employment or my home. As required by the university, all data will be stored for at least 5 years in locked cabinets under the custodianship of the researcher. Participants' ID was removed from all data and replaced by a code before it was stored on my home or work computer in order to protect anonymity. Pseudonyms have been used for research participants and any information linking real names with pseudonyms will be destroyed. Colleagues who assisted in checking the accuracy of the data were reminded of its confidential nature.

However, there are some situations where confidentiality can be over-ridden in order to fulfil another professional obligation (Mathers et al, 2002). For instance, if participants were to disclose suicidal intentions or issues such as abuse I would feel a professional obligation to report. Such obligation to report was included in the explanation of confidentiality in the information given to potential participants (Dean and McClement, 2002).

I also felt an obligation to report to the care providers any incidences of undue distress, unresolved grief or other concerns that were revealed or arose in the process of data collection. This included concerns about omissions in care or unsatisfactory practice.

It is acknowledged that ensuring anonymity in qualitative studies is inherently difficult because of small sample sizes and the detailed and personal information given in natural language and the frequent use of direct quotes (Dean and McClement, 2002; Seymour and Ingleton, 2005). Researcher-participant anonymity was impossible in this study, but every effort has been made to protect participants' anonymity in reporting it. Pseudonyms have been used to denote both settings and all those who took part in the research.

Informed consent

The Royal College of Nursing (2005) defines informed consent as "an ongoing agreement by a person to receive treatment, undergo procedures or participate in research, after risks, benefits and alternatives have been adequately explained to them". However, in qualitative

research, the risks and benefits of participation are not always apparent and purposive interviewing may lead both the researcher and participant to fresh ideas that may cause unanticipated reactions (Kellehear, 1998). Mason (1996) also argues that there are limits to how adequately you can inform all interviewees about all aspects of participation. Therefore informed consent was a process in which I monitored the situation and was prepared to discontinue the interview or renegotiate consent if I felt that it was straying beyond what the participants thought they had consented to.

The first stage of recruitment involved writing to potential participants with an information sheet about the nature and purpose of the research, and their role if they agreed to participate as well as the benefits and risks of participation. The information sheets were written in short, jargon-free sentences and printed in a large typeface (see appendix 7). The invitation letter included a tear off slip for them to complete and return to me stating whether they agreed or not to be contacted about participation (see appendix 8). When I received a positive response I telephoned the potential participant to arrange an interview, but they were again given the opportunity to decline at this stage.

Three months after the death of the patient I wrote to the bereaved carer to invite them to participate again (see appendix 9). In this letter they were informed that I would be contacting them in week's time to ask whether they were willing to be interviewed and a second information sheet was included (see appendix 10). Great care was taken at all stages in the recruitment process to ensure that carers did not feel coerced into participating in the research.

Before each interview they were reminded that participation was voluntary and that they could withdraw at any time without giving any reason and they were given sufficient time to ask questions before signing a written consent form (see appendices 11 and 12). A copy of the consent form was sent with a thank you letter to the participant (see appendix 13).

Role of the researcher

Difficulties can arise over potential confusion between the roles of nurse and researcher (Seymour and Ingleton, 2005). The Royal College of Nursing stresses that the patient and their family must always be put first (Johnson et al, 2004) and this was my ethical and professional position. I was able to use my experience to deal with distress or other concerns sensitively,

but I did not get involved in on-going support and referred questions about clinical conditions, prognosis etc. to the specialist palliative care team or general practitioner.

I was also very aware of the impact of the research process and data collection on myself. Listening to distressing and sensitive personal information has an impact upon the interviewer but I shared the participants' humour as well as their pain. I found it essential to use a reflective approach and I sought support as necessary through clinical supervision at my workplace and through research supervision at the university.

Summary

In this chapter I have described the methods used for this study of the expectations and preparedness of carers of family members who are dying at home. The study was based within an epistemology of health services research and underpinned by a philosophy of interpretivism. I have outlined the research aims which were to study the experience of current and bereaved carers and explore what helped and did not help them to cope through the dying process and to develop a theoretical framework to inform practice. In order to meet the aims, a longitudinal qualitative design was adopted following a grounded theory approach. The methods used were in-depth semi-structured interviews and observation with the prominent thread of reflexivity throughout the research process. The process of theoretical sampling from a population of carers of patients receiving a specialist palliative care service and the characteristics of the sample are described and illustrated. I have described how I began by following a grounded theory approach with the processes of constant comparative analysis but as the concepts and themes emerged a dramaturgical perspective was taken on the analysis. The limitations of the methodology, the importance of reflexivity and the ethical background to the study have also been discussed.

In the next chapter I outline the findings. This will include descriptions of the dramaturgical perspective and how it shaped the analysis. It will use quotes from the data to illustrate the concepts within the theoretical model of the carers' drama.

Chapter 4 Findings and Analysis

Introduction

In this chapter I will present the findings and the analysis using a dramaturgical perspective as outlined by Goffman (1959) and Hare and Blumberg (1988). Carers' performance as a leading player in the drama of the dying process will be described, including their types of performance. The importance of the setting for the death being at home and carers' feelings about the introduction of aids and equipment into the home will be discussed. Their expectations, feelings of uncertainty and of being unprepared will be discussed. Carers' ambivalence to seeking information and their need for support and direction from health professionals will be addressed. The role of paid carers as supporting cast and of other family members as part of the audience will also be presented. The concepts of being there and letting go will be discussed in relation to the moment of death. Finally the drama closes with the removal of the patient's body and the carer faces a new set of challenges.

Dramaturgical perspective

Dramaturgical analysis is a sociological perspective from which any aspect of social life can be studied. It is the perspective of the theatrical performance which in this study concerns the drama of a family member dying within the home. Hare (1985:7) presents the theory that views all social interaction as a form of drama, with creativity at the heart of the matter. In theatre the central concept is the communication of an idea to an audience. A major difference between everyday life and the theatre is that an ordinary person continually modifies the presentation of the idea in response to the reactions of the other person or people present, whereas the actor follows a fixed script (Hare 1985:8). Goffman (1959:26) argues that within any face to face encounter all the activity of a given participant on a given occasion which serves to influence in any way any of the other participants may be described as a performance. Others present in the encounter can be viewed as the audience, observers or co-participants. When someone plays the same part to the same audience on different occasions a social relationship and social roles are normally established or changed, as seen when a family member becomes a carer. Performance describes what carers do because they take on new, unfamiliar roles that require them to act in different ways from their previously held relationships and to interact with new sets of people, such as health professionals and paid carers.

It might be thought that the individual offers his performance and puts on his show for the benefit of other people, but Goffman (1959:28) suggests that we should turn the question around and look at the individual's own belief in the impression of reality that he attempts to engender in those among whom he finds himself. The individual may be sincerely convinced that the impression of reality he stages is the real reality. At the other extreme, the performer may not be taken in at all by his own routine. The cynical performer deliberately uses his performance to encourage others to believe in the impression he gives while not believing it himself. These extremes of sincere and cynical performances represent two ends of a continuum. In many situations individuals, such as carers, move back and forth along this continuum.

Hare and Blumberg (1988:11) refer to the debates about dramaturgical analysis which centre on whether social interaction is actually a series of dramas or whether drama is only being used as a metaphor to illustrate the way in which social interaction seems to take place. They conclude that there is continuum ranging from everyday activities that do not have a dramatic quality, through social events that are consciously staged, to theatrical productions.

The findings of this study took shape around the metaphor of the carers' drama and their performance within it. Others have identified 'pretending' as a coping response for carers to the awareness of dying. Yates and Stetz (1999) found that carers acknowledged that their relative was dying but chose to act as though the relative would continue to live. Metaphors can be powerful ways of communicating qualitative findings but they must be selected sensitively (Patton, 2002). There was a danger of offending carers by describing them as performers with the implication that their role was just an 'act'. But I hope that I will make it clear that the carers' performance of their role was absolutely genuine and vital in the dying process of their loved one. For the purposes of this study, drama is used as a metaphor because carers did not consciously stage the situation, but this does not diminish the dramatic quality of their performance and experience.

The carers themselves used metaphors in powerful ways during their interviews. Jim referred to the strength he gained from "the fortress that was our marriage". Sheila described how for her and her husband it had been "such a long walk together". Indeed a journey would be

another appropriate metaphor for the carers' experience. Walter (1994) proposes that the spiritual journey of dying has become a physical one and in time is becoming an emotional journey. Carers talked of moving through stages as the dying process progressed. However, a journey usually has a starting point or departure but for most of the carers their role gradually developed and they could not say when they started caring or when they first saw themselves as carers. For most carers there was no starting point of the dying process either. Carers also found that their journey did not end with the patient's death. It was a turning point but there was still a difficult road ahead of them. Similarly the story would be an appropriate metaphor. Walter's (1994) description of Kubler-Ross' theory on death and dying as a meta-story could easily refer to this study. "It is a story in the 150 year-old tradition that elevates female over male, feeling over technique, home over hospital – a story of the triumph of ordinary people and their experience, championed by a caring woman, over the depersonalisation of male technological rationality" (Walter 1994:71). It is true that the carers each had a story to tell. However, my decision to focus on a drama with a plot rather than a story as the metaphorical framework was because caring involves a lot of action and interaction.

Dramaturgical analysis can illuminate the many different aspects of a social situation. Hare and Blumberg (1988:3-4) identify the concepts used in dramaturgical analysis. These include the phases of the performance. First of all there must be an idea about a situation and the action that will unfold in the situation. The idea can be in the form of an image, theme, plot or script. For carers the situation is often foisted upon them by the terminal illness of their relative and the action that will unfold is in some senses expected but in many ways it is unknown. Carers may or may not have a script in the form of written information about the process ahead of them. While they can foresee the end of the drama, the full plot in terms of detailed scenarios, defined roles and an indication of the stages to be gone through evolves rather than being predetermined. Secondly, there needs to be an action area or setting for the performance and some sort of time scale over which the drama takes places. The time scale may be subdivided into scenes or acts where there are natural endings or changes in the situation. Carers may describe having some personal space away from the caring situation as needing a change of scene.

The third phase in Hare and Blumberg's scheme is the identification of the actors who must learn their roles and the audience. There may be a number of actors, with one or more

protagonists, an antagonist and/or auxiliary players. An audience is crucial for any theatrical performance. In everyday life often there is an audience present and the actors are aware of it, even if the audience consists just of members of the group who do not happen to be active at the time. Even in a group of two, when an image is presented, one person is in the role of protagonist and the other a member of the audience. The audience may have several functions, such as validating the performance, giving expressive cues that guide the performer, and providing continuity by constant observation, but the most relevant role of the audience to this study is demonstrating approval and disapproval of the role performance.

The enactment of the performance then becomes the fourth phase but, as with most stage theories when applied in real situations, the phases of the performance are not always neatly sequential. Finally, Hare and Blumberg suggest that there is a period of appraisal of the effect of the action and a new definition of the situation for actors and audience. This is inevitable for the carers of the terminally ill as they and the others involved reflect on their roles after the death of the patient.

Other concepts for dramaturgical analysis include different roles such as director, producer and supporting cast or chorus. Hare and Blumberg (1988:6) suggest that the director remains offstage providing the cues for action, hidden from the audience. However, in real life dramas the person or people directing and giving cues may be very visible, as seen in Proot et al's (2004) grounded theory study of terminally ill patients at home. They found the most commonly recurring theme was 'directing' by the patient, in the sense of directing a play. Directing for these patients involved deliberation with the players as to what sort of actions you want or not, asking for properties, and anticipating future scenes.

Whereas Hare and Blumberg (1988) focus on the presentation of an idea as central to performance, Goffman (1959) emphasises the presentation of self. Goffman uses the term performance to refer to all the activity of an individual which occurs during a period of continued presence before a particular set of people and which has some influence on them. He identifies 'front' as the part of an individual's performance that is relatively fixed and serves to define the situation for those who observe the performance. Front is the expressive equipment used intentionally or unwittingly by an individual during the performance. Front includes the setting, involving furniture, décor, physical layout and other background items

which supply the scenery and stage props for a spate of human activity. By setting the scene, consciously or unconsciously, the performer gives an impression of the situation and of himself to any observers. In addition to the setting, there is the personal front which includes items of expressive equipment that are most intimately identified with the performer and which follow the performer wherever he goes. These would include gender, racial characteristics, size and looks, posture, speech patterns, facial expressions, bodily gestures and the like. Such aspects of personal front can be divided into appearance and manner.

In general, we expect confirming consistency between appearance and manner and some coherence among setting, appearance and manner. Such coherence stimulates an awareness of exceptions from our expectations, as might be seen in our attention to negative cases in qualitative analysis. When someone takes on an established social role, s/he usually finds that a particular front has already been established for it. I would question how carers find out about their established front when they are unfamiliar with their new role and isolated from other carers in that role. However, health professionals and society in general have certain expectations of family members to take on the caring role and how that role will be performed. As Goffman (1959:37) points out, a given social front tends to become institutionalised in terms of abstract stereotyped expectations to which it gives rise. The front becomes a collective representation and a fact in its own right. Thus, when an individual presents himself before others, his performance will tend to incorporate and exemplify the accredited values of the society. However, we are all subject to variable moods and energies that change from one moment to the next and can reveal a crucial discrepancy between our ideal selves and our all-too-human selves. The performance therefore is fragile and subject to our human disposition.

Goffman's use of dramaturgical principles based on the notion that all interaction in which an individual's activities serve to influence the other person or people present is a performance can be hard to accept because it suggests a conscious effort to perform. However, he points out that "the legitimate performances of everyday life are not 'acted' or 'put on' in the sense that the performer knows in advance just what he is going to do, and does this solely because of the effect it is likely to have" (1959:79-80). He goes on to suggest that the unthinking ease with which performers consistently carry off the routines of their social roles does not deny that a performance has occurred, merely that the participants have been aware of it (1959: 81). It is these less contrived ways of viewing dramaturgical perspectives that reflect my

interpretation of the current and bereaved carers' accounts of their experiences. However, there were instances where carers deliberately used their performance to achieve some effect on others present.

There are obvious inadequacies in the dramaturgical model, in that real life differs from the stage. The theatre presents things that are make-believe, whereas life presents things that are real and often not rehearsed. There are clear distinctions in the theatre between the actor who presents himself in the guise of a character to other characters projected by other actors and the audience who observe their performances. In everyday life roles become interchangeable or compressed and the others present frequently constitute the audience (Goffman 1959:9). However, although a character staged in the theatre is not real as such, actors on the stage learn their craft from real life. The successful staging of a theatrical performance involves the use of real techniques, the same techniques by which ordinary people sustain their real social situations. Hence, the dramaturgical model provides a conceptual framework for the analysis of social situations. However, Goffman emphasises that dramaturgical analysis should not be used in isolation because it intersects with other perspectives such as technical, political, structural and cultural aspects of the situation (1959:233). In this study the dramaturgical perspective provides the theoretical framework but other theoretical aspects have been interwoven into the analysis.

The carer's initiation

The most striking impression from the analysis of the carers' interviews was that the carer of the terminally ill patient played a leading part in a drama. They were performing in a mystery play, not in the medieval biblical sense but in the sense of a Greek mystery. Mystery goes back to the Greek *muelin* meaning 'close the eyes or lips' and also 'initiate'. The connection between the two meanings probably arose from secret religious ceremonies in ancient Greece, which were allowed to be witnessed only by the initiated, who were sworn never to disclose what they had seen (Trumble, 2001). Carer's initiation is therefore the central theme of the dramaturgical analysis because carers found that they were acting a part for which they had not been initiated and they did not know the secrets of the dying process. As Kalish (1977:223) suggests, "there is a magic, a mystique, attached to death that is undoubtedly stronger than that attached to any other familiar event in human existence".

A drama can be defined as a situation or sequence of events that is highly emotional, tragic or turbulent (Collins, 1994). A drama emerged as a vivid metaphor because the carers experienced just such a situation. Indeed many would describe their scenario as akin to a melodrama which has been described as having a bad outcome that is attributed to the situation in which the actors find themselves (as opposed to a tragedy which has a bad outcome that is attributed to some person or persons) (Hare and Blumberg, 1988). The carers found themselves taking on a role that firstly they did not want because they did not want someone they loved to be dying, and secondly that they had no choice over taking. The exception was one carer who had been looking after her husband for a long time due to a non-life threatening condition that had changed his personality. She expressed relief that she would not have to go on caring for years more when he was diagnosed with terminal cancer. However, most of the time they felt it was the right thing to do and did not resent it. As current carers in the midst of caring they said things like.

Jim: It's um forced on you. Circumstances pushes it on you and um therefore you're, you're stuck with it. And I'm stuck with this job. Er, I didn't want this job but you've got to take the ball and run, you run with it.....I don't want to let her down. I want to be there for her all the time and I'm quite er happy to you know er cater for her needs. Whatever she wants she gets (current).

Naomi: If I had a choice I wouldn't be doing this. If, if I had any say in it, we would be having a normal life. Clive would be well and we'd be living our life. But that's not what we've got and I wouldn't not be there for him (current).

Later on, as bereaved carers, they looked back on their caring role with mixed feelings. They continued to feel that it was something you just do, need to do, or think it is good to do.

Sheila: It's something you need to do...but I'd never wish that situation on anybody (bereaved).

Paula: Looking back it all worked out quite well. I don't know how I did it, but I am never ever, ever, ever in capital letters, underlined going to do it again (bereaved).

But some felt much more positively about the role with hindsight.

Margareta: It was just something I had to see through to the end and honestly did it with pleasure (bereaved).

Jane: It was an amazing experience and I wouldn't have missed it for the world (bereaved).

As in theatrical drama, comedy also played its part in providing some relief from the seriousness of the situation and, as Donnelly et al (2006) also found, humour was a strong coping mechanism for some carers of the dying.

Paula: You do develop a gallows sense of humour (current).

Brian: We can still laugh about it (current).

Nicola: We do joke. I think that is the best way of doing it (current).

Naomi: I either laugh or I cry. It's easier to laugh. I just see the ridiculousness of it (current).

The scene at the time of dying has often been described as a stage (Donnelly et al, 2006; Sandman, 2005) and this concept underpinned the development of the metaphor of the drama of the carer's initiation and the carer's leading part in it. As it took shape, a dramaturgical perspective was taken on the analysis. Goffman (1959) used dramaturgical principles to portray the way in which the individual in ordinary situations presents himself and his activity to others, the ways in which he guides and controls impressions they form of him, and the kinds of things he may or may not do to sustain his performance before them.

Carers as performers

Some carers alluded directly and indirectly to their role as a performer.

Margareta: I found it extremely difficult to act as if everything was you know coming okay, because it wasn't (bereaved).

Nicola and Jane feared they would miss their cues.

Nicola: I'm just worried that I won't know and they keep saying that, the doctors say you'll know when you're at your last stages. I'm just worried 'cause I've got this bag of medicines in my cupboard ready on standby for the, for the time and I just worry...and I'm thinking is this the time when the medicines should be out?... What am I looking for? And they don't tell you any more. They just say you'll know (current).

Jane: I was worried to death that I'd, that am I going to know the signs, that am I going to miss him? (bereaved).

Sheila found that she could not change the plot.

Sheila: That is the hardest, hardest part, you know that no matter what you do in the day it's never going to change anything (current).

Paula felt very aware of having an audience when her husband died.

Paula: I was holding his hand and the district nurse was there. Oh and Dr Morris had turned up. There was a carer there so he had a bit of an audience...I think I would have liked to have been on my own with him but I was sort of a bit conscious of having an audience (bereaved).

From a dramaturgical perspective, any instance of social interaction is a performance (Hare and Blumberg, 1988). Goffman (1959:26) suggests something more purposeful when he describes a performance as all the activity of a given individual on a given occasion which serves to influence in any way any of the other participants. Goffman's interpretation of the presentation of self in everyday life can be complicated when applied to carers' performances because their sense of self becomes bound up in the dependent body of the patient (Lawton, 2000; Jenkinson, 2004). Lawton (2000:184) describes the situation where one person, the

carer, becomes the agent of another's, the patient's, bodily actions, and the body of the latter may become merged with the body and self of the former. Some carers were aware of the effects of caring of their own selfhood. Paula was grateful to her friends.

Paula: They remember who I am. I'm not just somebody who's looking after my husband. I'm still me (current).

Goffman (1959:28) claims that when an individual plays a part he implicitly requests his observers to take seriously the impression that is fostered before them and to do this the individual puts up a front. This front, by way of the individual's choice and arrangement of the setting, and by his or her appearance and manner, defines the situation for those who observe the performance. Goffman's interpretation of performance suggests something artificial, 'an act' in which the performer is either convinced of the reality of the impression he stages or cynically uses the performance to convince others of the reality of it while not believing in it himself. He points out that not all cynical performances are aimed at deluding audiences for self-interest or private gain. A cynical individual may delude others for what he considers to be their own good (Goffman, 1959:29). Although I would hesitate to use Goffman's prejudicial term 'cynical', carers did sometimes delude others with the aim of protecting them. Nicola and Margareta felt it was important not to cry in front of their husbands.

Nicola: You've got to be strong. Strong is the best thing. Don't be weak. Try not to cry and just try and laugh. On the telephone sometimes you've got to try not to crack up 'cause they can tell it in your voice (current).

Margareta: I'm actually not very good. I'm weepy in myself, not with him. That's why I need my nights alone (current).

Jean felt it was better not to talk with her husband about his illness.

Jean: I don't think he's too aware of his condition. To be honest we don't talk about it. In fact the family agree. If he doesn't know he can't worry about it (current).

Nicola found a way round her husband not wanting her to do things for him.

Nicola: He doesn't necessarily want me to interfere with helping him...so the help that I give him I don't think he realises I'm helping him....I'm helping him in a way that he doesn't know that I am...So although I'm not supporting him, I think I'm supporting him in a way that life has to flow nice and smoothly for him so he's not worried about things (current).

In any dramatic situation there are normally one or more protagonists (Hare and Blumberg, 1988). Sandman (2005:128) describes how historically the death bed was viewed as a stage where the main character, i.e. the dying person, was to be surrounded by the important characters in his life. However, as he points out, dying people might not be in a state in which they are able to stage or benefit from staging their departure. Indeed, in most of the situations in this study the carer took the protagonist role. Taking this leading role was often a necessity due to the declining mental and emotional condition of the patient. Naomi, for instance, had no choice but to take the lead. Her husband had a brain tumour which

Naomi: Affected his speech, his swallowing, his balance, his co-ordination and it just changed his character. He wasn't my Clive anymore....so I don't know if that Clive had any awareness of dying or even what was going on or even why he was ill (bereaved).

Similarly, Jean's husband had lost his short term memory and she was also obliged to be the protagonist.

Jean: He didn't talk, wouldn't talk. We don't know whether he realised what was happening or anything.....I think if he'd had more of his mind it wouldn't have been so bad (bereaved).

For some carers it was vitally important to them to play the leading role in order to gain some control over the situation. For Jane, this was her coping mechanism while caring for her dying father.

Jane: I didn't want anybody to deal with him except me. Um so I coped with being really territorial and in control (bereaved).

In a minority of situations the patient took the leading role. Jim's wife took the lead by example.

Jim: I was helped um by my wife because she was so tranquil and accepted um death...Because she was er so calm about everything .. it calmed me you see it calmed meso she did help me a great deal. It's still down to my wife (bereaved).

Nicola's husband wished to take the lead throughout by controlling information about his illness and declining help. His behaviour had damaging effects upon her relationship with him.

Nicola: His lack of communication and lack of um wanting help it has ruined our marriage.....I used to learn things through the keyhole or telephone conversations. I thought if you can't tell your wife of eighteen years is there any point being with him....The nurses asked me questions about personal care and I said I'm willing to do all of this you know but you've got to bear in mind we're not husband and wife. It depends on what Paul wants out of this you know. He's got to have his views and I just go along (current).

Proot et al (2004) suggest that terminally ill patients need to direct their lives as they would direct a play or orchestra and this includes making choices regarding who they talk to about their situation. It also means directing things related to their loved ones in the sense of taking care of them, rather than of excluding them as Nicola's husband chose to do. Sheila's husband exemplified directing things for his wife as they shared the leading role.

Sheila: It was a team effort, you know. I was caring for him. He was caring for me...he just wanted to have everything in place as much as he could for me because he knew that our paths were separating far sooner than we ever expected (bereaved).

Peter wanted his partner to take more of a leading role and felt frustrated that he just wanted to sleep all day.

Peter: I suppose John realised he was going to die. I think he gave up. He couldn't be bothered with the battle any longer (bereaved).

Whether the carer is the protagonist or not, s/he plays a leading role because carers are essential for enabling the patient to die at home.

Setting and props

Of the fifteen patients whose carers participated in the study, eleven died at home, two died in hospital and two died in the hospice. Two of the carers whose patients died elsewhere were disappointed that they did not die at home, one felt that the hospice was the right place and I do not know the feelings of the other as he did not have a bereavement interview. For most of the carers home was seen as the right place for their family member to die. There was a general feeling that once removed from the artificial settings of institutions, notably hospitals, people may die a more peaceful and natural death and the main ways of achieving this are to die at home (Walter, 1994). However, as Walter points out, the idea of natural death carries a price. While none of the carers described caring as a burden, they all found it hard work and tiring both mentally and physically. Paula put it most succinctly.

Paula: It is bloody hard work (bereaved).

And several carers described their own diminished mental faculties while caring. Sue was one of them.

Sue: I do find that my brain isn't operating very well at the moment. It's just focused completely on Graham and I just can't, I think I've lost the plot sometimes (current).

Goffman (1959:33) suggests that as a setting tends to stay put, geographically speaking, an individual may not begin their performance until they have brought themselves to the appropriate place and must terminate their performance when they leave it. For some carers, continuing to go to work allowed them to switch off from their role temporarily and this was a vital part of their coping mechanism.

Stephen: I don't want to be here all the time....I go to work and I don't think about it quite frankly ...I need space and different people to talk to (current).

Others who did not work also expressed their need for some space from the caring situation.

Sue: I need to get out ...I did have about three weeks not going out at all 'cause Graham was really poorly and I thought it was the end. And I thought no, I can't do this anymore. I can't stay in here, just can't do it. So, yeah, I go out every lunchtime for half an hour, forty minutes...It does make a huge difference (current).

Other carers found they could not leave the setting or terminate their performance because they were constantly worrying about their patient.

Jane: No, I didn't (*want any space for myself*) because I was offered that. You know my sister, but I didn't. I couldn't cope with going out. I was in the house really, I didn't go out for at least six weeks (bereaved).

While the setting at home was familiar, the props were not. Most situations required some forms of aids and equipment, such as walking and lifting aids and commodes, on loan from the Primary Care Trust (local health authority) to facilitate the care of the terminally ill patient. While carers found the equipment was useful, these props also changed the setting especially when an electrically adjustable hospital bed was introduced to the home. For Paula having the bed downstairs disturbed her normal 'front' because everybody could see if it was all crumpled. But some carers welcomed the arrival of the bed.

Margareta: I did find um it's twenty four hours a day which is quite a time. He had his own bed in his own room because it was a special bed you know that sang and danced and did everything. And um ...I did like that actually he was put in bed and slept a bit because I had to sleep a bit (bereaved).

However, dying at home is often viewed as synonymous with dying in your own bed. The bed itself becomes a metaphor representing intimacy and the reality of the physical deterioration

(Donnelly et al, 2006). Stephen felt under a lot of pressure from health professionals and the care agency to have a hospital bed downstairs.

Stephen: There was a lot of pressure to have a bed down here. It wasn't Sarah's wish I knew but at one stage I felt it was being imposed on us....I think Sarah's view of hospice at home can be summarised I think as being in the home in the manner at which she was accustomed and to be put downstairs in a hospital bed was not what she considered to be hospice at home. Hospice at home was to be as close to me as she could at night which actually made it easier for me and still does. There's still talk of her having a hospital bed in the front (bed)room (current).

Stephen resisted the pressure and his partner died next to him in their shared bed while he was asleep which he described in his bereavement interview.

Stephen: Yeah, because at twelve o'clock I sorted of made her comfortable, put her on her side because she wasn't, she was gurgling a bit, so I put her on her side and I sort of said to her 'Well you can go now but I somehow think you've got several more days of this' and then I woke up in the night, I don't know what time, I thought I can't hear her breathing and then I heard her breathe, a breath and then a little while later another one and I thought it was bit slow but she was there. And then I woke up at seven o'clock and she was too cold and um I'd been right up beside her. It just felt nice (bereaved).

Stephen said earlier in that interview that he did not get the feeling that the day she died was the day she was going to die and this illustrated the sense of not knowing what to expect that many carers expressed.

No rehearsals

In general the carers felt unrehearsed for the dying process. Even for those with previous experience of caring for terminally ill patients, such as Peter who had cared for his parents and Sheila who worked in a care home for the elderly, the final stage of their family member's life did not turn out as they expected. The current carers' expectations of the final stages ranged along a continuum from none at one end of the spectrum to some conceptions of fading out, going into a long sleep, or slipping away at the other, with a lot of uncertainty in between.

Sue's comments reflect a conceptual uncertainty around the dying process shared by most of the carers.

Sue: Well obviously I know what the end result's going to be but I don't know what the end stage is going to be (current).

Carers also experienced strategic and practical uncertainties. For instance, there were frequently expressions of not knowing what to expect, what signs to look for, what help was available and from whom and when to ask for it and what is expected of themselves as carers. In a similar study of 33 carers in the USA, all of the carers of terminally ill family members reported medical, practical, psychosocial or religious/spiritual uncertainty and although uncertainty was universal, the degree and type varied between individuals (Hebert et al, 2009). Uncertainty as a perception of doubt and not knowing is generally a discomfiting, uneasy sensation. It may be mediated by feelings of confidence and control but response to uncertainty is highly individual (Penrod, 2007). For some carers in the current study the sense of not knowing raised their anxiety levels. Jane felt constantly on edge.

Jane: I'm working blindly. I don't really know what I'm looking for. I don't know what's going to happen ...The thing that's missing is the fact that you don't know where you're going... You just don't know whether you should be doing this, that, the other, just working blindly (current).

Others appeared more able to take it as it comes.

Nicola: I've tried not to think about it. I, I know it's going to be bad but I don't know how bad. I don't know what to expect.....So my expectations are really every day's going to be a new day. I think that's the only way I can do it (current).

Emotional uncertainty was also very common among the carers. In general, they felt unrehearsed for the emotional intensity of caring through the dying process.

Naomi: I didn't think emotionally it would be so gut-wrenchingly hard (current).

Reflecting back after the death, many of the carers, like Stephen quoted above, said that the dying process was much quicker than they had expected, making the death rather unexpected. These temporal uncertainties concerned timing within the dying process.

Peter: It crept up rather more quickly than I expected and even though we knew what was on the cards I was quite shocked when it happened...It was a precipice type descent so I suppose that shocked me a bit (bereaved).

Jane: It was really, really very quick when he started to go down. It was very quickly.....I knew instantly that this was the time and I phoned my sister up. That was at half past five and he died at ten to nine (bereaved).

Naomi: I didn't know it was the last stage until, until half an hour before he died and I thought this is it (bereaved).

Sheila was particularly devastated because her husband's death within a few hours of being admitted to hospital at his request was so unlike what she had expected.

Sheila: You know you're not prepared for it because this wasn't the plan...and she (*the doctor*) said have you got family...and she said you know you're not going to be able to take your husband home tonight. I still, still didn't click...I still didn't realise you know. I suppose you just don't want to realise...By quarter past seven he was gone, you know all in the wrong place. So my role was over but not how I thought it was going to end up (bereaved).

By contrast, for some carers the reality of dying was better than the uncertainty beforehand.

Margareta: I had no idea what it should be like and it was far better than I thought it would be if I expected anything. He just fell asleep (bereaved).

Brian: If I had a choice of dying, that's the way I would have wanted to go (bereaved).

Uncertainty had conceptual, strategic, practical, temporal and emotional dimensions for the carers. Uncertainty feels threatening and people generally use coping strategies in an attempt to manage or ameliorate the threat (Hebert et al, 2009).

No script

Information is reported to be a key component of carers' coping strategies, but as Docherty et al (2008) found, there is little evidence about meeting carers' information needs on the dying process. Their systematic review of the knowledge and information needs of informal carers in palliative care found that most studies in this area emphasise needs in relation to pain management and welfare and spiritual support, with some mention of the implications of disease progression but nothing specifically about preparation for the dying process (Docherty et al, 2008).

Despite their state of uncertainty, the carers were ambivalent or even reluctant to seek out information about what to expect in the dying process. It seemed that because these carers knew how the drama would end, they did not want to read the script.

Sue: I actually bought a book, yes for that reason, but actually I couldn't, I couldn't read it beforehand.

JN: And what stopped you reading it?

Sue: Well I suppose yeah actually admitting it was going to happen for a start (bereaved).

Although there is a lot of information on preparation for dying available on the internet, few carers accessed any websites about caring or dying. The carers' low level of internet use for information about dying contrasts with findings from a study involving 200 carers for cancer patients in general, i.e. not necessarily in the palliative phase, where 49% of carers used the internet for cancer information (James et al, 2007). Again, it seemed that some did not want to confront the reality ahead.

JN: Have you looked at any websites?

Naomi: No. Ignorance is bliss. I'd rather not...looking for trouble, no, no. The monsters come and bite you when they want to (current).

Other reasons given included not realising the information was on the internet, feeling in unfamiliar territory and pressure on time.

David: I haven't had time to really go into a website...It's quite interesting having this conversation 'cause I, I am thinking to myself, yeah, what would I normally do in a work situation? You go on-line and you search and find all the answers that you were looking for and it, but it's the time component (current).

Carers who did use the internet did not access information about dying.

Nicola: I've looked up UK, Cancer Research UK and there's a couple of others ...I found it fascinating but you could really, anything I read I could associate with what has happened so far and then it had the end stages but for me it wasn't specific enough. It was what I knew already. And I just wanted that little bit. It's just that not knowing...that's the only niggle I've got is not knowing, the not knowing at the end (current).

Carers did not seem to seek out or ask for written information, either. However, two carers were given leaflets about dying by health professionals and both found them really helpful as preparation for the final stages. Naomi talked about their helpfulness while she was still caring and Paula reflected on their value afterwards.

Naomi: Diane (*community palliative care nurse*) gave us a couple of leaflets...ones on coping with dying um were hard to read. I mean not the English but it's difficult to accept what it is saying 'cause I knew it to be true....but I would rather know what to expect so at least something is not going to be unexpected...I can be aware of the signs, like if I hadn't read in the book for example that he would start eating less, drinking less, sleeping more, then I would have oh he's not eating...oh my God I must feed him (current).

Paula: I had a Marie Curie book about and it told you exactly what to look, you know what to expect and it (*the death*) was almost textbook. You know like the um the

breathing slowing down and 'cause I was sort of holding his hand and his breathing was getting slower and slower and I thought, are you still with us? (bereaved).

However, looking back on her experience, no amount of information could have prepared Naomi for some of the changes associated with the dying process.

Naomi: I mean he was a bodybuilder. He, you know, he was fit. He was gorgeous, you know, muscles. I mean I've shown you pictures, haven't I? Pictures of when he was Clive and he was gorgeous with a cute little bum and you know it was just pathetic at the end, this little bag of bones (bereaved).

Such agonising is described by Yates and Stetz (1999) as a context characterised by emotional conflict, turmoil and ambivalence as carers struggle to accommodate the observations, information and interactions that suggest their relative's disease is progressing. Others carers echoed Naomi's distress at changes they felt unprepared for.

David: It's very difficult to see Mum's situation deteriorate. You know you can see it happening before your eyes (current).

Jim: It is difficult to, to watch somebody fade away. You know it's very, very difficult to stare death in the face (current).

Peter: It's not the easiest task to take on 'cause you watch your partner, your wife, um your lover gradually deteriorate and you need to prepare yourself (current).

As well as the physical deterioration, carers were unprepared for the behavioural changes that some patients exhibited. At times patients could be quite nasty towards the carers, but the carers had found nothing in the leaflets or in professional advice to tell them to expect this or how to cope with it. Although they found it upsetting, the carers usually found their own ways of mitigating their family member's behaviour.

Paula: I mean I never showed him I was impatient but sometimes I would have to walk away.....when he said something horrible. You know when your husband's okay and

says something horrible you can retaliate but when they're really poorly you just think you can't, although I did tell him he was a pain in the butt.

JN: And how did that make you feel?

Paula: Better 'cause it was true. You do have to treat them as normal. So when he was being a complete arse I did tell him. But sometimes the things he would say would try the patience of a saint. But then I had to remember the stroke did change his personality and how would I feel if I was in that situation? (bereaved).

Naomi: Clive would wind me up because he would say horrible things. And I know it wasn't him....I know you have to rationalise it. That's not Clive. That's tumour. You know like I say, there was good Clive and bad Clive and good Clive was my Clive and bad Clive was that bloody tumour, you know....And you've just got to have a very short term memory. And realise that this isn't the person that you know. This is someone else and this someone else doesn't know you ... and your loved one wouldn't speak to you like that (bereaved).

Three of the carers attended a course offered at the hospice. It comprises five two hour sessions aimed at preparing carers for their role with their terminally ill family member, and includes one session on preparation for dying. Jane described the course as

Jane: Brilliant, absolutely amazing 'cause I learnt a lot about the tablets, how to lift him if I needed to, not that we lift him....and it was good to hear other people talk, talk to other people (current).

But neither she nor the others who attended the course mentioned it as preparation for the dying process. What carers said they wanted was some form of directory of services and supplies at the beginning of their caring role. Then they wanted step by step information and guidance from a health professional as they approached each stage in the process.

Direction

Communication is the primary way to manage and reduce uncertainty, thereby allowing carers to prepare for the death (Hebert et al, 2009) and most of the carers valued the direction and support of health professionals.

Sharon: When I first spoke to Daphne (*community palliative care nurse*) it was the first time I really thought um actually somebody understands what this is all about and can see that I don't (current).

District nurses, community palliative care nurse specialists and general practitioners (GPs) received most mention and were generally reported as helpful. Table 3 lists the most valued aspects of professional help cited in the interviews. These attributes are consistent with Hebert et al's conclusions that in order to better prepare carers for the death of a loved one, health professionals must develop a trusting relationship with carers, provide them with reliable information tailored to their uncertainty, and allow time for carers to process the information and complete important tasks. However the level and quality of professional support varied considerably across the sample. The most criticised aspects are listed in table 4.

Table 3 Most valued aspects of professional help

- | |
|---|
| <ul style="list-style-type: none">• Overall monitoring role• Accessibility• Acting as go-between with surgeries and hospitals• Sorting out medication issues• Recognising carer stress• Anticipating needs• Inspiring confidence• Advocating on behalf of patient and carer• Sources of information• Role models |
|---|

Table 4 Most criticised aspects of professional help

- | |
|--|
| <ul style="list-style-type: none">• Delayed or absent response especially out of hours• Overbearing, officious or insensitive manner• Lack of interest• Inconsistent advice |
|--|

Jim gives an example of direction by health professionals through monitoring the overall situation, recognising carer stress, anticipating needs and involving the carer in decisions.

Jim: I found that I couldn't cope, I realised I couldn't cope and er Chris (*community palliative care nurse*) was keeping an eye on me....That's when she stepped in and said right then we'll up the care. We'll do everything. And um it was done so subtly, that no nudging you aside....Everything stage by stage, um you know, day by day everything was explained to me, so you know I knew what was happening, what to expect. We had the (*community palliative care nurse*) come and um she went to the health centre to find out about the dose and the other doctor Fisher said if we up this dose then she's going to slip into unconsciousness and um although she could probably hear you she couldn't react to you. So Dr Fisher asked me would that be okay you know and I said well better to you know drift off that way than be in pain...So that's what they did (bereaved).

Brian described the district nurses as superb and was thankful that one of them directed him because he had not realised how near to death his wife was.

Brian: The district nurse came in to er administer her morphine patch thing, you know pump or whatever it was, and I was in the kitchen getting a cup of tea and the district came out and she said Brian, get the family ...and she said she's going and it was just like that, you know. So fortunately, you know, sounds terrible but we was all round her bed (bereaved).

Anticipating needs and advance care planning are core components of the government's End of Life Care Strategy (www.endoflifecareforadults.nhs.uk, 2009) which encompasses the Gold

Standards Framework (GSF) (www.goldstandardsframework.nhs, 2009) which aims to improve end of life care in community settings and the Liverpool Care Pathway (LCP) for the dying (www.mcpcil.org.uk/liverpool_care_pathway, 2009) which aims to guide care in the last few days of life in any setting. At the time and in the area of this study, the GSF was only in place in some general practices and the LCP had not yet been introduced in the community. However some aspects of anticipatory care by health professionals were evident from the carers' interviews. As seen from Nicola's comments earlier, anticipatory prescribing of medication 'just in case' can raise anxieties for the carer if its use is not fully explained. But for some carers the provision of just in case drugs was helpful in the end.

Stephen: I mean, they left me some, and I forgotten what the drug was but it had to be put in rear end um we'd had it since Christmas time but they hadn't actually explained what it was for. It was in this emergency pack you know if there was a problem I was to say it was there and then towards the end it was explained what this stuff was if she was very distressed it was to calm her down. And there was one night I think it was one night when the night timers didn't come or something so I had to phone the out-of-hours number and say well I've got this stuff. Are these the symptoms I should be using it for? To which they said yes, so I administered it and was quite amazed. The result was instantaneous more or less (bereaved).

Accessibility, availability and approachability of health professionals were viewed by carers as essential. There was generally a good relationship with the regular visiting professionals but problems arose at weekends and out-of-hours when they were off duty. Several carers reported a brusque, officious or non-compassionate manner from GPs or district nurses they did not know.

Stephen: I had a problem over a weekend when I was expecting them to come. I think it was the previous, the weekend before Sarah died I was expecting a district nurse to call 'cause they'd said they were coming every day and um the one who usually came she wasn't on that weekend so obviously wouldn't be her and um nobody turned up and they were coming really just to sort of make sure things were alright which I thought was very comforting because I'm not a medical person. If there's something wrong I might not spot it and er just for them to come in was nice. Well nobody came on the Saturday

and I actually rang up on the Sunday and the person, she actually is, has a foreign accent, apparently she can appear you know rather abrupt so I was told afterwards, but she sort of said well there's no medical need to come. And my argument was well I was told they were coming 'cause there was a need. So when I saw our own district nurse she sort of apologised 'cause she I think gave the wrong message to the duty district nurse over the weekend. And then actually on the night Sarah died we always had a night, a twilight visit and they were always very good (bereaved).

Sharon's bereavement interview was an angry monologue about the unfamiliar GP and district nurse who set up a syringe driver for her father hours before he died. (Her current carer interview was an angry monologue about the community hospital and care agencies). She felt that the syringe driver was the right thing for her father and it allowed him to die peacefully but she resented the manner in which it was done and she felt she was not listened to when she challenged the doses of the drugs he was given. She also felt upset that no-one had prepared her for another unfamiliar doctor's visit to verify her father's death.

Sharon: Oh, that's the other thing that happened. I couldn't believe this. He, Dad died at three o'clock in the morning so of course then we had to have some doctor we didn't know come out. No-one had explained to me, that was the thing that I didn't like actually he, nobody explained to me that when the doctor came he didn't come until it was ages afterwards, two hours, two and a half hours like that 'cause they knew he'd already died and the nurse was there didn't, it wasn't a priority and he came and even though it was hours afterwards..... and nobody told me he was going to do the listen to the chest for half a minute. I couldn't believe it. I didn't know he did that. It was horrible. Listening to see if he's going to breathe as if somehow we made a mistake. I can see that it's a legal process. It's his job to do but that long after. If they're going to do that they should come straight away. It was horrible, really horrible (bereaved).

In the absence of familiar professionals, a lot of the carers found the hospice 24 hour advice phoneline very helpful. There were also very positive comments about carers' experience of the community palliative care nurse specialists who are employed by the hospice. In addition to the support and direction of health professionals there was usually a supporting cast of paid carers.

Supporting cast

One way in which statutory services aim to support carers for the terminally ill at home is through the provision and funding of paid carers to supplement the care provided by the main carer. In many other caring situations funding for social care is means-tested and many recipients have to contribute towards the costs. However, for those individuals who have a terminal condition that is deteriorating rapidly characterised by an increasing level of dependency the National Health Service funds all care under Continuing Health Care legislation (DH, 2007). Paid carers funded under Continuing Health Care are normally employed by care agencies that are independent of the health service but contract to supply care assistants according to an individual patient's care plan developed by a health professional.

Most participants in this study had some paid care. Interestingly, none of the three patients who had no paid care died at home. Carers' experience of paid carers ranged from horrendous to very good. The most valued aspects of paid care are listed in table 5. The most consistently valued paid care was overnight carers, especially those employed by the Hospice at Home service provided by the hospice.

Naomi: Hospice at home at night, yeah, at the end, every night, yeah. Oh it was completely a lifesaver...it was just amazing to have them and they were all such stars (bereaved).

But other paid carers were also described as a great help.

Brian: Oh gee, I mean she got to know every one of them, you know. And it was seven o'clock in the morning in they would come, Laura, I'm here, you know. And they'd take her and wash her and get her to the toilet. Well um they, as you know we had ceiling hoists in, and they managed to get her up and into the toilet with the ceiling hoist in the toilet, but in the last few weeks they weren't even able to do that. They just picked her up and put her um bedpans underneath her, you know. Oh the carers were brilliant...and they all came to her funeral (bereaved).

Table 5 Most valued aspects of paid carers

- | |
|---|
| <ul style="list-style-type: none">• Regular, familiar carers• Flexible approach to tasks• Source of guidance• Relief from caring especially at night |
|---|

Some felt that they had to fight to get enough paid care, especially carers who continued to work and needed paid carers present for at least some of the time when they were working. Twigg and Atkin (1994:60) suggest that service providers sometimes interpret attempts by the carer to develop elements of a separate life as a form of selfishness or a sign of being a bad carer. However, as we have seen, going to work was an essential coping strategy for some carers.

Paula: Well the last week I had enough care so that I could actually do a decent amount of work 'cause I was really worried about paying the bills. 'Cause even if I hadn't been self-employed I guess I would have got compassionate leave but not paid for it. So you've always got that worry of sort of looking after them, how are you going to pay for everything? And sometimes the powers that be are not as forthcoming as they could be. But the last week or so it was brilliant because I had somebody um sort of morning and evening to help me put him to bed, although it only needed one person. And I was having six hours a day yeah three hours in the morning, three hours in the afternoons so I mean that's, I was really happy with that. But that only kicked in the last week or so and after a lot of grumbling from me (bereaved).

On the other hand, Jean felt that she had been coerced by the district nurses into accepting help when she had said in her first interview that neither she nor her husband wanted strangers in the house providing care.

Jean: My one regret was we had a carer.....and obviously he'd got this colostomy bag and he was very upset because she started to scrub his tummy and no, no, please don't do that, you'll knock the bag off and her attitude was no, I won't. I've done this before. It's perfectly alright. Well what did she do? She knocked the bag off and that

traumatised him.....and the person they sent in, she really smelled of cigarettes. She'd obviously just had one. Well neither of us likes cigarettes....we couldn't get rid of them quick enough (bereaved).

Sharon also had concerns about the quality of care.

Sharon: I've just changed agencies. I asked for it to be changed....and I find the whole care thing totally traumatic, very, very stressful...they were just, they weren't giving him very much time but what they were doing was very poor, the general quality. And I thought the organisation, the company was a total shambles (current).

Even those at the very good end of the spectrum experienced some negative aspects of paid care.

Sue: Initially I didn't want anybody. I wanted to try and do it on my own but then you realise you can't do it on your own. But we have the same person most days so that's quite good. Only when she's off, she has every weekend off, and it all goes slightly pear-shaped or if she's off sick we don't know if we're going to get somebody (current).

Jim: The carers, some of them are very good...but some of the other ones are only there for the money and if they can walk in the door, sign the book and walk out again they're happy (current).

The difficulties that carers encountered with paid carers are identified in table 6. These issues are of some concern as currently home care workers are not registered in England, although registration is seen as key to raising standards and protecting users (Mithran, 2008). The legal requirement for new staff to register with the Vetting and Barring Scheme operated by the Independent Safeguarding Authority has been put back from October 2009 to November 2010 (UKHCA, 2009). However, despite carers' very mixed experiences, when asked what they would advise a carer who was new to the situation, many said take all the help you can get.

Table 6 Difficulties encountered with paid carers

- Lack of continuity – different carers each time
- Inexperienced carers
- Erratic timing of visits and missed visits
- Poor time keeping
- Being hurried and cutting corners
- Rough treatment of patient
- No care plan or briefing of carers
- Poor management

Other family members also formed part of the supporting cast and but their level of practical and emotional support was very variable. Twigg and Atkin (1994:129) describe other kin in their role as the surrounding social ‘chorus’, commenting and judging the actions of the carer. Some carers certainly felt that members of the family were sometimes a critical audience for their performance as main carer.

Audience

There is no performance without an audience and in everyday life often there is an audience present (Hare and Blumberg, 1988). Carers were frequently aware of this. They were greatly reassured when the audience, whether it was made up of professionals or family members, praised their performance.

Stephen: Several people in (*the hospice*) have actually told the family that I’m doing a good job. Well at least I don’t have to blow my own trumpet (current).

Jim: Well, they’re all saying I did marvellous. They all said you were very good (bereaved).

Sometimes the audience, however, was less encouraging.

Naomi: His mum was going well have you done this? And I said yes, I've done this. Have you done that? Yes, I've done that. You know, you know and I felt that she was, I was getting a hard time from her. Argh! (bereaved).

The most critical audience was often the carer him/herself. Hare and Blumberg (1988:48) suggest that if a person is disgusted by his or her own behaviour, the "Me" can be said to be providing an audience capable of criticising and restraining the "I". Although none of the carers were disgusted with themselves, there were things they disliked especially when looking back on their whole performance.

Naomi: I wish I'd done things differently. I wish. If I'd known um I mean when he came out of the hospice he was only home for about six weeks and if I'd known that, I mean hindsight's a wonderful thing, but I would have spent every minute of every day with him. I just would've... I would have insisted that the er that they gave him a syringe driver for pain rather than the suppositories that they inflicted on him... When I lie awake at night sometimes, you know it's just like prodding a bruise or a cut, opening a cut just to make sure it's still bleeding and it does hurt, and I'll think about it. I think could you have done anything different? Torture myself with that, you know 'cause hey you're awake. And um and er and it's hard and then I argue with myself and say look it's done. You can't change anything. It's past. You did what you thought was right at the time and that's all you can do, you know..... No, I should have done more, I should have, I should have (bereaved).

As a research interviewer, I was also a member of the carers' audience. The interviews provided the carers with an opportunity for dramatic realisation where in my presence they could dramatically highlight and portray facts that might otherwise remain unapparent or obscure (Goffman, 1959). Although a few carers felt nervous about being interviewed, most found it helped them to have their opportunity to tell it how it is and was.

Margareta: What would have helped me um, but it was impossible to have, is indeed what we are doing now. An hour of talk with somebody to get it off my system but that I couldn't do because I couldn't leave him an hour alone you know, so that was fairly simple (bereaved).

Although they all had individual experiences to convey, they tended to fall into two styles of performing their role.

Types of performance

Twigg and Atkin (1994:122-126) identified the attitude of carers to their caring role as three modes of caring. Firstly there is the engulfment mode in which the carer subordinates his or her life to that of the cared for person. Caring becomes the centre of their life and accepting help becomes difficult and is sometimes seen as a threat to the relationship. The second is the balancing/boundary setting mode where carers place greater value on their own autonomy and make space for their own interests. This does not mean there are unaffected by the experience but they are better able to pull back and to ask for help. The third mode is symbiotic whereby carers gain in a positive way from their role as carer to the extent that they would not wish the responsibility and its consequences to be taken from them. These modes of caring could be recognised in the carers in this study. However, the performance of their role as carer fell into two types – combative and pragmatic. Whilst each carer displayed some elements of each type of performance they tended to fall into one or other category. Table 7 outlines the characteristics of each type.

Table 7 Types of carer performance

Performance type	Typical comments	Likely attributes	Universal experiences
Combative	It's a battle I put in a complaint I feel strong You've got to take over	Anger Need to be in control Obligation	Uncertainty Fatigue Emotional distress
Pragmatic	You just do it Take each stage as it comes I know I can ask for help	Coping Love Taking it in your stride Regrets in hindsight	

Combative performers took a heroic stance in which they felt the need to fight on behalf of their patient for the right level and quality of treatment, care and support. Their fight could be against health professionals, hospitals, care agencies, family members or any combination of these.

Jane: His doctor might as well not have been there.If I hadn't come in and I'm not blowing my own trumpet but he wouldn't be here. He would have died last year. ...I moved in and got things sorted for him. Didn't stand, 'cause they're so oh, yes sir, no sir, oh, the doctor knows right, and he, you know I said Dad, you know they're not all that (current).

Sharon was archetypal combative and she revealed how she used her performance as part of her weaponry.

Sharon: I was standing in the mall and in the end I was literally shouting down the phone. I didn't know how else to get through and actually it worked. And I was really sad that that worked. It was like we've got to do something to get this woman off our backs or you know we'll have a mental health case on our hands or something, 'cause I really just lost it completely um although I, part of me knew that I was winding it up a bit (bereaved).

She also demonstrated that one of the problems with a combative performance is that it takes energy and time.

Sharon: It was such a fight those last few days. It was all fighting 'cause I had all the stuff with the carers too before and I, it was just a fight. Yeah we got there in the end for him and you fight you do, don't you? When you know it's something that has to happen, you have to fight. But most of the fighting I think was unnecessary, completely unnecessary. I don't think there was anything, I made so many phone calls and was constantly on the phone, having a go at people and getting, getting more upset than I

really felt sometimes just to try and get through to people that. And it wasn't, they weren't our days in the end (bereaved).

On the other hand, a combative performance made carers feel strong, able and in control. The pragmatic performer, however, seems to take it all more as it comes. Jim presented himself in a very different way from the combative performance.

Jim: I'm not a hero..I only did what any mother would do..if you've got to face it, then you've got to face it and you do the best you can and that's all I did. I did the best I could (bereaved).

Brian also took a pragmatic view on his role

Brian: It didn't worry me at all. Not at all. I don't know where I got the strength you know but um it was never a problem (bereaved).

While caring, the pragmatic performance was a less stressful experience but one of the downsides was revealed by bereaved carers feeling maybe they could have done more. Naomi was pragmatic but with hindsight she regretted not being more combative.

Naomi: If, if I could have it over again, God forbid, I would say no, syringe driver. Get, do something else. Instead I thought no, no, it'll be OK, it'll be OK and I tried to work round it and I wish I'd been more of a Rottweiler (bereaved).

Regardless of the type of performance, for each carer the climax of their drama was the moment of death.

The climax of the drama

The climax of the drama was the moment of death itself. Two concepts of 'being there' and 'letting go' were of great importance for the carers at this time. Being there was a large part of the carer's role throughout the dying process but it took on immense significance at the moment of death, especially being able to hold the patient's hand. Of the thirteen carers who were interviewed after the death, all but two were physically present when the patient died.

Peter's partner died in the hospice and, although he was called, he was out walking his dog and he did not get there in time. Sue was on the phone in the next room. Both were very disappointed.

Sue: It was awful..I wanted to be with him at the end and I wasn't. I know I was here but I wasn't there holding his hand (bereaved).

Being at the bedside was not as difficult as some had anticipated and they instinctively knew how to cope. Their descriptions reflected the mystery of the moment of death, but also that it can be lovely and intimate (Donnelly et al, 2006).

Paula: I thought it was quite nice 'cause I'd never seen anyone die. I've never seen anyone dead before.. It's nothing to be frightened of (bereaved).

Nicola gave her teenage children a choice about being there when their father died in the hospice.

Nicola: The children decided to stay outside. They didn't, thought perhaps they didn't want to come in. Then the nurse, one of the nurses went outside. I don't know what they said to him, said to them. They never, I haven't really asked, I don't think. But they came in after a couple of minutes and um I said are you sure you want to stay? And they said yes. We know, the nurse has told us what to expect and things..... So they were all when he did actually die, they were all awake and aware and um it was all you know very dignified you know...It was a nice peaceful, it just seemed a natural, a natural thing (bereaved).

Being there was also symbolic of letting go. Lowey (2008) describes the concept of letting go before the death of a loved one as characterised by a shift in thinking about the acceptance of impending death and the realisation that its natural progression should not be impeded. She finds subtle differences between anticipatory grief, death awareness and letting go and suggests that before letting go, a family member experiences an internal turning point in which change is recognised to be inevitable and crucial for the dying person's best interests. In her first interview, Sheila was overwhelmed by anticipatory grief and fully aware that her husband

was going to die. In her bereavement interview, however, it was clear that she had not experienced that turning point of letting go.

Sheila: If they could have kept him going you know a lot longer. Kept him out of pain and he could carry on. That's what we'd have wanted (bereaved).

Most of the carers however did reach a point where they could let go. Naomi vividly described her process of letting go.

Naomi: And then I was just praying and saying look you've done ever so well and I'm really proud of you (*tearful*) and I love you very much and you can go home to Jesus now. Not that anything I could have said or done would have stopped it but it was almost like releasing him for me. It was really hard (*tearful*). But he couldn't have gone on like that. There was no way. He was so weak. (bereaved).

Lowey's (2008) suggestion that after letting go, the individual is freed of an emotional weight of unrest and turmoil, and healing and growth can begin to take place may be rather optimistic. But several carers expressed a feeling of relief on behalf of their patient and themselves after the moment of death.

The finale

After the death, the drama was brought to a close with practical arrangements and emotional adjustments. The carers continued their care of the body until the funeral directors came to collect it. Margareta shared this vigil with other members of the family but time alone with the deceased was also important.

Margareta: We sat downstairs and every time somebody would go and sit with him for a bit and I asked the children to leave me alone for a bit. (bereaved)

Stephen: She was just looking peaceful. I had that time with her 'cause they (*family*) didn't arrive until nine. (bereaved).

After all her difficulties with paid carers and professionals, Sharon found the funeral director's unconventional approach quite supportive. Her description also reflects the temporary euphoria that several carers felt at this time.

Sharon: I didn't know that he'd pull up in an estate car to the back of our garden, just an ordinary estate car and literally um just take him out and chuck him in the back of the car and take him down. You know I can take that 'cause I don't actually mind it 'cause I like Dave (*funeral director*) a lot. But he came in afterwards flopped on the back of my dad's chair and said cor, that was a bit of a weight, he said like that to me, 'cause he knows he can say that. And he made us laugh and we just and he, he said well, I'm going off then. I'll be chatting to him every morning, he said and things like that and he's really sweet. So I'm lucky 'cause Dave is so lovely and I know him. A lot of people would find that manner offensive but he knew he could do it with me. Um, not just me, it was everyone who was in, there were five of us in the room by then and it was lovely. (bereaved)

Some said how hard it was to let the body go.

Jane: He stayed here all night until about four o'clock. I didn't want him to go. (bereaved).

Margareta: I wanted to keep him then all night but they said no, he better go. (bereaved).

Others just felt it wasn't their loved one anymore.

Stephen: It was a curious feeling, you know, all the family came here and Sarah was still upstairs, but it wasn't Sarah. (bereaved).

Paula: That wasn't him lying there. It's not him in the cemetery either. When I go and put flowers on the grave I just think he's not there. (bereaved).

Although the removal of the body was the finale of the drama, the carers entered a new era with different challenges and uncertainties, summed up by David.

David: I think coping up to John's demise was a doddle by comparison to coping afterwards. I'd have him back with all that hassle again if I could. (bereaved).

Summary

During the analysis of the carers' interviews it became clear that they perform a leading role in the drama of the dying process of their family member. They take on this role out of necessity and with regret because they do not want their family member to be dying. They feel under-rehearsed for their performance which leaves them with uncomfortable uncertainties and anxieties. The carer's initiation for their role is therefore central to the drama. However, knowing the end of the drama is the death of someone they love, they do not want to seek out information about the dying process because it makes them face the reality and pain of this prospect. Nevertheless they do value the direction of health professionals although they experience varied levels of support and quality of care. They also experience a wide range of quality from paid carers. Being told you are doing a good job was very supportive for carers and they seemed to benefit from telling their story to me as research interviewer. Carers' performances fell into two types, combative and pragmatic, with some cross-over behaviour. Each performance led up to the climax of the drama at the moment of death. Being there was very important at this time and being able to let go helped some carers to feel a sense a relief. All carers experienced uncertainty, emotional distress and physical fatigue during their time caring for a dying loved one at home.

In the next chapter I will relate the dramaturgical perspective of carers' experiences of the dying process to existing literature on carers of the terminally ill at home. The main theoretical insights of the study will be discussed in relation to carers' performance in the carer's initiation.

Chapter 5 Discussion

Introduction

In this chapter I will discuss the findings of this study in relation to the existing literature on carers in home palliative care. New insights will be presented from the before and after death perspectives of the carers. The outcome of the dramaturgical analysis will be presented as a play of five acts called the carer's initiation. I will illustrate the concepts that make up the carer's initiation and I will explore how carers put on their performance with the feeling that they have had no rehearsals and no script to follow and yet they know the ending of the plot. The first act is carers' uncertainty and information seeking. Here I will make a differentiation between awareness of death, acquaintance with death and awareness of the dying process. This differentiation will demonstrate that carers may be aware of impending death but have many uncertainties about what the dying process entails and about their role within the process. I will also explore carers' expectations of the dying process and some of the barriers to information seeking despite their sense of uncertainty. In the second act, the role of health professionals as directors and paid carers as supporting cast in the carer's initiation will be discussed including some of the problems that carers encounter with these services. In the third act I will discuss carers' social isolation, the benefits and difficulties of carrying on at work while caring and the demographic challenges to caring within communities. The fourth act will address the emotional aspects of caring, both anticipated and unanticipated. The fifth act of the carer's initiation will highlight what helps and does not help carers on an individual level.

The carer's initiation

This study has confirmed many of the findings from previous research. The carers reported the many stresses and strains of caring for a dying family member at home. Although the emotional, mental, social and physical features of caring have been described as carer burden (Rabow et al, 2004), the carers in this study did not use the term 'burden'. It is arguable whether the carers equated their experience to burden which suggests that the patient and caring drag you down. In general, they performed their part willingly, even where there was an element of obligation, and when they looked back on it after the death they were pleased to have been able to do it. The positive aspects of caring for the dying and their feelings of

satisfaction and accomplishment mirrored the findings from other studies (Perreault et al, 2004; Salmon et al, 2005; Stajduhar, 2003; Hudson, 2004).

However, the dramaturgical analysis brought fresh insights to past literature about carers' experience of the dying process. In particular, it highlighted the drama of the situation and the anxiety of being the leading player on stage with minimal preparation for the scenes that lie ahead. Although carers in home palliative care have been reported as feeling they have no identity and are invisible or just part of the patient (Harding and Higginson, 2001), the dramaturgical analysis suggested that carers in fact play a leading role and are not just adjuncts of the patient. But carers put on their performance in a state of mystery that is akin to ancient Greek ceremonies where only the initiated know the rituals. As I looked at the dramaturgical analysis of the carers' interviews I could see that all carers go through this drama called the carer's initiation. The carer's initiation is a play with five acts. The five acts, based on the findings from the study, are uncertainty and information seeking; interaction with professionals and paid carers; social isolation; emotional impacts; and helps and hindrances (see table 8).

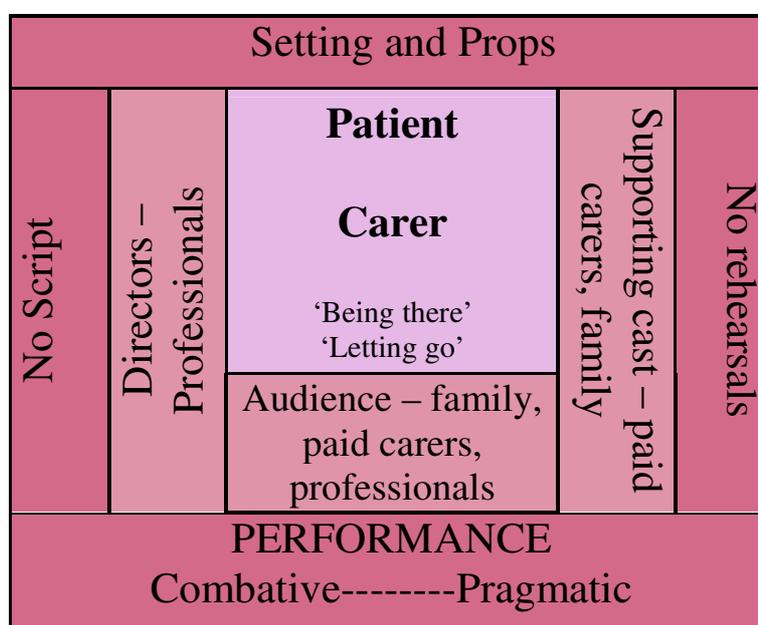
Table 8 The carer's initiation

Act 1	Uncertainty and information seeking
Act 2	Interaction with professionals and paid carers, including problems encountered
Act 3	Social isolation
Act 4	Emotional impacts – anticipated and unanticipated
Act 5	Helps and hindrances

Figure 1 outlines the dramaturgical concepts that make up the carer's initiation play. The play takes place within the setting of the home with the carer at centre stage alongside the patient. Carers are striving to include within their performance the key tasks of being there and letting go. Because their family member is dying, carers are aware that they have a short time in which to get their performance right and they become anxious that they will miss their cues. But carers are not all the same and they cope in different ways. The individual carer's

performance of their role tends to be towards one end or other of a continuum from combative at one end and pragmatic at the other. Around the patient and the carer are the other people involved in the play. The carer's initiation has an audience made up of a succession of professionals, paid carers and family visiting the home, observing and expressing approval and disapproval of the carer's performance. Professionals also act as directors, and paid carers and family are the supporting cast in the play. Significantly, in the carer's initiation play carers perform their role with no rehearsals and no script.

Figure 1 Dramaturgical concepts of the carer's initiation play



The plot of the carer's initiation takes each carer through a psychosocial transition in which their circumstances change irrevocably, thus challenging their previous expectations and assumptions of their life and world (Parkes, 1993). Parkes suggests that the outcome of such a transition is related to its magnitude, the extent to which it has been correctly anticipated and the supports and opportunities available. He also claims that any activity that helps people to prepare themselves for a life changing event is likely to reduce the risk of psychosocial complications (p. 98-99). The five acts of the carer's initiation explore anticipation and preparation for caring in the final stages of a family member's life and the supports and

opportunities available to de-mystify the dying process and to support carers in the performance of their role.

Uncertainty and information seeking

Without rehearsals and a script, all the carers in this study expressed uncertainty about what to expect as their family member died. Their uncertainty included conceptual, strategic, practical, temporal and emotional dimensions. The literature places much emphasis on awareness of dying as a turning point in preparation for death. Yates and Stetz (1999) describe families' awareness of dying as the process by which carers interpret and respond to the various observations, interactions and social experiences during the caring experience that suggests their relative is dying. Glaser and Strauss' (1965) seminal study on awareness of dying noted that once a family was aware that the patient was dying there was a marked difference in their behaviour and in the response of nursing staff to them. However, this work relates to care of the dying in 1960's America which took place predominantly in hospital where they reported that "a dying patient's family creates a chronic problem for nurses" (Glaser and Strauss, 1965:136). More recently, the shared needs for awareness between patient, family and health professionals have become recognised. Awareness of dying is seen as one of the central concerns for the dying person and his/her family as they attempt to make their experience as meaningful as possible (Kellehear, 1990). Knowing that the person being cared for is going to die from their disease is a key issue in understanding the experience of dying and how family members respond, adjust and prepare for death (Yates and Stetz, 1999). However, there are subtle differences between awareness of dying and awareness of the dying process. Knowing that death *will* happen is not the same as knowing *how* it will happen. All the carers in this study knew what the climax of the drama would be but they did not know how it would play out. There was also the question of when it would happen. Similar uncertainties were expressed in a study of carers for people with muscular dystrophy and motor neurone disease where no carers reported being ready for the final stage, even though they had been aware it was going to happen (Dawson and Kristjanson, 2003).

There is also a subtle difference between awareness of dying and acquaintance with death. Sandman (2005:66) assumes that the dying person will benefit if his or her carer has prior experience with death, although he acknowledges that the emotional distress faced by close ones might hinder them from putting former experience with death and dying into practice. As

current carers in this study, those with professional or past experience of caring for the dying were more anxious that death would occur than how it would occur. When bereaved, however, these carers were more distressed that the dying process for their family member was not as they had expected it to be. Hebert et al (2009) also found that carers with previous experience of a death in the family or who had been caring for a long time had a greater understanding of what to expect but, regardless of this, all carers expressed some elements of uncertainty about what would happen in the future. Thus prior acquaintance with death, which might be seen as a rehearsal for the current situation, seemed to give some reassurance, albeit false, during the lead up to the dying process, but did not help particularly at the time or after the death.

Most of the carers had no rehearsals. They had minimal or no previous experience and had little means of becoming acquainted with dying. How people die is rarely discussed. As in a Greek mystery, it is only the initiated, such as nurses and relatives at the bedside, who learn about dying. However, they rarely talk about their experience in view of the perceived morbid nature of the topic, with the result that knowledge about the dying process remains relatively unshared (Copp, 1999). Uncertainty about the nature of dying and what is required of carers at this time and the anxiety that it induces have been found to be universal (Hebert et al, 2009).

However, despite their uncertainties and knowing the ending of the plot, the carers in the carer's initiation did not want to read the script. As other studies have found, they expressed very mixed feelings about seeking information on dying (Cherlin et al, 2005; Harding and Higginson, 2001). For these carers, it did not seem, as McLoughlin (2002) found, as if to speak of their family member dying amounted to betrayal, or a superstitious feeling that talking about death will bring it on (Wienrich and Speyer, 2003). Although Payne (2002) and Pereira et al (2000) anticipated that patients and carers would increasingly go on-line for information, carers in this study did not use the internet as a means of preparation for what to expect when their family member was dying. In the carer's initiation it was just very difficult for carers to contemplate how their family member would die, let alone seek information about it. Sometimes the mystery around dying was easier to cope with than the reality.

Reimer et al (1991) described how carers recognise the transition into the final stages as a process of fading way, but there is a generally very little in the literature about what carers expect of the dying process. The findings from this study were that carers' expectations were

generally vague and mostly negative. As current carers interviewed in the few weeks before the death, most said they didn't know what the end-stage would be like, but thought it would be bad, harder, more challenging. They expected the patient to get weaker, thinner and bed-ridden, and talked of fading away, systems slowing down, or going into a long sleep. Their vagueness may represent lack of knowledge and information, an inability or unwillingness to articulate what they expected, or a desire 'not to go there'. Some carers said they tried not to think about it. Faced with the prospect of the painful experience of someone they love dying, carers find themselves feeling that they need to know what to expect so that they can anticipate and meet their family member's needs, but not wanting to hear, read or see the information about what to expect because it is too difficult, painful or real to face. These mixed feelings present a dilemma for health professionals trying to help carers to prepare for the end-stage. In order to address carers' strategic uncertainty of not knowing what happens next and who to call and under what circumstances it is necessary to 'go there'. There is also the difficulty that the evidence base for understanding carers' knowledge and information needs in palliative care is limited, disparate and predominantly descriptive (Docherty et al, 2008).

Interaction with professionals and paid carers

Health professionals have an important place as directors in the carer's initiation. Despite their ambivalence, current carers said they wanted more preparation and current and bereaved carers who were given written and verbal information about what to expect found it helpful. Carers were worried that they would miss their cues. Would they recognise the signs that indicate that the patient's condition is deteriorating; should they call the doctor; is it time to change the medication? They wanted health professionals to be the director giving them their cues. They especially valued being warned of physical changes such as reduced or absent need for food and drink, withdrawal from the world in terms of communication and level of consciousness, and changes in breathing. What carers seemed to find most helpful was being given information directly rather than being signposted to books or websites to look at on their own. And they wanted the information in a step by step fashion. Bereaved carers said they had needed professionals to anticipate each stage in the process and to prepare them accordingly. The importance of pacing information has been recognised from other interview studies with carers of dying family members (Dawson and Kristjanson, 2003; Kirk et al, 2004; Cherlin, 2005) but this study was able to confirm its value from both current and bereaved carers.

Health professionals also constitute part of the audience observing the patient's condition and the carer's performance. In this way they anticipate the changing needs of the patient and provide appropriate props. The provision of equipment and medication in advance was usually highly valued by carers but only when their use was fully explained. One carer's rejection of a hospital bed confirms that equipment needs to be introduced sensitively and with consent as it changes the internal environment of the home (Dawson and Kristjanson, 2003) and interferes with normal family life, relationships and intimacy. Health professionals also recognise when the carer needs a supporting cast of paid carers and/or other family members. Again, this needs sensitivity to individual preferences and privacy, as indicated by the carer who felt coerced into having paid care and regretted it.

Group educational and supportive interventions provided by health and social care professionals for carers in palliative care have been reported as well received and evaluated by participants. Among other topics, most group interventions provide information and preparation for death and dying in a supportive atmosphere amongst peers and away from the patient. Such interventions have been reported as reducing anxiety and giving a sense of safety and enhanced confidence for carers (Harding et al, 2002; Harding and Higginson, 2003; Milberg et al, 2005; Witowski and Carlsson, 2004; Henriksson and Andershed, 2007; Kwak et al, 2007). Three carers in this study attended this type of programme. However, in their interviews they did not mention attending the carers' course as preparing them for the dying process. The reason for this may be that the information was received too early for it to be relevant or acceptable to them. Timing of guidance and information-giving is therefore crucial for it to be helpful and effective. For instance, the carers who attended reported that the carers' course was helpful in meeting some of their practical uncertainties, especially concerning medication and lifting. They also valued meeting other carers in a similar situation.

Carers experienced temporal uncertainty especially around prognosis, timing of changes within the dying process and of the death itself. For most of the carers, the patient died more quickly than they expected. While professionals cannot always predict the precise timing of the death, if they are visiting regularly they can usually give adequate warning and guidance during the dying process. For instance, they can advise carers when to call other family and what to do when the patient dies and afterwards. This approach however assumes that the

professionals have the knowledge and skills to anticipate and provide appropriate and timely information and that they have the time and resources to do this. Carers felt that the professionals did not always know best or get it right. In a study with bereaved carers, Grande et al (2004) also found mixed favourable and unfavourable responses by carers to the support they received from GPs and district nurses. As with the carers in this study, they found that accessibility emerged as the most important aspect of support. Attitude and approach during interactions and information-giving were other significant aspects which when performed well made a huge difference to carers. However, professionals' levels of confidence and ability to discuss end of life issues are very variable (Cherlin et al, 2005; Yates and Stetz, 1999). In the carer's initiation, carers' performance types were also variable and these variations may have an impact on how professionals communicate with them. It is probably easier for professionals to communicate with a carer who has a pragmatic, relatively laid back approach than with one who is combative and shouting down the phone. Reviewing carers' needs when their relative is dying in a care home, Nolan and Hudson (2009:173-4) suggest that families want to play an active role but competitive relationships between staff and family can develop leading to confrontational care. They conclude that the best partnerships between carers and professionals exist when all parties within the caring relationships are able to work together and appreciate each other's perspective. It seems vital that in their role as director of the carer's initiation professionals have some understanding of how people respond differently to stressful situations like caring for a dying relative and develop communication skills appropriate to these differences. Taylor (2007:14) concludes that families are not expecting high levels of psychological input, but what they do want is a listening ear, someone to enquire after their own needs, and honest, accurate information sensitively delivered. The carers in this study described the importance of health professionals who were easy to talk to, explained things, inspired confidence, monitored them as well as the patient, and gave them the sense that they were not alone. In particular it helped carers to get some applause for their performance and to be told they were doing a good job.

Out-of-hours medical and nursing care was a particular concern for the carers. Towards the end of the patient's life it is usually the carer who makes the decisions about calling out-of-hours services. In the UK, centralised services covering large areas that provide a single point of access to all out-of-hours services have been established with the intention of offering simple and convenient access to advice and effective triage. The aim of these services is that

appropriate care can be delivered quickly and efficiently. However, responsibility has transferred from GPs to these services, which means that patients are now unlikely to receive care out-of-hours from a doctor who knows them. Worth et al (2006) found that palliative patients and carers had difficulty deciding whether to call out-of-hours services due to anxiety about the legitimacy of need, reluctance to bother the doctor, perceptions of triage as blocking access to care and of out-of-hours care as impersonal. However, they reported that an empathetic response outweighed the lack of continuity of care. The health professionals questioned in their study said that finding the time to address palliative care needs effectively is important but challenging in the context of providing a generic out-of-hours service. Limited staff and time often meant that acute conditions had to take preference over palliative care. The findings from this study suggest that out-of-hours doctors and nurses may not have the same commitment, interest or empathy as the professionals who are visiting regularly. It may be that out-of-hours staff are more stretched and have less time to invest in forming a relationship with the patient and carer. Nevertheless, this is not an acceptable disclaimer for brusque, unsympathetic behaviour with patients and carers experiencing the stress of end of life difficulties. In the carer's initiation, professionals are performers too, and they need to be able to adopt a suitably compassionate front regardless of the stress they feel under, even if it is an act. Faced with concerns about out-of-hours services, the carers in this study found the hospice 24 hour advice line, which is available to patients, carers and professionals, hugely reassuring. Access to 24 hour specialist palliative care telephone advice was also reported as a universal requirement for both GPs and district nurses (Worth et al, 2006).

As the supporting cast in the carer's initiation, paid carers emerged as another area of concern. The carers reported very variable quality of paid care. In 1994 Twigg and Atkin reported that carers were often exposed to a particularly unstable pattern of provision of home care services, and one in which they may have to reassert their needs. It seems that the situation has changed very little since then. Several carers reported that caring for their dying family member was a 24 hour job and they could not do it all themselves. Others needed to continue to go to work. Most received help in their caring role from paid carers. Paid carers are generally care assistants who are employed by a private agency that is independent of health and social services but contracts with health or social services or the individual patient to provide personal care for the patient at home. Paid care may involve one or more daytime visits and/or overnight stays and even live-in 24 hour carers in some situations. In the study area the local

hospice is one provider of paid care through its Hospice at Home service, but a number of other agencies were also involved in supplying care assistants to the participants.

While there is a great deal of emphasis in the literature on the role of health professionals in supporting carers of terminally ill patients at home, the place of paid care is rarely mentioned as an intervention to support carers. This may be because paid care is seen as a service for patients. Payne and Hudson (2009) provide a framework of supportive measures for family carers in home palliative care which includes firstly interventions directed at carers and secondly those directed at patients that have secondary benefits for carers. Respite, day care and in-home sitting services are listed in the second category, but they do not fully address the type of paid care that constituted the supporting cast for many of the carers in this study. Paid carers who contribute to a 'package of care', visiting once or more times a day to provide direct care for the patient, could be described as providing respite. However, this is not the usual understanding of the term 'respite', where the carer is entirely relieved of caring responsibilities, such as when the patient is removed from the home to an institution for a period of time. Also the paid carer frequently assists the carer with the patient's personal care in the home and is therefore not providing respite for the carer. Day care can provide a few hours respite but the dying patient is rarely well enough to attend day care facilities away from the home. In-home sitting service does not adequately reflect what the overnight paid carers are required to do. When the patient is within the dying process they do more than the term 'sitting' implies. They frequently support the carer and other family members through the process and immediately after the death as well as tending to the patient's needs. The role of paid carers in supplementing the main carer's role seems to be hidden from view, occasionally mentioned in passing in the literature, and yet is vital in most cases to maintaining the patient at home.

The carers reported very mixed experiences of paid carers, ranging from very good to very poor. There is very little research on carers' experience of paid care in home palliative care. Walker's (2008) anecdotal report confirmed the misgivings that some of these carers had about paid care. She found the paid carers assisting with her dying mother's care had poor understanding of her condition and needs. A recent BBC Panorama programme (2009) revealed alarming shortcomings in domiciliary paid care in general, including some terminally ill recipients of care. As investigative journalism one might expect some sensationalism in the

presentation of the evidence, but the carers in this study had experienced many of the problems with paid care that the programme identified. The problems included inadequate training, overloading of work to carers causing them to be late or missing calls altogether, no space for any extra care needs and travel time not factored in, frequently changed carers, inadequate or no care plans and poor co-ordination and communication with management (BBC, 2009). However, some carers in this study were highly satisfied with most of the paid carers. They recognised and valued their contribution to the overall care of the dying patient and saw paid carers as supporting them in the performance of their role as main carer. Rhodes and Shaw (1999) found that carers who had used a night caring service said that they would not have been able to manage without it. However the carers in this study who said similar things like they couldn't have done it without them were referring to day-time and night-time paid care services.

Several of the carers particularly mentioned the high standards of care and support that they received from Hospice at Home paid carers. This service is based at the local hospice and provides care assistants who have been specifically trained in care of the dying. They also receive a higher level of support themselves than most agency-employed paid carers. However this service rarely provides all the paid care for an individual patient during the terminal illness. It is usually a combination of Hospice at Home and care from other agencies. Marie Curie Cancer Care provides another specialist care service for the terminally patient at home, but has minimal availability in the area for this study. Marie Curie has provided subsidised nurses and care assistants for patients in their own homes for many years and has recently changed its articles of association to include non-cancer patients. It has also successfully piloted a more extensive service called the Marie Curie Delivering Choice Programme which includes planned domiciliary care and rapid response for urgent care needs. It is currently confined to a limited number of areas of the country but plans to expand its availability (Munroe, 2009). Specialist care services with appropriate training and support for their staff caring for the dying are likely to provide better care and support for terminally ill patients and their carers. However, they reflect the issues that all specialist palliative care services face in terms of equity of access and who is eligible to receive these limited resources. There is also the wider social issue that all recipients of care, and their carers when they have them, regardless of whether they are dying or not, deserve a decent standard of domiciliary paid care.

Social isolation

Although some carers mentioned neighbours or local church support, they generally felt isolated, sometimes trapped within the home. Personal space away from the patient and the care setting, or even within the home, was an important part of keeping going. Most of the carers had regular contact with other family members but they were cut off from normal life and their normal social activities. Work outside the home was a financial imperative for some carers and it also provided respite from caring and social isolation. However, combining caring in home palliative care and employment is difficult. In this study five carers (33%) had suspended their jobs in order to be full-time carers. Grunfeld et al (2004) also noted that in the terminal period most employed carers had to miss some work because of caregiving responsibilities. But the value of continuing to go to work as a coping mechanism has not been fully explored.

It is also noteworthy that the wider community is not identified within the dramatic setting of the carer's initiation (figure 1). As Kellehear (2009:28) points out, professional support services have only a brief involvement in helping carers compared with their many other relationships and social contacts and supports. However, so many carers describe social isolation that it appears their normal supports systems within the community do not always know how to respond effectively. Developing community capacity to support people through caring for a dying family member and their bereavement afterwards therefore remains a challenge.

One aspect of this challenge is the demographic changes over last few decades which mean that there will be fewer people within families available to care for their dying relatives at home. There are more people living alone, single-parent and step-families and work and lifestyle migration means that family members live at greater distances from each other. Between 2001 and 2025 the population of people aged 65 and over is expected to increase by 46% in England (CarersUK.org.uk). In our aging population there are fewer younger family members available to care and women who have traditionally been the carers are more likely to be in paid employment now than in past generations. It seems imperative therefore that carers are nurtured and valued by health and social care services and by society as a whole.

Emotional impacts

The emotional impact of caring for a dying family member at home is widely reported in the literature (Stajduhar and Davies, 1998; McLoughlin, 2002; Dawson and Kristjanson, 2003; Milberg et al, 2004). The carer's initiation is therefore not only about the changes to expect in the patient. The emotional changes and uncertainty experienced by the carers themselves during the dying process are equally important. Hebert et al (2009) suggest that addressing emotional uncertainty involves carers mentally and emotionally preparing for the death. However, as carers become subsumed by the needs of their patient they do not focus their own emotional expectations and needs (Harding and Higginson, 2001). It is generally reported that carers experience high levels of anxiety and depression (Grunfeld et al, 2004; Payne et al, 1999). This study reveals that anxieties are raised by being centre-stage performing a leading role with no rehearsals or script. It also suggests that carers feel frustrated and helpless that they cannot change the plot. Knowing the climax of the play is coming, the current carers seemed to be affected by anticipatory grief rather than depression. Some carers were unsettled that their own mental faculties became impaired and they could not concentrate or remember as normal. Most found caring very tiring and emotionally difficult. The carers in this study described the emotional labour and emotional impact of caring at the end stage as more demanding than meeting the patients' physical needs. In the carer's initiation, as well as performing a leading role, carers are also members of the audience and they inevitably become distressed as they witness the physical, mental and behavioural changes in the patient caused by advancing disease and approaching death. As death approached most carers went through a process of letting go, whereby they recognised the inevitability of death and that it was time for the patient to go (Lowey, 2008). However, a few carers were overwhelmed by the emotional impact and felt that nobody and nothing could have helped them prepare emotionally for the dying process and death.

The climax of the play is the death of the patient. As in the carer's initiation, Donnelly et al (2006:355) describe how "the scene at the moment of death resembles a stage with people taking up their positions around the bed. The professionals who have been acting as guides recede into the background and the individual who is dying and the main carer remain centre stage". Carers express their commitment to care for their dying family member at home by being with them (Stajduhar and Davies, 1998ii). Being there at the moment of death was

particularly important for carers, as was the need for connection usually represented by holding the dying person's hand.

Helps and hindrances

After the climax of the play the carers were able to reflect on the helps and hindrances they had experienced in the earlier scenes. There were intrinsic and extrinsic factors that helped and did not help the carers in this study to perform their role, as seen in table 9.

Table 9 Factors that helped and did not help carers to perform their role

Factors that enhanced performance	Factors that hindered performance
<p><i>Intrinsic:</i></p> <p>Humour</p> <p>Spiritual beliefs</p> <p>Sense of control</p> <p>Being able to adapt to the situation</p> <p>Personal space</p> <p>Exercise/getting out</p> <p><i>Extrinsic:</i></p> <p>Supportive friends and family</p> <p>Being told you're doing a good job</p> <p>Work and supportive employer</p> <p>Timely information</p> <p>Relief from caring especially at night</p> <p>Supportive professionals visiting regularly</p> <p>Meeting other carers in similar situation</p>	<p><i>Intrinsic:</i></p> <p>Uncertainty</p> <p>Emotional demands and impact</p> <p>Fatigue</p> <p><i>Extrinsic:</i></p> <p>Patient deterioration</p> <p>Patient in pain</p> <p>Patient behaviour – unpleasant - constant demands</p> <p>Demands of other family members</p> <p>Inadequate and/or sub-standard paid care</p> <p>Insensitive and/or delayed response from professionals</p>

Despite all the emotional distress, there was some comedy within the carer's initiation. Humour has been researched as a coping mechanism for terminally ill patients (McKinlay, 2001) but is rarely mentioned in the context of carers. Many of the carers in this study retained a sense of humour before and after the death and it proved to be an essential coping

mechanism for some. It was important to remember, however, that carers are not all the same. The findings confirmed that each carer's circumstances, needs and coping strategies are unique (Stajduhar and Cohen, 2009) and that their individuality was revealed in the ways they performed their caring role and what they found most helpful.

This study found that the individual carer's performance of their role tends towards combative at one end of a continuum and pragmatic at the other. The combative performance is characterised by the carer feeling that s/he has to fight to get a decent standard of care and treatment for their dying family member. This performance usually involves many requests and complaints to health and social care providers, which takes time and energy away from direct caring and being with the patient. For carers at the combative end of the spectrum a sense of control over the situation is an important aspect of coping. For combative carers manageability was a particularly beneficial aspect of coping in home palliative care (Milberg and Strang, 2004). The components of manageability are power, competence, accessibility and support. The pragmatic performer, on the other hand, is generally more laid back. For these carers adapting to the situation and taking each step at a time are more important in enabling them to cope. Pragmatic carers seem to reflect Mok et al's (2002) findings that carers find empowerment through a trusting relationship, confidence to carry out caring tasks, acceptance of the patient's death, sustained self worth and feeling peace at heart.

Recognition of helpful and unhelpful factors and an understanding of carers' individual performance styles and needs seem to be essential for effective carer support. There are therefore implications for health and social care providers at both policy and practice levels to ensure that what helps and does not help carers to cope is recognised and appropriate support is provided. Some of these implications will be discussed in the final chapter.

Summary

By using a dramaturgical approach, I have presented a new perspective on the experience of carers of dying family members at home which is that carers are performing in a five act play called the carer's initiation. By interviewing carers during their caring time and after the death of their family member I have been able to use their two viewpoints of their performance. These two perspectives have shed light on their expectations of the dying process as it approached and then to compare them with what actually happened. While caring they

expressed their many anxieties and uncertainties about what lay ahead because it was unknown and difficult to think or talk about. Before and after the death carers were able to critique the health and social care services they received. They all experienced the emotional impacts of anticipatory grief and bereavement and the social isolation of caring. Current carers and especially bereaved carers who with hindsight were able to view the whole process, expressed what had helped and not helped them to prepare and to cope. In the final chapter I will summarise the thesis and discuss the limitations of the study. I will also suggest implications for policy and practice and future directions for research.

Chapter 6 Conclusion

Introduction

In this final chapter I will summarise the thesis and present the limitations of the study. I will then discuss the implications of this study for health and social policy and practice and make suggestions for further research. I will examine the roles of health promotion, public health and community development to enhance carers' support and reduce the health risks of caring. I will discuss the importance of accessibility of health professionals in reducing carers' anxiety; the need for education of professionals to ensure high levels of competence in communication with carers; the value of multi-disciplinary working; and the need for sensitive and timely information provision. I will raise some issues concerning paid care. I will then suggest further areas for research.

Thesis summary

In this thesis I have presented a qualitative study involving fifteen carers of patients receiving palliative care at home. As current and bereaved carers, they spoke freely and in-depth in semi-structured interviews about their experiences and it became clear during analysis of the data that there was a dramaturgical meaning in what they were doing and saying. The dramaturgical analysis demonstrated that carers were lead performers in a play which was called the carer's initiation. From the findings it was apparent that carers perform their role with only vague expectations of the dying process because dying is rarely experienced and discussed. They therefore feel unprepared and uncertain about it. This was compared to a Greek mystery where only the initiated know what to expect and what to do in secret ceremonies and they are not allowed to divulge these secrets. The carer's initiation took place in the familiar setting of the patient's home but the props and many other aspects of caring for a dying relative were unknown to the carers. However all carers expressed ambivalence, or even reluctance, towards seeking information about dying because avoiding the painful prospect of their loved one dying frequently outweighed their need to know what to expect and what to do.

The study confirmed that caring for a loved one through the dying process at home is demanding and fulfilling. Carers placed a lot of emphasis on the importance of being there with the patient through the dying process, but particularly at the time of death, and of being

able to let go. The findings also showed that despite the barriers to information seeking, the experience of caring was enhanced when carers were adequately and sensitively directed and prepared by health and social care professionals. Support from paid carers was a mixed blessing, very helpful in some situations and a source of added stress in others. The carers in the study had individual performance styles but they tended to be predominantly either combative or pragmatic. Their performance type had implications for how they coped and how they interacted with professionals and care agencies. All the carers described their performance as tiring, emotionally traumatic and stressful, but they looked back on it with a sense of satisfaction alongside their feelings of grief.

Limitations of the study

The summary of the thesis must be put in the context of the limitations of the study. With only fifteen participants, it was small scale research and reflects only their accounts of their experiences and my interpretation of them. I did not ask the participants to comment on their interview transcripts or my interpretation of them as I felt respondent validation was inappropriate for this study, but this can be seen as a limitation. Also the study took only the perspective of the carers. Including the perspectives of the patients, other family members and/or the professionals involved could have given a broader understanding of the issues, but might have diluted the essence of the study which was the carer's perspective before and after the death of their family member.

The study started with a grounded theory approach but my focus changed to a dramaturgical analysis during the process of theory building. Thus it did not follow a pure methodology. Using dramaturgical analysis I relied heavily on the theatrical metaphor with the potential danger of manipulating the data to fit the metaphor (Patton, 2002:505). However, the dramaturgical perspective arose through an inductive process where the data produced the metaphor rather than the other way round.

I was dependent upon referral of potential participants by my colleagues who may have been selective, consciously or unconsciously, about who they thought would be suitable and whom they were happy for me to interview. This may mean that certain types of carers were excluded although I had no indication from my colleagues that they were gate-keeping in this way. However, my methodology meant that I could only recruit carers who were aware that

their family member was dying and were prepared to talk about it. Thus carers who were unaware, in denial or unable or unwilling to talk about dying were excluded. Their perspectives on the experience of caring might have been very different but could only have been gained second-hand by using professionals or other family members as proxies.

The participants were all white which reflects the predominantly white local population, but is not representative of much of the UK. Diverse cultural aspects of caring were therefore not addressed. The range of participation was also limited because most of the patients receiving care had cancer which generally has a more predictable dying trajectory compared with other life-threatening illnesses, such as heart failure and chronic lung diseases. Cancer has also traditionally received more attention from specialist palliative care services. All the patients in the study were receiving specialist palliative care which includes support for the family as one of its central tenets. Therefore one would expect the carers who participated in the study to have a good level of information, preparation and support for the dying process. A study comparing carers with and without specialist palliative care involvement could have been more worthwhile. However the ethics of raising highly emotional issues without the backup of specialist support is questionable. Therefore the findings of the study cannot be generalised to other populations of carers, although this does not mean that they are not relevant or of interest to those working with carers in any end of life care settings.

Implications of the study for policy and practice

This study asked carers about their experiences of caring through the dying process when they were actively caring and with hindsight after the death of the patient. I have suggested that rather than being mere adjuncts of the patients, carers are leading players in home palliative care. The implications are that their leading role needs further recognition and support within health and social policy and practice and within society as a whole.

Health promotion

This study confirmed previous research findings that caring for a terminally ill patient at home can adversely affect the physical and mental well-being of the carer. Any activity that reduces these adverse effects will therefore be health promoting and needs to be incorporated into health policy. Palliative care has always emphasised a holistic approach that incorporates the care of the family as well as the patient and addresses physical, social, psychological and

spiritual dimensions of care. However, Kellehear (1999) advocates more actively health promoting palliative care. One of the concerns raised in this study is that many carers have no prior acquaintance with death and dying because these topics are never discussed. This situation means that they feel unprepared and it provokes feelings of uncertainty and anxiety. It is not feasible, and probably not desirable, to give carers rehearsals for death and dying, but it is desirable to encourage more open discussion about preparation for dying. Health promoting palliative care is about providing education and information for health, death and dying and combating death-denying health policies and attitudes in the wider society (Kellehear, 1999:19-20). Education and information for individual carers is vital at a practice level in order to de-mystify the dying process and thus reduce some of their anxiety. There is also a place for group interventions that incorporate education, support and opportunities to meet other carers. Health promotion is also about preparing carers for the physical and emotional demands of caring and promoting coping strategies and opportunities for relief from caring. Health promoting practitioners will encourage and legitimise carers looking after themselves, having personal space and taking breaks from caring. Health promotion therefore may be orientated towards individuals and groups of carers but it also fits within broader public health and community development policies.

Public health and community development

Public health is about everyone's well-being and concerns harm-reduction across the whole population. Everyone will face their own or a family member's dying process and death, but death and dying are associated with fears, anxieties and ignorance. A public health approach that raises awareness of death could help to reduce some of the harmful effects of fear and anxiety and encourage people to prepare practically and socially for their own and their relatives' dying. Public education initiatives on death and dying may not specifically prepare carers for the dying process of their patient, but they can make it more acceptable to talk about death and dying. Following the model of other public health campaigns, death education can be delivered through many community outlets, such as schools, workplaces, social groups, religious establishments, health centres and the media. It will aim to target misinformation, ignorance and/or community-wide fears and prejudice (Kellehear, 2009:28), and to promote healthier coping strategies across communities. This study showed that remaining at work helped some carers to cope. Current legislation to give the carers the right to flexible working only applies to those caring for a spouse, partner or relative who lives in the same home as the

carer (DH, 2008). Public health policies can inform employers of the benefits of retaining workers with palliative caring responsibilities and encourage a flexible, sympathetic attitude to these workers especially as their family member approaches the dying process.

Community development initiatives can develop from a public health approach to palliative care. These initiatives foster recognition within communities of their own health and social needs and ways to address them. Hospices are generally valued within the communities they serve and are therefore well placed to develop initiatives around communities supporting families who are caring for a dying relative, neighbour or friend. However, other establishments within the community that are experienced in campaigning and mobilising resources, such as religious organisations and community groups, can also take a lead in raising awareness and support for carers. Community development goes hand in hand with public education on death and dying because education gives people the language to talk with those facing death and with those who care for them.

Practice - accessibility

Uncertainty was experienced by all carers in the study and they valued professionals who could relieve aspects of uncertainty. In home palliative care, GPs, district nurses and specialist palliative care nurses have the greatest responsibility for supporting the carers of terminally ill patients. In the UK, community matrons who have a responsibility for people with chronic illness are increasingly supporting carers of people dying with non-cancer diagnoses, either with or without the involvement of specialist palliative care. Social workers may also play a part. Accessibility of these key professionals is of prime importance in reducing anxiety and stress for carers. Early identification of carers and greater awareness of carers' needs by GPs and the primary health care team is also recommended by CarersUK as the first step in reducing carers' health inequalities (www.caretotakealook.com, 2009). The Gold Standards Framework (GSF) should ensure accessibility by flagging up terminally ill patients within the general practice so that reception staff and professionals are all aware of their special needs and their carers. It should also encourage better communication with out-of-hours and ambulance services to alert them of individual patient needs and preferences. However, not all general practices have signed up to GSF and even where it is in operation, as with all policy frameworks, it is only effective where there is organisational commitment.

Accessibility of GPs and district nurses is particularly important because they also provide access to other services, such as Continuing Health Care funding for paid care, and to aids and equipment. Carers do not know what is available to help them in their caring role and rely on the primary health care team and specialist palliative care to inform them. Carers said they would have benefited from a checklist of services and equipment and how to access them early on in their caring role because finding out about these things was difficult and time-consuming. In addition to a checklist, I would suggest that some of the medical and nursing gate-keeping processes need to be reviewed and/or removed because they delay access to other services and equipment and frustrate carers.

Organisational culture has been found to influence patients' and families' perception of the care they receive. Positive experiences depend not only on relationships with individuals but also the context or climate of care (Gallagher et al, 2009). The problems raised by carers with the accessibility and approach of out-of-hours professional services expose some issues about the resources and organisational climate of these services and about the education and communication skills of the personnel. These issues are in need of attention at policy and practice levels.

Education and communication

When interviewed for this study, carers were able to articulate what they found helpful and unhelpful in fulfilling their role. Carers therefore should be given a voice to express their needs especially about what helps and does not help them in the final stages of the patient's life. They need to be involved in the development and evaluation of strategies for carers, such as group interventions. They can also contribute to the planning and delivery of education for health and social care professionals. Carers may not have the time or energy to get involved in professional education while caring but this study has shown that they have a lot to contribute as bereaved carers.

From a dramaturgical perspective, health and social care professionals were identified as performers as well as directors in the carer's initiation. As such they need to learn their role. Education of key professionals is essential to ensure that they have the knowledge, communication skills and confidence to listen to and understand carers' needs and to prepare them for the final stages of the patient's life. In particular, it is essential that these key

professionals have the skills to build up a level of trust between themselves and the carers of the terminally ill patient at home. They are then in the best position to help carers. From this study we have seen that good communication between professionals and carers was pivotal in the success of home palliative care. Professionals being accessible, anticipating needs, role modelling and inspiring confidence were also important to carers. The study suggested that being able to adapt to carers' different performance styles was vital. These attributes need to be incorporated into professional education and practice.

While professionals cannot always solve the difficulties that carers face, they can reduce some of the stress by acknowledging and normalising their problems and anxieties (Munroe and Oliviere, 2009). For instance, by encouraging carers, and those around them who may wish to 'treat' their distress, professionals can explain that grief is a normal response to impending and experienced loss and that people tend to grieve in a very individual manner (Kellehear, 1999). Professionals will also support carers by telling them they are doing a good job, confirming their coping capabilities and affirming the positives attributes of caring. Professionals who have built up a level of trust with carers can crucially guide them in the process of letting go by allowing carers to talk about what letting go means for them and how to achieve it. However, communicating with carers effectively and with empathy takes time as well as expertise.

Multi-disciplinary approach

A multi-disciplinary approach involving the primary health care team and specialist palliative care should make best use of time and expertise. Regular multi-disciplinary meetings of all those involved in the care of palliative patients and carers, such as practice meetings recommended in GSF, generally enhance continuity of care and best allocation of skills and resources. Within the teams involved, carers may need a specific allocation of staff to ensure that their needs are addressed (Harding and Leam, 2005). On the other hand, while it is important to see the needs of the individuals - the patient, the carer and other family members - it is also important for the practitioner to appreciate the whole as a set of relationships that act, react and interact (Munroe and Oliviere, 2009). Good communication and documentation between the individual practitioners involved in the support of a patient and the carer at home should ensure that assessment of the carer's needs and discussions with and information given to the carer are viewed as just as important as assessment and interaction with the patient.

Harding and Leam (2005) recommend more systematic approaches to recording carers' needs and interventions. There is a place for standardised carer assessment forms but it should be remembered that they are tools to aid the professional carrying out the assessment and should not be overly rigid or prevent carers from expressing their needs (Help the Hospices, 2009). The findings of this study suggest that it is particularly important for practitioners to record any methods they have used to prepare carers for the dying process. For instance, if a doctor or nurse suggests a prognosis or estimated time of death this information should be documented for the benefit of other professionals involved. Documenting when issues concerning the patient, such as behavioural changes, not eating or drinking, breathing changes, are discussed with the carer will help continuity of advice and guidance and should prevent mixed messages that cause confusion and distress.

Information provision

Information is fundamental to the carer's initiation. It is an essential part of carers' preparation for the performance of their role and for what to expect as the patient enters the final stages of the dying process. Professionals need to recognise their role as directors and be proactive by giving appropriate and timely information. Anticipation and preparation are key tasks of the director but they require skilful and sensitive approaches because carers are emotionally vulnerable due to the forthcoming death of a loved one. Information seeking and giving were identified in this study as areas of ambivalence for both carers and professionals. The timing of receiving information was crucial to whether carers found it helpful or even acceptable. Despite carers' apparent ambivalence to information about dying, they want and need to be offered information in anticipation of the changes associated with the dying process. This would include preparation for the emotional, physical and social impacts of the dying process on themselves as carers and leading players in the process. In this way carers can be supported on an individual basis in a step by step fashion. How the information was given was also significant to its acceptability and usefulness. Carers did not want to be signposted to finding information for themselves. Carers reported deficiencies in their memory and concentration while caring and therefore they may need information to be repeated and verbal delivery needs to be backed up with written booklets and leaflets which can also be shared with other family members. 24 hour access to specialist telephone advice, such as a hospice helpline, is also essential to relieve some of the anxiety of caring through the dying process which can be particularly acute out-of-hours. Although the carers in this study made minimal use of the

internet, there is generally an increasing reliance on the internet for information. It seems therefore appropriate to guide carers to relevant websites while recognising that they may not have the time or inclination to access them. Some carers may also benefit from online networking for virtual support and contacting other carers in a similar situation. Sources of information may be included in the checklist that carers requested but it should not be assumed that they will access them.

The issue of paid care

Carers in this study needed the supporting role of paid carers especially in the final stages of the patient's life, but there were some worrying deficiencies in paid care provision with quality of care ranging from excellent to very poor. Hospice at Home was generally better received than non-specialist agencies. These deficiencies and inequalities need to be addressed. I have suggested that there is an ethical dilemma of equity concerning the further development of specialist care agencies for end of life home care. On the one hand, paid carers in this field of work need training and support in caring for the dying because of the special needs of the patient and the family and the emotional demands that this work places on the paid carers. On the other hand, all recipients of care, whether they are dying or not, need paid carers who are adequately trained and supported. The aging population means there will be an increasing demand for domiciliary paid care and a reducing availability of people willing to work on low wages as paid carers. With this limited resource, is it equitable to prioritise training, support and availability of paid carers for palliative care? I suggest that the whole field of domiciliary paid care requires attention and this will involve addressing the issue of adequate funding and wages to attract and retain quality staff at management and carer levels.

Suggestions for further research

There are other aspects of equity concerning the support of carers in home palliative care which require further investigation. In this study all the patients were receiving community specialist palliative care, most had cancer and all were white. Further research is needed to evaluate or compare the carer support needs of those receiving and not receiving specialist palliative care. Similarly, research comparing carers of patients with cancer and non-cancer diagnoses is required. Studies involving a wider ethnic and cultural mix of carers are also needed to highlight different perceptions, customs, expectations and needs across the whole population, especially concerning the dying process. Professionals and paid carers also come

from a wide ethnic and cultural range but there appears to be very little research on diversity in the workforce and how this impacts on the recipients of palliative care and their carers. More research into domiciliary paid care in general is required and further studies on the interface between paid care and carers in home palliative care are needed. Research involving multiple perspectives of paid carers, professionals and carers would give a broader analysis of the issues.

The whole issue of accessibility and acceptability of information for carers on death and dying requires further investigation. For instance, further research is required with larger samples of carers to evaluate the many sources of information about caring for the dying which are available in written forms and on-line. I would suggest that further studies are also required into communication styles and competencies of professionals when delivering information on dying to carers. In particular, are professionals able to adapt their communication styles to the performance style of the carer?

I believe that this study has demonstrated that carers can make a huge contribution to research. Their views and experiences as leading players in home palliative care must be listened to in order to enhance our understanding of how best to support them.

References

- Andershed, B. and Ternestedt, B-M. 2001 Development of a theoretical framework describing relatives' involvement in palliative care *Journal of Advanced Nursing* 34 (4) 554-562.
- Andrews, S.C. 2001 Caregiver burden and symptom distress in people with cancer receiving hospice care *Oncology Nursing Forum* 28 (9) 1469-1474.
- Angrosino, M.V. 2005 Recontextualizing observation in Denzin, N.K. and Lincoln, Y.S. (Eds) *The Sage Handbook of Qualitative Research (3rd Ed)* Thousand Oaks, Sage.
- Antonovsky, A. 1987 *Unraveling the mystery of health: how people manage stress and stay well* San Francisco Jossey-Bass cited by Andershed and Ternestedt.
- Aoun, S.M., Kristjanson, I.J., Currow, D.C. and Hudson, P.L. 2005 Caregiving for the terminally ill: at what cost? *Palliative Medicine* 19 551-555.
- Bakas, T., Lewis, R.R. and Parsons, J.E. 2001 Caregiving tasks among family caregivers of patients with lung cancer *Oncology Nursing Forum* 28 (5) 847-854.
- Barbow, R.S. 2001 Checklists for improving rigour in qualitative research: a case of the tail wagging the dog? *British Medical Journal* 322 1115-1117.
- BBC 2009 *Panorama: Britain's homecare scandal* Broadcast BBC1 9.4.09.
- Bee, P.E., Barnes, P. and Luker, K.A. 2009 A systematic review of informal caregivers' needs in providing home-based end care to people with cancer *Journal of Clinical Nursing* 18 (10) 1379-1393.
- Benton, D.C. 1984 Grounded theory in Cormack, D. (Ed) *The Research Process in Nursing (4th Ed.)* Oxford, Blackwell.
- Bolmsjo, I. and Hermeren, G. 2001 Interviews with patients, family and caregivers in amyotrophic lateral sclerosis: comparing needs *Journal of Palliative Care* 17 (4) 236-240.
- Bowling, A. 2001 *Research Methods in Health (2nd Ed.)* Maidenhead, Open University Press.
- Brazil, K., Howell, D., Bedard, M., Krueger, P. and Heidebrecht, C. 2005 Preference for place of care and place of death among informal caregivers of the terminally ill *Palliative Medicine* 19 (6) 492-499.
- Brobback, G. and Bertero, C. 2003 How next of kin experience palliative care of relatives at home *European Journal of Cancer Care* 12 339-346.
- Brown, M-A and Stetz, K. 1999 The labor of caregiving: a theoretical model of caregiving during potentially fatal illness *Qualitative Health Research* 9 (2) 182-197.

- Bruera, E., Neumann, C.M., Mazzocato, C., Stiefel, F. and Sala, R. 2000 Attitudes and beliefs of palliative care physicians regarding communication with terminally ill patients *Palliative Medicine* 14 (4) 287-298.
- Bryman, A. 2004 *Social Research Methods (2nd Ed.)* Oxford University Press.
- Cameron, J.I., Franche, R-L., Cheung, A.M. and Stewart, D.E. 2002 Lifestyle interference and emotional distress in family caregivers of advanced cancer patients *Cancer* 94 (2) 521-527.
- Carers UK www.carersuk.org.uk accessed 15.6.07 and 29.6.09
- Carolan, M. 2003 Reflexivity: a personal journey during data collection *Nurse Researcher* 10 (3) 7-14.
- Charmaz, K. 2005 Grounded theory in the 21st century in Denzin, N.K. and Lincoln, Y.S. (Eds) *The Sage Handbook of Qualitative Research (3rd Ed)* Thousand Oaks, Sage.
- Cherlin, E., Fried, T, Prigerson, H.G., Schulman-Green, D., Johnson-Hurzeler, R. and Bradley.E.H. 2005 Communication between physicians and family caregivers about care at the end of life: When do discussions occur and what is said? *Journal of Palliative Care* 8 (6) 1176-1185.
- Clayton, J.M., Butow, P.N., Arnold, R.A. and Tattersall, M.H.N. 2005 Discussing end-of-life issues with terminally ill cancer patients and their carers: a qualitative study *Supportive Care in Cancer* 13 (8) 589-599.
- Coffee, A. and Atkinson, P. 1996 *Making Sense of Qualitative Data* Thousand Oaks, Sage.
- Cohen, M.Z., Kahn, D.L. and Steeves, R.H. 2000 *Hermeneutic Phenomenological Research: a practical guide for nurse researchers* London, Sage.
- Collins 1994 *Collins English Dictionary (3rd Ed)* Glasgow, Harper Collins.
- Copp, G. 1999 *Facing impending death: experiences of patients and their nurses* London, Nursing Times Books.
- Dawson, S. and Kristjanson, L.J. 2003 Mapping the journey: family carers' perceptions of issues related to end-stage care of individuals with muscular dystrophy or motor neurone disease *Journal of Palliative Care* 19 (1) 36-42
- Dean, R.A. and McClement, S.E. 2002 Palliative care research: methodological and ethical challenges *International Journal of Palliative Nursing* 8 (8) 376-380.
- Dearnley, C. 2005 A reflection on the use of semi-structured interviews *Nurse Researcher* 13 (1) 19-28.

- Denzin, N. K. and Lincoln, Y.S. (Eds) 1994 *Handbook of Qualitative Research* Thousand Oaks, Sage.
- Department of Health 1999 *Caring for carers* London, DH.
- Department of Health 2005 *Carers and Disabled Children Act 2000 and Carers (equal opportunities) Act 2004 Combined Policy Guidance* London, DH.
- Department of Health 2007 *The National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care* London, DH (accessed via www.dh.gov.uk 28.9.08).
- Department of Health 2008 *Carers at the heart of 21st century families and communities* London, DH.
- Docherty, A., Owens, A., Asadi-Lari, M., Petchey, R., Williams, J. and Carter, Y.H. 2008 Knowledge and information needs of informal caregivers in palliative care: a qualitative systematic review *Palliative Medicine* 22 153-171.
- Donnelly, S.M., Michael, N. and Donnelly, C. 2006 Experience of the moment of death at home *Mortality* 11 (4) 352-367.
- Fielding, N.G. and Lee, R.M. 1998 *Computer Analysis and Qualitative Research* London, Sage.
- Gallagher, A., Horton, K. and Lister, S. 2009 Exploring the views of patients with cancer on what makes a good nurse – a pilot study *Nursing Times* 105 (23) 24-27.
- Gatrell, A.C., Harman, J.C., Francis, B.J., Thomas, C., Morris, S.M. and McIlmurray, M. 2003 Place of death: analysis of cancer deaths in part of north west England *Journal of Public Health Medicine* 25 (1) 53-58.
- Glaser, B.G. and Strauss, A.L. 1965 *Awareness of dying* London, Weidenfield and Nicolson.
- Glickman, M. 1997 *Making Palliative Care Better – quality improvement, multiprofessional audit and standards* London, NCHSPCS.
- Goffman, E. 1959 *Presentation of self in everyday life* New York, Anchor books.
- Gold Standards Framework www.goldstandardsframework.nhs.uk accessed 2007
- Goldstein, N.E., Concato, J., Fried, T.R., Kasl, S.V., Johnson-Hurzeler, R. and Bradley, E.H. 2004 Factors associated with caregiver burden among caregivers of terminally ill patients with cancer *Journal of Palliative Care* 20 (1) 38-43.
- Grande, G.E., Farquhar, M.C., Barclay, S.I.G. and Todd, C.J. 2004 Valued aspects of primary palliative care: content analysis of bereaved carers' descriptions *British Journal of General Practice* 54 772-778.

- Grande, G.E., Farquhar, M.C., Barclay, S.I.G. and Todd, C.J. 2006 The influence of patient and carer age in access to palliative care services *Age and Ageing* 35 (3) 267-273.
- Grande, G.E. and Ewing, G. 2009 Informal carer bereavement outcome; relation to quality of end of life support and achievement of preferred place of death *Palliative Medicine* 23 (3) 248-256.
- Gray, J.D. and Forster, D.P. 1997 Factors associated with utilisation of specialist palliative care services: a population based study *Journal of Public Health Medicine* 19 (4) 464-469.
- Grbich, C., Parker, D. and Maddocks, I 2001 The emotions and coping strategies of caregivers of family members with a terminal cancer *Journal of Palliative Care* 17 (1) 30-36.
- Grundy, E., Mayer, D., Young, H. and Sloggett, A. 2004 Living arrangements and place of death of older people with cancer in England and Wales: a record linkage study *British Journal of Cancer* 91 (5) 907-912.
- Grunfeld, E., Coyle, D., Whelan, T., Clinch, J., Reyno, L., Earle, C.C., Willan, A., Viola, R., Coristine, M., Janz, T. and Glossop, R. 2004 Family caregiver burden: results of a longitudinal study of breast cancer patients and their principal caregivers *Canadian Medical Association Journal* 170 (12) 1795-1801.
- Gysels, M., Shipman, C. and Higginson, I.J. 2008 "I will do it if it will help others:" Motivations among patients taking part in qualitative studies in palliative care *Journal of Pain and Symptom Management* 35 (4) 347-355.
- Harding, R. and Higginson, I. 2001 Working with ambivalence: informal caregivers of patients at the end of life *Supportive Care in Cancer* 9 (8) 642-645.
- Harding, R., Leam, c., Pearce, A., Taylor, E. and Higginson, I.J. 2002 A multi-professional short-term group intervention for informal caregivers of patients using a home palliative care service *Journal of Palliative Care* 18 (4) 275-281.
- Harding, R. and Higginson, I.J. 2003 What is the best way to help caregivers in cancer and palliative care? A systematic review of interventions and their effectiveness *Palliative Medicine* 17 63-74.
- Harding, R., Higginson, I.J. and Donaldson, N. 2003 The relationship between patient characteristics and carer psychological status in home palliative cancer care *Supportive Care in Cancer* 11 (10) 638-643.
- Harding, R. and Leam, C. 2005 Clinical notes for informal carers in palliative care: recommendations from a random patient file audit *Palliative Medicine* 19 639-642.

- Hare, A.P. 1985 *Social Interaction as Drama: applications from conflict resolution* Beverly Hills, Sage.
- Hare, A.P. and Blumberg, H.H. 1988 *Dramaturgical Analysis of Social Interaction* New York, Praeger.
- Hearn, F. 2004 Setting up a support group for carers in palliative care *European Journal of Palliative Care* 11 (5) 204-206.
- Hebert, R.S., Schulz, R., Copeland, V.C. and Arnold, R.M. 2009 Preparing family caregivers for death and bereavement. Insights from caregivers of terminally ill patients *Journal of Pain and Symptom Management* 37 (91) 3-12.
- Help the Hospices 2009 *Identifying carers' needs in the palliative setting* London, Help the Hospices.
- Henriksson, A. and Andershed, B. 2007 A support group programme for relatives during the late palliative phase *International Journal of Palliative Nursing* 13 (4) 175- 183.
- Henry, C. and Seymour, J. 2008 *Advance care planning for adults affected by a life limiting condition (2nd Ed)* www.endoflifecareforadults.nhs.uk accessed 22.6.09
- Heyman, B. (Ed.) 1995 *Researching User Perspectives on Community Health care* London, Chapman and Hall.
- Higginson, I.J., Jarman, B., Astin, P. and Dolan, S. 1999 Do social factors affect where patients die: an analysis of 10 years of cancer deaths in England *Journal of Public Health Medicine* 21 (1) 22-28.
- Higginson, I.J. and Sen-Gupta, G.J. 2000 Place of care in advanced cancer: a qualitative systematic literature review of patient preferences *Journal of Palliative Medicine* 3 (3) 287-300.
- Hinton, J. 1999 The progress of awareness and acceptance of dying assessed in cancer patients and their caring relatives *Palliative Medicine* 13 19-35.
- Holland, J. 2007 Emotions and research *International Journal of Social Research Methodology* 10 (3) 195-209.
- Hudson, P. 2003 Home-based support for palliative care families: challenges and recommendations *Medical Journal of Australia* 179 (6) S35-S37.
- Hudson, P. 2003 The experience of research participation for family caregivers of palliative care cancer patients *International Journal of Palliative Nursing* 9 (3) 120-123.
- Hudson, P. 2004 Positive aspects and challenges associated with caring for a dying relative at home *International Journal of Palliative Nursing* 10 (20) 58-65.

- Hudson, P., Aranda, S., Kristjanson, L and Quinn, K. 2005 Minimising gate-keeping in palliative care research *European Journal of Palliative Care* 12 (4) 165-169.
- Hudson, P. and Payne, S. (Eds) 2009 *Family Carers in Palliative Care* Oxford, Oxford University Press.
- Ingleton, C., Payne, S., Nolan, M. and Carey, I. 2003 Respite in palliative care: a review and discussion of the literature *Palliative Medicine* 17 (7) 567-575.
- James, N., Daniels, H., Rahman, McConkey ,R., Derry, J. and, C. Young, A. 2007 A study of information seeking by patients and their carers *Clinical Oncology* 19 (5) 356-362.
- Jenkinson, A. 2004 *Past caring: the beginning not the end (2nd Ed)* Clifton-under-Teme, Polperro Heritage Press.
- Johnson, M., Buchanan, I., Long, T., Peacock, L. and Williamson, T. 2004 *Research Ethics* London, Royal College of Nursing.
- Kalish, R.A. 1977 Dying and preparing for death: a view of families in Feifel, H. (Ed) 1977 *New Meanings of Death* New York, McGraw-Hill.
- Kellehear, A 1990 *Dying of cancer: the final year of life* London, Harwood Academic.
- Kellehear, A. 1998 Ethical issues for the qualitative researcher: some critical reflections *Annual Review of Health Social Sciences* 8 14-17.
- Kellehear, A. 1999 *Health promoting palliative care* Melbourne, Oxford University Press.
- Kellehear, A. 2009 Understanding the social and cultural dimensions of family caregiving in Hudson, P. and Payne, S. (Eds) 2009 *Family Carers in Palliative Care* Oxford, Oxford University Press.
- Kessler,D., Peters, T.J., Lee, L. and Parr, S. 2005 Social class and access to specialist palliative care services *Palliative Medicine*19 (2) 105-110.
- King, N., Bell, D. and Thomas, K. 2004 Family carers' experience of out-of-hours community palliative care: a qualitative study *International Journal of Palliative Nursing* 10 (2) 76-83.
- Kirk, P., Kirk, I., and Kristjanson, L.J. 2004 What do patients receiving palliative care for cancer and their families want to be told? A Canadian and Australian qualitative study *British Medical Journal* 328 (7452) 1343-1347.
- Koffman, J. and Higginson, I.J. 2001 Accounts of carers' satisfaction with health care at the end of life; a comparison of first generation black Caribbeans and white patients with advanced disease *Palliative Medicine* 15 337-345.

- Kristjanson, L.J., Cousins, K., White, K., Andrews, L., Lewin, G., Tinnelly, C., Asphar, D. and Greene, R. 2004 Evaluation of a night respite community palliative care service *International Journal of Palliative Nursing* 10 (2) 84-90.
- Kwak, J., Salmon, J.R., Acquaviva, K.D., Brandt, K. and Egan, K.A. 2007 Benefits of training family caregivers on the experience of closure during end-of-life care *Journal of Pain and Symptom Management* 33 (4) 434-445.
- Lawton, J. 2000 *The dying process: patients experiences of palliative care* London, Routledge.
- Lecouturier, J., Jacoby, A., Bradshaw, C., Lovel, T. and Eccles, M. 1999 Lay carers' satisfaction with community palliative care: results of a postal survey *Palliative Medicine* 13 275-283.
- Lee, R.M. 1993 *Doing Research on Sensitive Topics* London, Sage.
- Lee, S. and Kristjanson, L. 2003 Human research ethics committees: issues in palliative care research *International Journal of Palliative Nursing* 9 (1) 13-18.
- Lincoln, Y.S. and Denzin, K. 1994 The fifth moment in Denzin, N. K. and Lincoln, Y.S. (Eds) *Handbook of Qualitative Research* Thousand Oaks, Sage.
- Liverpool care pathway www.mcpcil.org.uk/liverpool_care_pathway accessed 27.6.07
- Lowey, S.E 2008 Letting go before a death; a concept analysis *Journal of Advanced Nursing* 63 (2) 208-215.
- Maher, J. and Green, H. 2002 *Carers 2000* London, The Stationary Office.
- Marcus, G.E. 1994 What comes (just) after "post"? in Denzin, N. K. and Lincoln, Y.S. (Eds) 1994 *Handbook of Qualitative Research* Thousand Oaks, Sage.
- Marriot, H. 2003 *The Selfish Pig's Guide to Caring* London, Time Warner
- Mason, J. 1996 *Qualitative Researching* London, Sage.
- Mathers, N., Howe, A. and Hunn, A. 2002 *Ethical Considerations in Research* Sheffield, Trent Focus Group.
- McKinlay, E.M. 2001 Within the circle of care: patient experiences of receiving palliative care *Journal of Palliative Care* 17 (1) 22-29.
- McLoughlin, P.A. 2002 Community specialist palliative care: experiences of patients and carers *International Journal of Palliative Nursing* 8 (7) 344-353.
- McPherson, C., Wilson, K.G. and Murray, M.A. 2007 Feeling like a burden to others: a systematic review focusing on the end of life *Palliative Medicine* 21 (2) 115-128.
- Milberg, A., Strang, P. and Jakobsson, M. 2004 Next of kin's experience of powerlessness and helplessness in palliative home care *Supportive Care in Cancer* 12 (2) 120-128.

- Milberg, A. and Strang, P. 2004 Exploring comprehensibility and manageability in palliative home care: an interview study of dying cancer patients' informal carers *Psycho-Oncology* 13 (9) 605-618.
- Milberg, A., Rydstrand, K., Helander, L. and Friedrichsen, M. 2005 Participants' experiences of a support group intervention for family members during ongoing palliative home care *Journal of Palliative Care* 21 (4) 277-284.
- Miles, M.B. and Huberman, A.M. 1994 *Qualitative Data Analysis* Thousand Oaks, Sage.
- Mithran, S. 2008 Sector losing patience over long delay to registration *Community Care* 1737 7.
- Mok, E., Chan, F., Chan, V. and Yeung, E. 2002 Perception of empowerment by family caregivers of patients with a terminal illness in Hong Kong *International Journal of Palliative Nursing* 8 (3) 137-145.
- Morris, S.M. and Thomas, C. (2002) The need to know: informal carers and information *European Journal of Cancer Care* 11 183-187.
- Morse, J.M. 1994 Designing funded qualitative research in Denzin, N.K. and Lincoln, Y.S. (Eds.) 1994 *Handbook of Qualitative Research* Thousand Oaks, Sage.
- Morse, J. 2006 Biased reflections: principles of sampling and analysis in qualitative inquiry in Popay, J. (Ed) 2006 *Moving Beyond Effectiveness in Evidence Synthesis* London, National Institute for Health and Clinical Effectiveness.
- Munroe, B. and Oliviere, D. 2009 Communicating with family carers in Hudson, P. and Payne, S. (Eds) 2009 *Family Carers in Palliative Care* Oxford, Oxford University Press.
- Munroe, S. 2008 60 years of care *Inside Palliative Care* 6 18-19.
- Murray, S.A., Boyd, K., Kendall, M., Worth, A., Benton, T.F. and Clausen, H. 2002 Dying of lung cancer or cardiac failure: prospective qualitative interview study of patients and their carers in the community *British Medical Journal* 325 929-943.
- National Council for Hospice and Specialist Palliative Care Services 1995 *Specialist Palliative Care: A Statement of Definitions* London, NCHSPCS.
- National Council for Palliative Care 2008 *National survey of patient activity data for specialist palliative care services MDS full report for the year 2007-2008* London, NCPC.
- National Council for Palliative Care 2009 *Palliative Care Explained* www.NCPC.org.uk accessed 21.6.09

- National Institute for Clinical Excellence 2004 *Improving supportive and palliative care for adults with cancer* London, NICE.
- Nolan, M. 2001 Positive aspects of caring in Payne, S and Ellis-Hill, C. 2001 *Chronic and terminal illness: new perspectives on caring and carers* Oxford, Oxford University Press.
- Nolan, M. and Hudson, R. 2009 Family and palliative care in care homes for older people in Hudson, P. and Payne, S. (Eds) 2009 *Family Carers in Palliative Care* Oxford, Oxford University Press.
- Office of National Statistics www.statistics.gov.uk accessed 29.5.09
- Oldham, L. and Kristjanson, L.J. 2004 Development of a pain management programme for family carers of advanced cancer patients *International Journal of Palliative Nursing* 10 (2) 91-99.
- Parkes, C.M. 1993 Bereavement as a psychosocial transition: processes of adaptation to change in Stroebe, M.S., Stroebe, W. and Hansson, R.O. (Eds) 1993 *Handbook of Bereavement: theory, research and intervention* Cambridge, Cambridge University Press.
- Patton, M.Q. 2002 *Qualitative Research and Evaluation Methods (3rd Ed.)* Thousand Oaks, Sage.
- Payne, S., Smith, P and Dean, S. 1999 Identifying the concerns of informal carers in palliative care *Palliative Medicine* 13 37-44.
- Payne, S. 2002 Information needs of patients and families *European Journal of Palliative Care* 9 (3) 112-114.
- Payne, S. and Hudson, P. 2009 EAPC task force on family carers: aims and objectives *European Journal of Palliative Care* 16 (2) 77-81.
- Penrod, J. 2007) Living with uncertainty: concept advancement *Journal of Advanced Nursing* 57 (6) 658-667.
- Pereira, J., Bruera, E., Macmillan, K. and Kavanagh, S. 2000 Palliative cancer patients and their families on the internet: motivation and impact *Journal of Palliative Care* 16 (4) 13-19.
- Perreault, A., Fothergill-Bourbonnais, F. and Fiset, V. 2004 The experience of family members caring for a dying loved one *International Journal of Palliative Nursing* 10 (3) 133-143.

- Proot, I.M., Abu-Saad, H.H., ter Meulen, R.H.J., Goldsteen, M., Spreeuwenberg, C. and Widdershoven, G.A.M. 2004 The needs of terminally ill patients at home: directing one's life, health and things related to beloved others *Palliative Medicine* 18 (1) 53-61.
- Rabow, M.W., Hauser, J.M. and Adams, J. 2004 Supporting family caregivers at the end of life *Journal of the American Medical Association* 291 (4) 483-491.
- Ramirez, A., Addington-Hall, J. and Richards, M. 1998 ABC of palliative care: the carers *British Medical Journal* 316 208-211.
- Reimer, J.C., Davies, B. and Martens, N. 1991 The nurse's role in helping families through the transition of 'fading away' *Cancer Nursing* 14 321-327.
- Rhodes, P. and Shaw, S. 1999 Informal care and terminal illness *Health and Social Care in the Community* 7 (1) 39-50.
- Richardson, L. 1994 Writing: a method of inquiry in Denzin, N.K. and Lincoln, Y.S. (Eds.) 1994 *Handbook of Qualitative Research* Thousand Oaks, Sage.
- Romanoff, B.D. 2001 Research as therapy: the power of narrative to effect change in Neimeyer, R.A. (Ed.) 2001 *Meaning, Reconstruction and the Experience of Loss* Washington, American Psychological Association.
- Royal College of Nursing 2005 *Informed consent in health and social care research* London, RCN.
- Salmon, J.R., Kwak, J., Acquaviva, K.D., Brandt, K. and Egan, K.A. 2005 Transformative aspects of caregiving at life's end *Journal of Pain and Symptom Management* 29 (2) 121-129.
- Sandman, L. 2005 *A Good Death: on the value of death and dying* Maidenhead, Open University Press.
- Schwandt, T.A. 2003 Three epistemological stances for qualitative inquiry in Denzin, N.K. and Lincoln, Y.S. (Eds) 2003 *The Landscape of Qualitative Research (2nd Ed)* Thousand Oaks, Sage.
- Scott, G., Whyler, N. and Grant, G. 2001 A study of family carers of people with a life-threatening illness 1: the carers' needs analysis *International Journal of Palliative Nursing* 7 (6) 290-297.
- Scott, G. 2001 A study of family carers of people with life-threatening illness 2: implications of the needs assessment *International Journal of Palliative Nursing* 7 (7) 323-330.

- Seamark, D.A., Gilbert, J., Lawrence, C.J. and Williams, S. 2000 Are post-bereavement research interviews distressing to carers? Lessons learned from palliative care research *Palliative Medicine* 14 55-56.
- Seymour, J.E. and Ingleton, C. 2005 Ethical issues in qualitative research at the end of life *International Journal of Palliative Nursing* 11 (3) 138-146.
- Sheldon, F. 1997 *Psychosocial Palliative Care* Cheltenham, Stanley Thornes.
- Sherwood, P.R., Given, B.A., Doorenbos, A.Z. and Given, C.W. 2004 Forgotten voices: lessons from bereaved caregivers of persons with a brain tumour *International Journal of Palliative Nursing* 10 (2) 67-75.
- Smith, P.C. 2000 *Family caregivers in Palliative Care: perception of their role and sources of support* unpublished PhD thesis University of Southampton.
- Soothill, K., Morris, S.M., Harman, J.C., Francis, B., Thomas, C. and McIlmurray, M.B. 2001 Informal carers of cancer patients: what are their unmet psychosocial needs? *Health and Social Care in the Community* 9 (6) 464-475.
- Somerville, J. 2001 Palliative care: the experience of informal carers within the Bangladeshi community *International Journal of Palliative Nursing* 7 (5) 240-247.
- Stajduhar, K.I. and Davies, B. 1998 (i) Death at home: challenges for families and directions for the future *Journal of Palliative Care* 14 (3) 8-14.
- Stajduhar, K.I. and Davies, B. 1998 (ii) Palliative care at home: reflections on HIV/AIDS family caregiving experiences *Journal of Palliative Care* 14 (2) 14-22.
- Stajduhar, K.I. 2003 Examining the perspectives of family members involved in the delivery of palliative care at home *Journal of Palliative Care* 19 (1) 27-35.
- Stajduhar, K. and Cohen, R. 2009 Family caregiving in the home in Hudson, P. and Payne, S. (Eds) 2009 *Family Carers in Palliative Care* Oxford, Oxford University Press.
- Stalker, K. 2003 *Reconceptualising Work with 'Carers'* London, Jessica Kingsley Publishers.
- Steeves, R.H. 2000 Sampling in Cohen, M.Z., Kahn, D.L. and Steeves, R.H. 2000 *Hermeneutic Phenomenological Research: a practical guide for nurse researchers* Thousand Oaks, Sage.
- Steinhauser, K.E., Clipp, E.C., McNeilly, M., Christakis, N.A., McIntyre, L.M. and Tulsky, J.A. 2000 In search of a good death: observations of patients, families and providers *Annals of Internal Medicine* 132 (10) 825-832.
- Steinhauser, K.E., Christakis, N.A., Clipp, E.C., McNeilly, M., Grambow, S., Parker, J and Tulsky, J.A. 2001 Preparing for the end of life: preferences of patients, families,

- physicians and other care providers *Journal of Pain and Symptom Management* 22 (3) 727-737.
- Strang, V.R. and Koop, P.M. 2003 Factors which influence coping: home-based family caregiving of persons with advanced cancer *Journal of Palliative Care* 19 (2) 107-114.
- Strauss, A. and Corbin, J. 1998 *Basics of Qualitative Research: techniques and procedures for developing grounded theory (2nd Ed.)* Thousand Oaks, Sage.
- Takesaka, J., Crowley, R. and Casarett, D. 2004 What is the risk of distress in palliative care survey research? *Journal of Pain and Symptom Management* 28 (6) 593-598.
- Taylor, E. 2007 Supporting families of dying patients *End of Life Care* 1 (3) 8-15.
- Tremble, B. (Ed.) 2001 *Wordpower Dictionary* London, Reader's Digest.
- Twigg, J. 1992 *Carers: research and practice* London, HMSO.
- Twigg, J. and Atkin, K. 1994 *Carers Perceived: policy and practice in informal care* Buckingham, Open University Press.
- United Kingdom Homecare Association 2009 *Important news on Independent Safeguarding Authority implementation* (accessed via www.ukhca.co.uk, 31.3.09)
- Vachon, M.L.S. 1998 Psychosocial needs of patients and families *Journal of Palliative Care* 14 (3) 49-56.
- Vafads P. 2001 *Mutual Care in Palliative Medicine* Sydney, McGraw Hill.
- Valentine, C. 2007 Methodological reflections: attending and tending to the role of the researcher in the construction of bereavement narratives *Qualitative Social Work* 6 (2) 159-176.
- Walker, W.M. 2008 End-of-life care in the home: a relative's critical reflection *End of Life Care* 2 (1) 54-59.
- Walter, T. 1994 *The Revival of Death* London, Routledge.
- Webb, C. and Kevern, J. 2001 Focus groups as a research method: a critique of some aspects of their use in nursing research *Journal of Advanced Nursing* 33 (6) 798-805.
- Weitzman, E.A. 2000 Software and qualitative research in Denzin, N.K. and Lincoln, Y.S. (Eds) 2000 *Handbook of Qualitative Research* London, Sage.
- Wienrich, S. and Speyer, J. (Eds) 2003 *The Natural Death Handbook (4th Ed)* London, The Natural Death Centre.
- Williamson, G.P. 2005 Illustrating triangulation in mixed-methods nursing research *Nurse Researcher* 12 (4) 7-18.

- Willig, C. 2001 *Qualitative Research in Psychology: a practical guide to theory and method* Buckingham, Open University Press.
- Wilson, V. 1999 Palliative care: meeting the needs of dying patients and their carers *Journal of Community Nursing* 13 (9) 1-8.
- Witkowski, A. and Carlsson, M.E. 2004 Support group programme for relatives of terminally ill cancer patients *Supportive Care in Cancer* 12 (3) 168-175.
- Wong, R.K.S., Franssen, E., Szumacher, E., Connolly, R., Evans, M., Page, B., Chow, E., Hayter, C., Harth, T., Andersson, L., Pope, J. and Danjoux, C. 2002 What do patients living with advanced cancer and their carers want to know? – a needs assessment *Supportive Care in Cancer* 10 (5) 408-415.
- Woodthorpe, K. 2009 Reflecting on death: the emotionality of the research encounter *Mortality* 14 (1) 70-86.
- World Health Organisation 1990 Cancer pain relief and palliative care *Report of a WHO Expert Meeting WHO Technical Report Series 804* Geneva, WHO.
- Worth, A., Boyd, K., Kendall, M., Heaney, D., Macleod, U., Cormie, P., Hockley, J. and Murray, S. 2006 Out-of-hours palliative care: a qualitative study of cancer patients, carers and professionals *British Journal of General Practice* 56 6-13.
- www.caretotakealook.com accessed 29.5.09
- www.endoflifecareforadults.nhs.uk accessed 22.6.09
- Wyatt, G.K., Friedman, L., Given, C.W. and Given, B. 1999 A profile of bereaved caregivers following provision of palliative care *Journal of Palliative Care* 15 (1) 13-25.
- Yates, P. and Stetz, K.M. 1999 Families' awareness of and responses to dying *Oncology Nursing Forum* 26 (1) 113-120.

Appendices

Appendix 1

Interview guide - Current carers

Carer information

Name:

Age:

Male/female:

Ethnicity:

Relationship to patient:

Work situation:

Patient information

Name:

Age:

Male/female:

Ethnicity:

Diagnosis:

What is it like for you in’s last stages?

- What is it like being his/her carer?
- Is it how you expected it to be?
- How do you expect it to be in the final stages?
- How did you feel about what you have to do?
- How are you coping?

What kinds of things or people do you find helpful at this time?

- By things I mean websites, leaflets, media, church, equipment
- By people I mean friends, family, health professionals, services etc

- What is it about ... that is helpful?
- Is anything unhelpful? In what way?
- Can you think of anything that would be more helpful?

What would you like to tell someone just becoming a carer of someone like?

Appendix 2

Interview guide – Bereaved carers

Carer id:

What was it like for you in’s last few days?

- What was it like being his/her carer?
- Was it how you expected it to be?
- How did you feel about what you had to do?
- How did you cope?

What kinds of things or people did you find helpful at this time?

- By things I mean websites, leaflets, media, church, equipment
- By people I mean friends, family, health professionals, services etc

- What was it about ... that was helpful?
- Was anything unhelpful? In what way?
- Can you think of anything that would have been more helpful?

What would you like to tell someone just becoming a carer of someone like?

Appendix 3 Inclusion and exclusion criteria

Inclusion criteria:

Main carer for a terminally ill person with an expected prognosis of 4 weeks or less
Age over 18 years
Able to understand the information about and informed consent process of the project
Able to communicate verbally
Able to communicate in English

Exclusion criteria:

Carer of any patient for whom the researcher has or is likely to have professional involvement.

Appendix 4 Example of coded transcript of current carer's interview

Current carer interview

Carer: Jane (M11)

Age: 55

Female

White

Daughter of patient

Works as PA to recruitment agency, working from home

Patient: IR

Age: 87

Male

White

Diagnosis: Prostate cancer

Interview 15.8.08 at their home.

Duration of interview 30 minutes.

1 JN OK, that's recording now and I think that will be alright with um the background, bit of
2 background noise because it is quite close to us. I hope so anyway. And I'm going to ask
3 you a few questions really about being a carer for Dad in these last stages of his life.
4
5 M11 Mmm
6
7 JN So you just say how it is. There are no right or wrong answers. And if you feel we're
8 going into painful areas that you don't want to go to you just tell me and we, we stop.
9
10 M11 Yes
11
12 JN Is that OK? And maybe just in your own words you could just say a little bit about what
13 it's like being a carer, what sort of things you need to do and that sort of thing.
14
15 M11 OK, um, I feel honoured that I'm in a position to look after my Dad because he's
16 looked after me all my life. And so I wouldn't have had it any other way and I'm sure that
17 if my sister had been in the same position she would have done the same. That I'm able to
18 live with him, do my work from home and I wouldn't have it any other way. And er I just
19 feel I'm giving things back to him what he's done for me all my life. Um and it's, it's no
20 bother at all to me. It just comes naturally 'cause that's what I want to do.
21
22 JN Excellent. Is it anything like you expected it to be?
23
24 M11 Um
25
26 JN Particularly looking after someone who's dying.
27
28 M11 Well I think 'cause I've been living with him for a year I just gradually took over.
29 I've let him have his independence as far as he can. You know he used to make his own
30 breakfast and I just let him carry on. So really it was just a gradual take over and I was
31 doing more things and I just accepted everything that came my way and I just did
32 everything that happened and was told to do. Everything that happened I had to do and I
33 just did it and um, um I just monitored him and just took everyday and you know learnt
34 more as it went along which was good. It's a learning process as well.
35
36 JN And do you have any expectations about how these last stages are going to be?
37
38 M11 Um, no. Um, I'm, I don't want to let him go and I'm, because I'm frightened. Um,
39 although he's 87 he's had a fantastic life. On the other hand I don't want to be selfish about
40 it, not letting him go 'cause he is quite ill now obviously and he's going to slip away. I
41 hope he just slips away. Um and I don't really know what I'm looking for. I don't know
42 what's going to happen. I don't know, I'm sort of asking people when they come like Pam
43 (Community Palliative Care Nurse) and people you what comes next 'cause I'm working
44 blindly. You know I'm not, so I don't know what I'm going to.
45
46 JN You said you're a bit frightened. Do you want to say a little bit more about that?
47
48 M11 Just um being here without my dad. My Mum died five years ago that was a shock
49 but she died suddenly, so it was a shock but it was just like that. With Dad it's been a
50 process, a gradual process and it's been frightening along the way but I haven't been
51 scared of looking after him and being there for him or finding him in bed one morning not

Comment [J1]: Reciprocity
Honoured, he's looked after me, giving back

Comment [J2]: Caring
No bother, comes naturally, what I want to do

Comment [J3]: Caring
Gradual take over, doing more things, monitoring, learning process

Comment [J4]: Expectations?
No

Comment [J5]: Feelings
Don't want to let him go, frightened, don't want to be selfish, not letting him go

Comment [J6]: Dying
Hope he just slips away

Comment [J7]: Uncertainty
Don't know what I'm looking for, what's going to happen, what comes next, I'm working blindly, what I'm going to

Comment [J8]: Afterwards
Without dad, who am I going to turn to?

1 there or whatever but it's just I am frightened of him, who am I going to look to without
2 him? Who am I going to take advice from?

Comment [J9]: Feelings
Not scared of caring or finding him gone

3
4 JN Life without him

Comment [J10]: Feelings
Frightened of who will I turn to without him

5
6 M11 Yeah

7
8 JN That seems worse than the caring.

9
10 M11 That is frightening me to death. Looking after him just comes natural. It's just like a
11 baby really. It's just er I don't wash him. I mean I do the top half but the carers, the nurses
12 come in 'cause I don't want him to lose his dignity. Although he said to me I don't care
13 anymore I still wouldn't go there. I would if I had to. If there wasn't anybody I would and I
14 would just do it because he's my Dad.

Comment [J11]: Caring
Comes natural, like a baby, I do top half, would do bottom half if no-one else

15
16 JN And how do you feel about doing things like personal care for him?

Comment [J12R11]: Paid carers
Come in 'cause don't want him to lose dignity

17
18 M11 That doesn't bother me. I haven't ventured down that area yet but if I had to I would
19 but if somebody else can do it you know without him worrying about me seeing he doesn't
20 anyway. I don't really want to go there but if I had to I would and I would do it quite
21 happily and easily but I just want to keep his dignity as long as we can.

22
23 JN And you're wondering how it's going to be. Do you feel adequately prepared?

24
25 M11 Sometimes I'm stronger than other days and then when he's slipping then I get
26 frightened and I have to readjust myself and I've got lots of support from my sister and her
27 husband and my other half and my kids. But it's still you know, it's just wondering so um.

Comment [J13]: Coping
Sometimes stronger than others, get frightened when he's slipping, readjust myself

28
29 JN And how do you, how do you cope day to day with the situation?

Comment [J14]: Help
Family support

30
31 M11 Um, I take, I just, I just confront things that are there. I try not to think, it's when I'm
32 sitting and he's out of it. Um, how do I cope day today? Um I just take it as it comes and
33 then I'm as I say when I'm sitting it sometimes hits me and I just cry. But or of I'm talking
34 to him and he says some nice things or he's worried about me and then I, you know, I just
35 break up.

Comment [J15]: Uncertainty
Wondering

36
37 JN So it's, it's all the emotional side that is more difficult than the physical.

Comment [J16]: Coping/not coping
Confront things, take it as it comes, sometimes hits me and I cry, he says things and I break up

38
39 M11 Yeah

40
41 JN The actual physical care

42
43 M11 Is easy

44
45 JN Isn't it not an issue. It's more the emotional side of it that's really hard.

46
47 M11 Yeah. That is hard, that's hard. 'Cause I mean I did the er course at er the hospice on,
48 which was brilliant, but it was me that was most cry baby. Every time I see one of them I
49 was crying. And that's how I am. I really, I'm just an emotional person.

Comment [J17]: Caring
Emotional harder than physical

50
51 JN And did you find that helpful going on the course?
52

1 M11 Brilliant, absolutely amazing. 'Cause I learnt a lot about the tablets. How to lift him if
2 I needed to, not that we lift him. How to, like I came home one night and he was on the
3 floor. Luckily he was in the recovery position so I said well done Dad and we had a little
4 laugh. Um then J (*partner*) came over and we, we did exactly what they told us to do and it
5 was brilliant. But since then because he can't do anything we're having to lift him
6 physically more you know around the chest sort of thing not really J. But er that was
7 amazing and it was good to hear other people, talk to other people. Um and I felt that I was
8 being, I was um the best off out all of them because they had their parents with bowel
9 cancer which is awful. I mean I know he's got prostate cancer which is awful but I felt they
10 were having to struggle with much more than me. So I felt privileged that I was the least
11 one you know, you know. So and one of the girls it was her mother that died and she's died
12 and um that was, that must have been horrendous for her. But at least she was with her and
13 she was looking after her like I am with my dad. And if I'd realised how my Mum was
14 'cause I was living away I would have done the same for my mum because I, she needed
15 somebody really you know 'cause she didn't understand really what was happening. And
16 when she knew dad had prostate cancer I think she died on purpose. Do you know what I
17 mean? She wasn't going to go on her own. If I'd been up here and realised what they were
18 actually going through without saying I would have moved in a long time ago. I just you
19 know they've given me such a lot.

Comment [J18]: Help
Course at hospice, brilliant, learnt about tablets and lifting – put into practice, brilliant

Comment [J19]: Shared experience
Good to talk to other people

Comment [J20]: Narrative
Comparison of mother's death with other's experience on the course

20
21 JN It's much easier with hindsight.

22
23 M11 Yeah. Oh yeah. Oh yeah.

24
25 JN But this time you're here and you're seeing it through.

26
27 M11 Mmm

28
29 JN And you mentioned um the nurses and some help, what sort of help do you get with his
30 physical care?

31
32 M11 Um Just they've just started to come, the nurses to wash to him three times a week
33 but like today they came and he's just too out of it really I didn't.

Comment [J21]: Paid carers
To wash him 3 times a week

34
35 JN When you say nurses are they

36
37 M11 They're auxiliaries

38
39 JN Are they auxiliaries from the district nurses or are they agency nurses?

40
41 M11 No, at the moment district, they're auxiliaries from the district nurses. Yeah, yeah.
42 We had an auxiliary in, I think it was from you from the hospice, the other evening um
43 we'd had two quite traumatic nights so Pam (*CPCN*) said look I'll get somebody in but she
44 sat here all night and we you know which I thought, I thought give it somebody that really,
45 really, really needs that help because there's two of us. Er we get up and do what we need
46 to and this nurse couldn't do anything that we can't do. You know she couldn't change the
47 catheter so we just all. You know, so I thought you know we, I mean it's great that we've
48 been offered her and we might need it in the future but at the moment um we are coping
49 fine. So we, we've had her once which was brilliant and then I've just got the um the other
50 ladies coming in three times a week just to wash him for me.

Comment [J22]: Paid carers
Auxiliaries from district nurses

Comment [J23]: Paid carers
Night auxiliary from hospice, couldn't do anything we can't do, couldn't change catheter, might need in future but not now

51
52 JN And that's helpful?

Comment [J24R23]: Coping
We are coping fine

1
2 M11 Yup, yup.
3
4 JN Thinking about looking after him, what do you find most helpful for you as a carer?
5 What helps you most?
6
7 M11 I tell you what helps me most when my sister comes up and prepares lunch and last
8 week she came up and she brought some food up and she cooked it at home and she
9 brought it up. That was wonderful because I'm just slacking and not even thinking about
10 getting anything for me or make yourself a sandwich or you know or some cereal or
11 something. And so she's been up and she's been amazing and I really am grateful to her
12 coming up with pre-cooked food and she's put it on and that is, that is helpful having
13 somebody give you a meal because if you've had some late nights, you know a couple
14 times in the night and you're not used to it and the stress as well you just want to be quiet
15 and you even want to do anything. You know that is a big effort, that is a bigger effort
16 looking after yourself than it is to look after my dad.
17
18 JN Yes. And yet so important but you haven't got the energy or the will
19
20 M11 Or the will. And you just, you know, I'm not important. I'm fit and well. My dad, I'm
21 fit and well so I can wait, I can wait until I'm on my own and then sort myself out but this
22 is more important, to be with my dad at the moment.
23
24 JN You mentioned your partner and children. Are they living here with you or are they in
25 your own home?
26
27 M11 Um J is with me. We got a place in T so he's been doing that up but he is here every
28 night and he's usually here in the morning, you know, mornings just to check that
29 everything's alright and then he has to whizz across to T and then he'll come back and then
30 my sister and R, her husband, have been up nearly every day since the last fortnight. Um
31 my kids come in and see us um and L my eldest did actually help with lasagne last week
32 just prepared and whatever but if they, if I ask them to do something you they say you
33 can't get out come for a coffee down town but I just don't want to leave him. Don't want to
34 miss anything just in case something happens when I'm not here.
35
36 JN And how does that make you feel?
37
38 M11 If I miss, if I wasn't here when he died I, that would be worse for me because I just
39 want to be there for him.
40
41 JN And this is where you want him to be.
42
43 M11 Yeah
44
45 JN And where he wants to be.
46
47 M11 Absolutely. We talked it through. Er don't want. It's easier such a stress to go down
48 to BH (*local hospital*) everyday sit in a, in a room or a, a hospital ward on hard chairs or
49 whatever, just sat watching and you know trying to make a conversation. It's so much
50 more natural if he's here. His own bed, his sitting room, all his family coming in and out
51 whenever we want, the babies although it might, it might drive him mad but we can come
52 in. It's no stress on the family and no stress for him although you know 'cause he's in the

Comment [J25]: Help
Sister bringing and preparing food

Comment [J26R25]: Consequences of caring
Not getting food for myself, looking after self bigger effort than looking after Dad

Comment [J27]: Altruism
I'm fit and well, I can wait, being with Dad more important

Comment [J28]: Help
Family support

Comment [J29]: Caring
Don't want to leave him, in case something happens when I'm not here

Comment [J30]: Being there

Comment [J31]: Caring in final stages
Not being here when he died would be worse, want to be there for him

1 hospital they're left for hours on their own not, you know, only because of the system. And
2 I just feel that these last, he's a prisoner of war man you know, he's, we're here because of
3 a person like him and he needs the best and I am trying to give it to him.

Comment [J32]: Place of care/death
Talked about it - Home less stressful and more natural than hospital

4
5 JN Absolutely. And have you been able to talk to him about where he wants to die and his
6 wishes er afterwards and that sort of thing?

Comment [J33]: Reciprocity
Trying to give him the best

7
8 M11 We have sort of during the course and when I first moved in. We've always talked a
9 lot you know. Actually he's always wanted to go to Holland, is it? He wanted to go the um
10 what's it called? I always want to say um just to have an injection and die.

Comment [J34]: Euthanasia
He always wanted to go to Holland

11 JN He wanted euthanasia.

12
13
14 M11 Always, always from as long as I can remember and I think although I said to him,
15 talked to him yesterday about um I said to him until a couple of days ago are you? He was
16 in a lot of discomfort. I said are you frightened, Dad? He said frightened, what am I
17 frightened of? And I thought oh he doesn't know where he is at the moment. He doesn't
18 know that he is dying because he's in another stage. I don't know, that's what I felt and
19 then I was here yesterday and I was um he was really out of it yesterday but he came to and
20 I talked to him and I said about um it would be great when you go and see Mum and they
21 also had a daughter who would be sixty five but died of meningitis at five and a half
22 months and he visits her grave up in S two times a year minimum and we went up a few
23 weeks ago and that was the last thing he did the grave up. I said it would be really lovely
24 'cause Mum'll be there and the baby .Oh that'll be fantastic. And I said, he's been seeing
25 another woman, well not really, I mean. She, she has been my stress, my biggest, she's
26 trying to interfere, trying to overrule me and um she has been my biggest, biggest stress in
27 this whole situation. And um I said to him yesterday, I said well you better take some
28 flowers with you dad 'cause Mum's going to give you a right going over. So we had a
29 laugh. I said I shall buy some flowers for you and give you to give to my Mum. I said
30 'cause you are going to be in big trouble and so we laughed yesterday afternoon. Um so
31 but I don't, I don't think. I don't know, I don't feel that he, he's, he knows that that's
32 where he's going. No, not that he knows he's going but that I don't think he knows

Comment [J35]: Dying
Not frightened. Not aware of dying

Comment [J36]: Beliefs
Talked about being with Mum and baby after he dies - that'll be fantastic

Comment [J37]: Hindrance
Dad's other woman interfering

Comment [J38]: Humour
Had a laugh about facing Mum after death

33
34 JN That it's imminent

35
36 M11 Yeah. Or that he's able to think at the moment what's going on. Oh my god what's
37 going on? I've got prostate cancer. Don't think, I don't think he knows that. I think he's
38 gone past that

Comment [J39]: Dying
He's not able to think about it now

39
40 JN And is that easier to deal with do you think or would you prefer to be able to?

41
42 M11 I think it's easier for me. 'Cause I, last week he knew he was because he was worried
43 about me. How I was going to cope without him and was I going to have enough money
44 and all those sort of things. So last week he knew but I think Dad's had so much trauma
45 since then that I don't think that he's. I don't think he knows he's in that situation now. I
46 just think he thinks he's not very well which is easier for me. Yeah it is, emotionally.

Comment [J40]: Afterwards
He was worried about me

Comment [J41]: Dying
Easier for me emotionally that he is not aware

47
48 JN And possibly easier for him

49
50 M11 Yeah, I think so too. Yeah

51
52 JN 'Cause he was quite anxious last week, worried about you seems to have passed

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52

M11 That seems to have gone, yeah, yeah. But he is really not um you know we had a lot of trauma this last couple of days. He's, I think that's what's, well he's better today, but I think that's what um I think he might come out of it again and go back into it again you know are you going to be alright? I think, I think well I hope that really 'cause

JN What's been happening over the last few days? You said it's been quite traumatic.

M11 Catheter blocking all the time. Er, couldn't get through to my surgery at twenty five past five to get some help. 'Cause I thought I'd do it, I'll monitor it and make sure and then I thought right let's get it sorted now, well obviously now, but before he was, I knew it was blocked, but he didn't know. So I started twenty five past five, couldn't get through to the doctor's, six o'clock they were they're not finished until half past six. Something was the matter with the phone so I could not get hold of anything, anybody 'cause the out of hours is closed as well, um.

Comment [J42]: Hindrance
Couldn't get through to doctor re blocked catheter

JN So you must have felt quite abandoned or how did you feel when you couldn't get through to the surgery?

M11 I was worried that the, that the, um problem I knew he was going to be in excruciating pain 'cause I've been there had a block and I know it's awful. But the thing is eventually, eventually at half past eight a nurse came out, couldn't unblock it. I mean he was in, by that time excruciating. They said that the doctor was you know they said I'll phone the doctor She phoned the doctor with me. I saw her do it. But twenty minutes later nobody rang. So J said we've got to dial 999 'cause he was writhing and I just was not going to, couldn't bear to see him like that. He didn't deserve to be there. Three o'clock in the morning we got home. So that was traumatic. Next day it blocked again but what amazed me when I got to my answer machine eleven o'clock that doctor rang. Eleven I mean that was from half past eight the nurse had made so um I was quite stressed because I was aware of the pain that he needn't have been in. I'd started to get sorted at twenty five past five and it should have been all over within two hours really. So then again the next morning it was blocked but in fact what is happening now is it's um er, er spasms his bladder which Pam (CPCN) said yesterday Oxy

Comment [J43]: Feelings
Worried that he'd be in excruciating pain

Comment [J44]: Professional help
Nurse couldn't unblock catheter, doctor didn't respond

Comment [J45]: Caring
999, couldn't bear to see him in pain, didn't deserve that

Comment [J46]: Professional help
Doctor's delayed response

JN Oxybutinin

M11 Oxybutinin so he's on that and he's so much better. So you know very, very traumatic for him and he was totally out of it with being tired. So that was very stressful for me, just thinking of him. Just couldn't get through. So

Comment [J47]: Caring
Very stressful

JN And how have you found um the GP system up until then?

M11 His doctor er I um, he might as well not have been there. Since Pam took over it's been amazing. I didn't, I don't need to see his doctor. He hasn't been really at all. I've been quite cross with him, quite upset, because as soon as Pam came on the scene his tablets were totally changed and he was a totally different person. He was, if I hadn't come in and I know I'm blowing my own trumpet but he wouldn't be here. He would have died last year because he was falling, he wasn't communicating, he was, he was desperately ill, high blood pressure. Well he was just desperately ill and I, I and then BH (local hospital) as well. So with BH and Pam um we got him in a whole new ballgame and er so I think, I think because I came as I say I'm not blowing my own trumpet but because I moved in and got things sorted for him. Didn't stand, 'cause they're so oh yes sir, no sir, oh the

Comment [J48]: Professional help
GP not helpful, CPCN changed tablets, different person

1 doctor knows right and he you know I said Dad you know they're not all that. You need to
2 talk to other people. We need, but I didn't want to override him all the time I just wanted to
3 keep you know I didn't want to right, right, right let's do and take care of his life. You
4 know but I you know I pleased in the end that his doctor talked with Pam and the other two
5 girls that came before, the lady who had the baby

Comment [J49]: Organising
the situation
Moved in and got things sorted

6
7 JN H

8
9 M11 Yup, and there was another lady in between and Pam and all the nurses and
10 everybody we've got hold of

11
12 JN Does that include the district nurses?

13
14 M11 Oh yes, absolutely. Oh yes, the district nurses, you know Pippa comes in. They're
15 brilliant. Absolutely amazing.

Comment [J50]: Professional
help
D/Ns brilliant, amazing

16
17 JN So on the whole the (*hospice*) nurses and the district nurses have been helpful.

18
19 M11 Yup

20
21 JN Doctors less helpful.

22
23 M11 Yup. It was all the nurses that were they've, they've supported and helped me the
24 best. I mean you know the doctor well you know like he was supposed to have a catheter
25 put in one night and I said in the afternoon can you get that sorted today 'cause and he said
26 yup. Four weeks later and it was four weeks later when we had our first visit to (*hospice*).
27 Um the doctor took him in and we were in there one or two hours and he took just under a
28 litre of fluid from my dad but that time he wasn't in he was in pain but more discomfort
29 'cause he was peeing at night, six or seven times a night, just dribbling and very painful.
30 And but my, he didn't even come back to me the doctor. Didn't even come back to me.
31 That was bad, very bad. You know I had a lot of things like that with him 'cause you feel
32 you just haven't got that backup.

Comment [J51]: Professional
help
Nurses supportive, GP unreliable,
unsupportive

33
34 JN The medical backup for caring for him at home

35
36 M11 No. So, so I was glad when (*hospice*) came along and then with that the district
37 nurses started um that was a tower of strength, a tower of strength.

Comment [J52]: Professional
help
Pleased with hospice, D/Ns tower
of strength

38
39 JN Good So family have been very supportive. Nurses have been helpful.

40
41 M11 Yup

42
43 JN Is there anything else that you've found helpful in being the carer for dad?

44
45 M11 Um. Helpful, anything else helpful? Just I suppose because I'm taking a load off you
46 know giving the nurses a chance to go and see someone else who needs more than my dad
47 at the time. Um and I just feel that er it's other people, well there's not a lot of people who
48 can do it 'cause they're at work every day I'm lucky that I'm working at home I was in a
49 really good situation that I could do it. But helpful what else?

Comment [J53]: Caring
Relieving nurses, lucky to be able
to do it

50
51 JN Have you found any organisations

52

1 M11 Oh yes
2
3 JN Or websites or information?
4
5 M11 Carers support, the carers support I'd forgotten about them. 'Cause usually every
6 fortnight but I think she hasn't phoned me for probably three weeks now. She usually
7 phones and I've been over there a couple of times. They've been very helpful too. You
8 know there's another backup.
9
10 JN Yes. In what way have they helped you?
11
12 M11 Just talked to me, talked through things with me and er when I was at my lowest, my
13 very lowest because I had this woman giving me stress um and I just poured it all out to
14 them for a couple of hours. That was a real good ear bend 'cause I was at a point where I
15 was um desperately um that was before it all started on the and I felt oh and I always
16 wanted to see somebody like a hypnotherapist just you know seeing me through and giving
17 me some strength. Strength, that's what I needed but I've got that along the way from all
18 these supporters. The carers support, is it carers support that are up at S?
19
20 JN Yes the W carers support
21
22 M11 Yes, those and as I say Pam has been brilliant.
23
24 JN Good
25
26 M11 She's been brilliant. And that course I went to, that was amazing, that was amazing.
27
28 JN Good. Um, you mentioned, we talked about the doctor's surgery, we talked about the
29 other woman. Is there anything else that you actually found unhelpful?
30
31 M11 Um, no, I don't think so. Nothing no. Everything, every time somebody comes in it's
32 um helped. Yeah. No, I haven't had anything that's unhelpful. Um, no
33
34 JN Do you feel there's anything missing that you would like to be helping you or guiding
35 you?
36
37 M11 Um, I think the thing that is missing is the fact that you don't know where you're
38 going with a. You're working blindly and every time I went to the course I was saying you
39 know what do I expect next? What am I, um what am I looking for? What signs am I
40 looking for? 'Cause I didn't want to miss a sign that I was going to not be helpful for my
41 dad. So um that's, it was working blindly, not being a nurse or had a medical background
42 you just didn't know whether you should be doing this that and the other you know just
43 working blindly.
44
45 JN Something about the process that he will, the dying process
46
47 M11 Yeah, that's right
48
49 JN What to expect. What to look out for and how to respond to those things.
50
51 M11 Exactly. Yeah, that's right.
52

Comment [J54]: Help
Carers' support, regular phone calls, someone to talk to, poured it all out, gained strength

Comment [J55]: Professional help
CPCN brilliant

Comment [J56]: Help
Carers' course amazing

Comment [J57]: Uncertainty
Where you're going, working blindly, what to expect, what am I looking for, didn't want to miss a sign, should I be doing this that the other?

1 JN Would be more helpful.
2
3 M11 Yeah. That's sort of I mean then I would have had to go on a nursing course really.
4 But you know that course was brilliant, helped me a lot.
5
6 JN OK. And finally if you met someone else who was just about to become a carer for
7 someone who was dying, what advice would you give that person?
8
9 M11 Um, Listen to what they're telling you. Take as much advice and information as you
10 can. Go on the course. Um just soak in as much information as you can and do your, just
11 stay with your dad or stay with your mum and just be there for them and that's it, just be
12 there for them. And you know it's the advice and the information just to take it all in. It's a
13 learning curve. It's interesting. It's been interesting because I'm not um I'm not um
14 squeamish um and I'm sure I could put the catheter in now, I know I could. I think
15 sometimes I know what needs to be done. So just to stick in there and try, enjoy it but not
16 that sort of context it's not the word but just enjoy the time you've got left. And just, just er
17 make it good for both of you. It's just been brilliant. I've enjoyed it if you want to say
18 those words. It's not the right words but I'm glad that I was able to do it. I feel honoured
19 actually that I was privileged to be able to sit here and be here, work from home and look
20 after my dad because he ain't going to be here anymore.
21
22 JN Yes. Is there anything else you'd like to add that we haven't really covered about this
23 experience of caring for somebody you're very close to who's coming very close to the
24 end of his life?
25
26 M11 I think I've said it all. It's tiring. It's not the tiring of doing things. It's the stress part
27 of it but you, I think I'm on a high all the time and I think when it's finished I shall be flat
28 on me back. But I'll get up because I've got all these supporters here. Um
29
30 JN You're on a high, what's giving that?
31
32 M11 Just um, making sure, being tuned in to him, you know monitoring his bag, making
33 sure like I did that night I thought no that is not right. I'll give it another half an hour and
34 just monitoring and making a decision and it's good it, it makes you feel you've done the
35 right thing and you've helped. You know you've actually given somebody some help. I
36 think, I think in my relationships I've always been put down and I've been able to um do
37 something and made myself think well I can do it and I can do it again um. It's made me
38 feel strong, very strong and able.
39
40 JN Yeah. Well you obviously are so that's er that's wonderful. Anything else you want to
41 add? You don't have to.
42
43 M11 No, I think I've said it all. Cried once. Yeah. It's been brilliant. It's lovely. It's been,
44 I'd do it again, and actually I do feel that maybe I ought to join the team.
45
46 JN Yes, good for you. You're welcome.
47
48 M11 Thank you
49
50 JN I'm really grateful for that. Thank you. I'm going to turn this off now um

Comment [J58]: Help
Carers' course helped alot

Comment [J59]: Advice to new carer
Listen and take all the advice and info, go on the course, be there for your dad or whoever

Comment [J60]: Caring
Learning curve, interesting, I'm sure I could put catheter in now

Comment [J61]: Advice to new carer
Stick in there, enjoy it and the time you've got left, make it good for both of you

Comment [J62]: Caring
Been brilliant, enjoyed it, glad able to do it, able to work from home, honoured, privileged, because he ain't going to be here anymore

Comment [J63]: Consequences of caring
Tiring, stress, on a high all the time, when it's finished I'll be flat on my back

Comment [J64]: Caring
Being tuned in to him, monitoring, making decisions, makes you feel done right thing, you've helped

Comment [J65]: Consequences of caring
Self esteem- I can do it, made me feel very strong and able

Comment [J66]: Caring
Brilliant, lovely, I'd do it again, I ought to join the team

Field notes

This interview took place in the small bungalow where IR lives and his daughter. Jane has moved in to be his carer. Her sister and brother-in-law and Jane's partner as well as IR were present in the open plan living/dining room and kitchen. There was a lot of background chatter, the Olympics were on the TV, there was cooking activity and the neighbour's strimmer. I suggested to Jane that we should do the interview with a bit more privacy, especially out of IR's earshot but she said there wasn't anywhere else. The situation did not seem to inhibit her from talking freely. On the whole I felt the interview went well, but I did sometimes ask leading questions or put words in her mouth. After the interview had finished we talked a while about what to expect in the dying process and who to talk to about her questions and anxieties. I also mentioned that I would like to contact her again after her father has died.

Overview:

Main theme: "It's a privilege to look after my dad after all he has done for me, I have enjoyed it and it has made me feel strong and able"

Supporting texts:

I feel honoured that I'm in a position to look after my Dad because he's looked after me all my life. 2:17-18

I wouldn't have had it any other way 2:18

I just feel I'm giving things back to him what he's done for me all my life...it's, it's no bother at all to me 2:21-22

This is more important, to be with my dad at the moment. 5:36

I just don't want to leave him. Don't want to miss anything just in case something happens when I'm not here. 5:47-49

If I wasn't here when he died I, that would be worse for me because I just want to be there for him 6:3-4

We're here because of a person like him and he needs the best and I am trying to give it to him 6:20-21

It's just been brilliant. I've enjoyed it if you want to say those words. It's not the right words but I'm glad that I was able to do it. I feel honoured actually that I was privileged to be able to sit here and be here, work from home and look after my dad because he ain't going to be here anymore 11:2-6

I'm on a high all the time 11:13

It makes you feel you've done the right thing 11:20-21

I've been able to um do something and made myself think well I can do it and I can do it again um. It's made me feel strong, very strong and able 11:23-24

It's been brilliant. It's lovely. It's been, I'd do it again 11.29-30

Sub-plot: "I'm working blindly"

Supporting texts:

I don't really know what I'm looking for. I don't know what's going to happen. 2:44-45

I'm working blindly 2:47

I think the thing that is missing is the fact that you don't know where you're going with a. You're working blindly and every time I went to the course I was saying you know what do I expect next? What am I, um what am I looking for? What signs am I looking for? 'Cause I didn't want to miss a sign that I was going to not be helpful for my dad. So um that's, it was working blindly, not being a nurse or had a medical background you just didn't know whether you should be doing this that and the other you know just working blindly. 10:20-26

Appendix 5 Example of coded transcript of bereaved carer's interview

Bereavement interview with Jane (B11) at what was her father's home and is now hers.

Date of interview: 18.11.08

Duration of interview: 31 minutes

1 JN OK that's recording now and that should pick both of us up, I think.
2
3 B11 Good
4
5 JN I'll put that there so it's definitely going to pick you up.
6
7 B11 Good
8
9 JN Um. And basically just tell me if it gets too much. You know if it's too difficult or
10 whatever, because what I want to is take you back to that time when you were looking after
11 Dad.
12
13 B11 Mmm
14
15 JN And I don't want to be a downer.
16
17 B11 No, that's fine 'cause I will get upset 'cause I work because I don't, you know I talk
18 about him, but um this is a bit different, isn't it?
19
20 JN Yeah, well if you can just think back to looking after him, particularly in that very end
21 last stage. I mean what, what was it like for you?
22
23 B11 Um, I presume, I think some of it was a relief because I was, he was getting near his
24 end and it, it was relief for him, um and me as well I suppose if that's not being selfish,
25 Because I, well I couldn't, it was the, I didn't like to see him so hurt, upset and in pain and
26 the last three weeks there was a couple of times where it was really not nice at all and
27 where he was er asking me to help him. You know because of the pain um and I just felt
28 useless so it was, it was, I was, I think almost looking, looking forward, if that's the word,
29 for him to go. So that he didn't, wasn't in pain anymore.
30
31 JN When you said he was looking for you to help him.
32
33 B11 Relying, relying on me which he would never ever, ever do in his life and it really was
34 um like that towards the end and the one night when he was, had a blocked catheter and he
35 was in terrible pain and we couldn't get anybody to come. He was just writhing around
36 with pain and he's never ever let you know that he's in any sort of pain. And I couldn't do
37 anything. So that was hard um and he was looking to me and you know, can you, what can
38 you do? How can you help me? What can we do? And all I could do was keep phoning and
39 phoning so that was hard. That was one of the worst times you know towards the end
40 'cause his catheter blocked quite a lot, nearly every day which was um and I was looking
41 for it and just being on the ball and trying to you know organise things so that we could get
42 somebody quickly before the night people came on. You know 'cause it's harder to get
43 them obviously. But um that really does stick in my mind, that particular time.
44
45 JN And what other ways did you have to help him?
46
47 B11 Walk, um, eat, well he wasn't eating, but everything, everything. He was calling me,
48 asking me for every single thing. Um he couldn't do anything on his own, nothing at all.
49 And quite rapidly, quite rapidly um you know it was sort of one day he was talking and the
50 next minute he couldn't talk. And then the next minute he could talk a little bit and then
51 you know it was really, really very quickly when he started to go down. It was very
52 quickly.

Comment [J67]: The interview
I will get upset

Comment [J68]: Dying
Relief for him and for me

Comment [J69]: Caring in final stages
Didn't like to see him hurt, upset, in pain. He was asking me to help him because of the pain

Comment [J70]: Feelings
Felt useless, looking forward for him to go so he wasn't in pain anymore

Comment [J71]: Caring in final stages
Relying on me, would never do before

Comment [J72]: Helplessness
Blocked catheter, terrible pain, couldn't get anyone to come

Comment [J73]: Caring
Hard, looking to me for help, all I could do was keep phoning, hard

Comment [J74]: Caring in final stages
One of worst times, catheter blocking, having to look out for it, be on the ball

Comment [J75]: Organising the situation
To get someone quickly before night people came on

Comment [J76]: Caring in final stages
Needed help with everything, calling me for every single thing, couldn't do anything on his own

Comment [J77]: Deterioration
Rapid change, very quickly when he started to go down

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52

JN Was that anything like you expected it to be?

B11 No, I didn't know what to expect. I didn't know what to expect at all. I thought he'd go on forever, like you do. Er but I knew he wasn't. Um but no, I didn't expect, didn't expect it. I was expecting anything but didn't know what to expect you know. I was expecting the worst but I didn't know what to expect.

Comment [J78]: Expectations
Didn't know what to expect, thought he go on forever but knew he wasn't, expecting the worst but didn't know what to expect

JN Did you feel prepared at all for the end, for when he died?

B11 Well funny enough I, I was obviously upset but I knew, I was worried to death that I'd, that am I going to know the signs, that am I going to miss him? Is he going to go in the night? But when my daughter and my sister and her husband were here all that day and um he was, he sat in the chair I think most of the day. No, in the morning and then he went back in, he went back to bed and they went about quarter to five and I was clearing up in the kitchen and J (*partner*) was, 'cause we had the baby monitor here, so J could see that there was something the matter, and he went in and then he came out and said I think you ought to go in and see him. And I knew instantly that this was the time and I phoned my sister up. That was at half past five and he died at ten to nine.

Comment [J79]: Intuition
Upset but I knew

Comment [J80]: Uncertainty
Worried that I'd miss the signs, miss him, is he going in the night?

Comment [J81]: Intuition
Knew instantly this was the time

Comment [J82]: Dying
Phoned sister 5:30, died 8:50

JN What was it about that change, you said you knew instinctively, can you think about what it was?

B11 He was restless. He didn't know what to do, wanted something to drink and then he wanted something to eat. He hadn't eaten for three weeks he, he, his taste, he wanted, he just wanted something. I think, I think the body was just grasping. I don't know um he was just, didn't know what he wanted, I couldn't understand him, couldn't understand what he was saying which was really upsetting. Um so er I called my sister to come back which they did. And he want, oh I heard, he said I want prayers. So I called round, called the friend of ours that was he could make communion. So him and his wife came round. Um and he and then by the time I, and then I thought right I'm going to get the doctor because I think he needs maybe one of those injections that relaxes them stops them being so irritable. He couldn't keep still. He didn't want to, when I got back in the room he was, they were getting him out of bed, he wanted to get in the chair. He was all over the place you know and um he sat in the chair and I was, I could see that he wasn't comfy in the chair 'cause he was all over the place and then I got him back into bed or we got him back into bed. And no, I'm not comfortable. He could make us understand that. You know, you know whatever and so he just wasn't comfy and I couldn't get him comfortable. And then I think he, he knew that he couldn't get comfortable so he said yeah I'm alright. I mean he didn't say it like that but I think he thought oh I'm being too fussy and too, too um hard on her, you know what I mean? My dad would, this is what hurt because he never let us know when he was ill, and you know he wouldn't, he wouldn't give in because he was such a proud man and he didn't want anybody to um have to help him. Um you know um and then um we just. I was a little bit upset because the guy that came to do with the church, he was, he was too loud. This was the first time he'd been to somebody like this and he was too loud and he was saying he's alright now I'm holding his head. You know God's with you, God's with you. He's alright. He's you know and I just didn't want and I said could you leave us now? And he just kept on and he wouldn't leave us so that last, very important hour was taken up with this guy holding his head saying he'd be peaceful. Be peaceful you're alright now. God's taking you. Just going over and I mean OK but it was just too much and I just wanted to be there to talk to him and I couldn't. He just wouldn't go this guy. I know he was you know being helpful and loving my dad but um. And then

Comment [J83]: Dying
Restless, didn't know what he wanted, body grasping

Comment [J84]: Communicati on
Couldn't understand him - upsetting

Comment [J85]: Beliefs
He wanted prayers, called a friend who could do communion

Comment [J86]: Caring in final stages
Get the doctor, might need injection

Comment [J87]: Dying
Restless, couldn't get comfortable

Comment [J88]: Not so helpful
Guy from church too loud

Comment [J89]: Inappropriate help
Last haor taken up with overbearing, persistent behaviour of church guy

Comment [J90]: Being there
Just wanted to be there and I couldn't

1 he told me to stop holding his hand and I said no I want to hold his hand. He said no, no
 2 leave him. I said no I want to hold my dad's hand. And then his breathing was really bad
 3 and I don't know, I really don't know whether he suffered because the breathing was bad
 4 you know gasps and I don't know what that is whether it's, whether he was unconscious
 5 then because his eyes were rolling and he didn't squeeze my hand. I wasn't aware that he
 6 was squeezing my hand. But and he, he had some grimace on his face. I don't, again he
 7 didn't sort of squeeze my hand in pain and I just wonder if that was the body and the
 8 muscles reacting or um.

9
 10 JN Are you talking about right at the very end?
 11
 12 B11 Yeah
 13
 14 JN In the last few minutes
 15
 16 B11 Yeah, yeah
 17
 18 JN Ten minutes or something.
 19
 20 B11 But he was gasping for quite a long time and I know that the breathing is bad but I
 21 didn't know whether that, he was actually still hanging on. I didn't know, I knew he wasn't
 22 going to be here for long but I was trying to understand what was happening to his body
 23 you know um. So I could understand and know that he wasn't in any pain but I just
 24 presume he wasn't in any pain I don't know. Then it happened, you know from the day
 25 before and then all of a sudden it was the process was there and he was dead, you know.
 26 And er I, he, he stayed here all night until about four o'clock. I didn't want him to go and
 27 my son was coming down and he, he wanted to see him so that was good.
 28
 29 JN And did you feel prepared for the afterwards, for what to do after he died?
 30
 31 B11 Um, we just, we phoned up straight away. Um yeah, I think, I think because my mum
 32 had died five years ago, we knew exactly what to do. Um but it was really weird because
 33 my sister and I said it's weird because S's husband's father died at 23 really badly and J his
 34 father died about 23, when he was 23, really nasty he and neither of them really could talk
 35 about their dads but this sort of brought it all out and because they weren't actually there
 36 but they were popping in and out to see how we were. And so this really was amazing and
 37 then after he died we came out here and we all talked, my daughter was there as well, and
 38 my ex-husband. Um we talked and it was good for the two guys that's fathers had died
 39 early. It was amazing actually. It really sort of got them going and then J said right let's
 40 crack a bottle of whiskey. I don't drink. And by, within two hours we're actually crying
 41 with laughter. It was really weird just because we were talking about Dad and Mum and
 42 you know like you do reminisce. And um, we were, some, then we were all deciding
 43 where we were going to sleep and I said well you're not having my bed. And um and we
 44 were all, it, you know silly things were happening and we would, I suppose that's the. I
 45 don't know we were, we ended up what two o'clock in the morning just crying and aching
 46 with laughter. It was really weird. My son who was taking um er a medical for air traffic
 47 controlling, a sight test and everything, he was supposed to be having it done on the
 48 Monday and we said to him in the week well we won't text you if Dad dies, Granddad
 49 dies, because we don't want. Anyway Monday morning of course we were antici, just
 50 waiting for him to call us about half past ten and he didn't call. So we were all here waiting
 51 and thinking obviously W's not passed because he's into aeroplanes like Dad was. So they
 52 had that. On the day he died we said to him in the afternoon, this is really weird that he

Comment [J91]: Inappropriate help

Church guy wouldn't go, told me to stop holding his hand

Comment [J92]: Being there

No, I want to hold his hand

Comment [J93]: Dying

Breathing bad, gasps, don't know whether he suffered, unconscious, didn't squeeze my hand, grimace

Comment [J94]: Dying

Gasping

Comment [J95]: Uncertainty

I didn't know

Comment [J96]: Dying

Knew he wasn't going to be around for long, trying to understand what was happening to his body, presume he wasn't in pain

Comment [J97]: The moment of death

Then it happened, all of a sudden, and he was dead

Comment [J98]: Afterwards

He stayed here all night, didn't want him to go

Comment [J99]: Preparation

Previous experience. Knew what to do because Mum died 5 years ago

Comment [J100]: Afterwards

We all talked

Comment [J101]: Grief

Good for the guys who's fathers had died early

Comment [J102]: Afterwards

Bottle of whiskey, crying with laughter, reminiscing

1 could talk every now and again, and then when he, other times he couldn't talk, but he said
2 all of a sudden said W'll walk it. And then half past twelve in the lunchtime W phoned up
3 and said hi Mum are you alright? I said oh yeah fine. You know are you alright, how did
4 you get on? And he passed and I thought, I said oh I said I'm so glad 'cause you know I
5 said Granddad died. He said I know. He said I had a feeling and I've packed my case and
6 I'm on my way home. So it was almost as if my dad was with him and since then I mean
7 W's now took his first part, he's got 96% on his first exam he's taken. And um it's as if
8 he's been with us all the time. I know he's been with us. And as for preparing I know, you
9 know we've done everything. He, it came quite easily, you know sort of just we did it. And
10 er so that was fine, that's fine.

Comment [J103]: Narrative
The morning after he died

11
12 JN Going back to when he was still alive and those last few days, how did you feel about
13 the changes in him and what, and what that required of you?

14
15 B11 Um, I was just on edge obviously all the time, just going backwards and forwards,
16 backwards and forwards and asking if he was comfortable. Did he want anything? Um just
17 being aware that he was in the room. Oh I better go and see dad and see if that bag's
18 blocked up and er is he sleeping? Is he comfortable? Um you know er, just checking
19 everything to see if he was. I hated him being in there. I wanted him to be here. I asked if
20 he wanted to come in and he'd say yes and he'd, he'd be uncomfortable in that chair and or
21 he was saying he was comfortable and then I'd say do you want to go back to bed? He'd
22 say no, no, no but I was just trying to make sure that everything was perfect for him.

Comment [J104]: Caring in final stages
On edge all the time

Comment [J105]: Caring in final stages
Backwards and forwards constantly checking Comfortable? Want anything? Bag blocked? Sleeping?

23
24 JN And how did you cope?

Comment [J106]: Caring in final stages
Trying to make it perfect for him

25
26 B11 Um, I felt quite, well I was glad I was in control. I didn't want anybody to see to him
27 and J was here at night and then pop off in the day till later on. He was on the sofa and that
28 was good because I needed him to help me if he needed to get out of bed so I couldn't hold
29 him. He needed to carry you know or put the weight if he needed to go into the chair, to
30 wheel him out to get him into the chair for me. My brother in law came and my sister and
31 you know they said right shall we do anything? What shall we do? I said no it's alright, it's
32 fine. I'm coping, don't worry. And then if my dad was coming out er him and J he would
33 go in to get him. I'd say to J go and see you know make sure he does it right, you know,
34 because we had a way of doing it and I didn't want anybody to touch him. In fact the
35 nurses were supposed to be coming three days a week to wash him and I didn't want them
36 to do it because he was clean and er I didn't want them to disturb him because it, and also
37 what they told me on that time when we had the um courses at the centre, (hospice), that
38 they don't get their energy back. They don't you know, they don't sleep and get their
39 batteries charged. So everything that he did was taking his life away and I didn't want
40 them to come and move him because it was such an effort to wash in the bathroom. But
41 they came so I was saying no, no he's alright you don't need to he's sleeping or you know
42 and then on the day he died they came in on the morning and they took him in and he had
43 a, a full wash and I felt that that took, he might have lasted the next day, you know. Um so
44 I didn't want anybody to deal with him except me. Um so I coped with being really
45 territorial.

Comment [J107]: Coping
Glad I was in control
Didn't want anybody to see to him

Comment [J108]: Helpful
Partner needed for transfers

Comment [J109]: Coping
Declining help as way of coping

Comment [J110]: Coping
Didn't want anyone to touch him, didn't want nurses to wash or disturb him

Comment [J111]: Source of information
Carers' course

Comment [J112]: Dying
Everything he did taking his life away

Comment [J113]: Paid carers
Didn't want them to come and move and wash him – too much effort but they did on the day he died – might have lasted another day

46
47 JN Yes

48
49 B11 And in control. Um so

Comment [J114]: Coping
By being territorial

50
51 JN And the nurses who came to wash him, I think you told me before they weren't agency
52 carers, they were actually auxiliaries

Comment [J115]: Coping
In control

1
 2 B11 Yeah
 3
 4 JN From the district nurses
 5
 6 B11 Mmm
 7
 8 JN So you didn't have any agency carers involved.
 9
 10 B11 Only I think it was just was no, no one night I'm sure she came from (*hospice*)

11
 12 JN Hospice at home

13
 14 B11 Yes, that's right that one night. Which she didn't need to be she just sat up all night
 15 and I felt awful because that particular night my dad slept through. Excuse me, so I don't, I
 16 didn't ask, because we coped, we coped you know and she couldn't have changed,
 17 unblocked his bag anyway and that was really what I wanted somebody on hand to snap
 18 and get it sorted. That's, that's the only thing I needed instantly because that was where my
 19 dad's pain was. Um but she was lovely. They were all fantastic, absolutely amazing,
 20 absolutely amazing.

Comment [J116]: Paid carers
 H@H one night – not needed

Comment [J117]: Coping
 Didn't ask for H@H because we coped

Comment [J118]: Paid carers
 Couldn't unblock catheter

Comment [J119]: Professional help
 Needed catheter unblocked instantly because of pain

21
 22 JN And what did you find most helpful for you as dad's carer? You wanted to do the
 23 caring, but what did you find most helpful to help you to do that?

Comment [J120]: Paid carers
 Lovely, all fantastic, amazing

24
 25 B11 Er the backup system, um you know somebody, the, you know I could, (*the hospice*)
 26 and er the sisters that came, the nurses that came, um

Comment [J121]: Helpful
 Backup from hospice and D/Ns

27
 28 JN The district nurses

29
 30 B11 Yeah because that's yeah they were coming.

31
 32 JN And what were they doing that was helpful?

33
 34 B11 Well it was just that they came in to wash him which they didn't need to but just
 35 somebody knocking on the door um and to see that everything was OK and just a support
 36 system. That's what was most important to me. Um because, as I said before, I was
 37 working blindly, but it was just that backup system but of course in the night it was the
 38 worst time because you just couldn't get hold, you could but it was always a long time
 39 because they had lots of other people you know. Um but of course it always happens at
 40 night as well, doesn't it which is always worse. But I wished I'd, um I wish I was qualified.
 41 I could have done it and helped him with that. That was the worst bit, that pain because I
 42 had that happen to me that retention when you can't have a wee. And we ended up in
 43 hospital one night with him. That was the worst night because the lady, the nurse came she
 44 couldn't do it. At half past eight we phoned the doctor up, I was with her. And um he
 45 phoned to come to see to him and twenty minutes after he hadn't come and J said right
 46 we're going to call 999. And we, he didn't come home till three in the night, in the
 47 morning. And they, it was awful for him. That was the worst night and I got home and did
 48 my 1571 and that doctor didn't call me until eleven o'clock. Well I think he would have
 49 passed out, I think or something bad would have happened. So that was I think the worst
 50 night. So it's the um the backup system which was good in the day. I mean it was good in
 51 the night you know, they were brilliant but um it seemed to them more you know after

Comment [J122]: Professional help
 D/Ns – somebody knocking on the door to see everything OK – support system

Comment [J123]: Uncertainty
 Working blindly

Comment [J124]: Professional help
 Worst at night, couldn't get hold of, took long time

Comment [J125]: Caring in final stages
 Wish I was qualified. Pain was worst bit

Comment [J126]: Narrative
 Worst night, nurse unable to help, delay getting doctor, 999, home 3am

1 hours services seem take a long, more time. And it always happened, well it didn't always
2 happen at night.

Comment [J127]: Professional help
Backup good in day but out of hours takes a long time

3
4 JN So that particular night the out of hours service wasn't very helpful for you.

5
6 B11 No

7
8 JN Is there anything else that was actually unhelpful through the process, particularly the
9 dying process of caring for him? Was there anything else that was actually unhelpful for
10 you?

11
12 B11 No, no

13
14 JN Or anything that would have been more helpful? Can you think of anything that was
15 missing for you as his carer?

16
17 B11 Um, the only thing I said to you before was, which was food. It was you know trying
18 to make the food, although dad wasn't eating, I was still having to make myself and I
19 didn't have the, not the energy, I wasn't in the right frame of mind. Um a few times
20 somebody brought some things and my sister came up and she brought some food and it
21 was wonderful. Just wonderful just to sit down and eat it because I didn't have time,
22 although I did have time, I didn't have time in my mind. That was the last thing on my
23 mind. I lost, actually I lost a stone, er which was good 'cause I needed to anyway because
24 I'd been on steroids for two and half years and I put on that stone so it was um that was
25 good really. Although if I was this weight I wouldn't have liked to have lost that stone.
26 Um, but I think it was just er the food, somebody looking after me I think, food wise
27 'cause everything else was automatic.

Comment [J128]: Consequences of caring
Not in right frame of mind to make food for myself

Comment [J129]: Helpful
Sister bringing food, wonderful to sit and eat

Comment [J130]: Consequences of caring
Preparing food last thing on my mind, no time in my mind, lost a stone

28
29 JN And did you have any space for yourself?

Comment [J131]: Helpful
Somebody looking after me - food

30
31 B11 No

32
33 JN Did you want any?

34
35 B11 No. I didn't because if I, because I was offered that. You know my sister but I didn't, I
36 couldn't cope with going out. I was in the house really, I didn't go out for at least six
37 weeks I'm sure it was that much. If I did it was literally to out and get some milk or
38 something or quickly get some groceries but somebody like J. I only really trusted J being
39 here which was really weird because he was here from the beginning with me and we just
40 went along together and um I knew that he knew what to do. So I didn't go out.

Comment [J132]: Consequences of caring
No space, didn't want it, sister offered, couldn't cope with going out, didn't go out for at least 6 weeks

41
42 JN So how did that feel being in, in for six weeks?

Comment [J133]: Helpful
Only trusted partner, he knew what to do

43
44 B11 I didn't think about it until I went out afterwards and it was really weird 'cause I was
45 obviously thinking I've got to get back, I need to get back because of Dad. Gosh what am I
46 doing out here? I can't be sitting having coffee, I must get back. And then of course reality
47 kicks in. Er which is weird and then I got that job.

Comment [J134]: Afterwards
Really weird, kept thinking must get back because of Dad

48
49 JN Yes

50

1 B11 Which was good and it is good 'cause I need some money. Um and I haven't had time
2 to sit um and talk like this. Even when I read his cards, they didn't mean anything for me.
3 So er yeah, that was weird.

Comment [J135]: Grief
No time to sit and talk like this, or read his cards – didn't mean anything

4
5 JN And I asked you this before, um and maybe now with the benefit of hindsight, the
6 whole experience, if you met someone who was just taking on a caring role for someone
7 who's terminally ill, what advice would you give that person?

8
9 B11 To, to do as much as you can. I'd still do it again. I wouldn't have it any way as far as
10 I was concerned. But my sister in law, well it's J's sister in law, her father's, he's starting
11 to give up, and I just said to her you've got to take over. You've just have to take over.
12 Although I didn't, not take over the with right this is what you're doing der der der, but
13 you've just got to um organise something, you know. Just don't let him go. Just have as
14 much time. 'Cause she saw dad when he was like it obviously when he was ill and she
15 thought it was amazing what we were doing and that she, you know, it was lovely how we
16 were together and what we said to each other. And I said just think of that, F, just think of
17 that and just make sure you do it. 'Cause she can't even tell her dad that she loves him. So
18 she said it's amazing how you used to talk to your dad and what you used to talk about.
19 And I said but you have to do it, just do it. Don't let him go to hospital because the hospital
20 was great obviously, but he'd be sat on his own or laid in bed on his own most of the day,
21 because they have to see to other people. But my dad had the last, the most important time,
22 well not the most important, but the, those times, eighteen months with me being with him
23 all of the time and he loved it. He loved me being there although he didn't want me to take,
24 didn't want to take my life away from me. Um but he loved having me here and I loved
25 being here with him. And he gave me this bungalow which was lovely um but I would tell
26 them to do exactly what I did. Just do it. Just get the backup system and just do it if you
27 can. Um, I mean I was lucky to be in this position that I could stay at home with him and F
28 is too. And she's got lots and lots of money. I mean I had nothing although my dad, my
29 dad had money. I mean I think carers ought to be paid more money. There is noth, I mean
30 fifty quid a week. And it's er absolutely nothing. But I was lucky 'cause my dad had
31 money but there's not. Other people haven't and that's why they can't stay at home to look
32 after them. So it's, money would be um very, very important in a lot of people. And I was
33 lucky, very lucky because, as I said, dad had money. Um but there's a lot of people that
34 have to go to work and they couldn't even begin to have time off with their dad or their
35 whoever. So I think if I'd, if dad hadn't had money I think money would have been the
36 biggest worry, the biggest worry. But I was lucky.

Comment [J136]: Advice to new carer
Do as much as you can

Comment [J137]: Caring in final stages
I'd do it again, wouldn't have it any other way

Comment [J138]: Advice to new carer
Got to take over

Comment [J139]: Advice to new carer
Organise, don't let him go, have time

Comment [J140]: Relationship
Lovely how we were together

Comment [J141]: Communication
Amazing how you talk and what you talk about

Comment [J142]: Advice to new carer
Just do it, don't let him go to hospital

Comment [J143]: Relationship
Last 18 months with me and he loved it

Comment [J144]: Reciprocity
Loved having me here and vice versa

Comment [J145]: Advice to new carer
Just do it, get backup system

Comment [J146]: Coping
Lucky I could stay at home

Comment [J147]: Would be helpful
Carers ought to be paid more

Comment [J148]: Coping
Lucky, Dad had money

37
38 JN Good. And you've already been in a position to be able to give that advice to your sis

39
40 B11 Yes

41
42 JN Well J's sister in law. That's another positive thing that's coming out of

43
44 B11 Oh yes

45
46 JN A very sad thing but you, you've already been able to hand on some of your
47 experience.

48
49 B11 Oh I would, I've done, not just to F, I've talked to lots of people about it. Um I really
50 have said it's, well I suppose it's how close you are to your mum or your dad or the person
51 that's ill, because I just wouldn't have it any other way. Because I feel that you know my
52 dad's done and my mum has done such a lot for me and they've been there whatever time

Comment [J149]: Shared experience
Talked to people about it

Comment [J150]: Coping
Wouldn't have it any other way

1 of the day or night and given me that time and it was the least I could do. I just wish I
 2 could have given him more time.
 3
 4 JN Now you've helped, talked to a lot of other people. Did anybody help you, apart from
 5 the professionals, was there anybody else or any organisations, anything that helped,
 6 anything else that helped you to be dad's carer right up to the, to when he died?
 7
 8 B11 Er the um what's it, the carers' association? Yeah.
 9
 10 JN The local one?
 11
 12 B11 Yeah
 13
 14 JN Carers' support
 15
 16 B11 They phoned me up often um which was good to see how I was. I went to have an
 17 interview with them at the beginning when I first um started, when I really needed to be
 18 here. They were very supportive and I had a nice facial which was good. I didn't have time
 19 to have anything else unfortunately. So they were very good. Um so it was only really the
 20 district nurses, the hospice, and um the carers, that's the only people that were involved as
 21 far as professional. Um my sister, as I said, towards the end came up and gave me some
 22 food or made me some food. Then afterwards, one of my daughter's best friends who is
 23 also my best friend sort of she came um and brought me some food round afterwards
 24 which was lovely. She did that a couple of times. Um but that was all I think.
 25
 26 JN Is there anything else that we haven't touched on that you'd like to add about being a
 27 carer in the final stages of his life?
 28
 29 B11 Um, like what?
 30
 31 JN Anything, it doesn't matter, there might not be anything, but I just didn't want to miss
 32 the opportunity if there's anything else that you think you need to say about that
 33 experience that I haven't touched on, I haven't asked about. It doesn't matter if there isn't.
 34
 35 B11 No
 36
 37 JN I don't want you to feel oh she didn't even think about that.
 38
 39 B11 No, no, no don't. I should say.
 40
 41 JN Good
 42
 43 B11 Um. No. I don't think so. I was just happy and lucky that I was able to look after him
 44 and I just hope lots more people do it because it worries me that there's people in hospital
 45 that could be, could be at home. But you know not everybody's in my situation or. But no
 46 basically, I was really pleased with the support I had and the only thing is the money which
 47 would have, as I say, I was alright because my dad was OK but with money, but there are
 48 people that you know it must be dreadful. Um, it was an amazing experience and I
 49 wouldn't have missed it for the world. I only wish that I'd been able, my mum went into
 50 hospital and died the same day, and we didn't even know that she was dying, so that was
 51 the biggest shock. I was determined, determined not to have that happen. And I was
 52 determined that he was going to be with me or I was going to be with him. Um, but and it's

Comment [J151]: Reciprocity
The least I could do

Comment [J152]: Feelings
Wish I could have given him more time

Comment [J153]: Helpful
Carers' association, phoned often, interview, very supportive, facial

Comment [J154]: Professional help
D/Ns, hospice, carers

Comment [J155]: Helpful
Sister bringing food

Comment [J156]: Afterwards
Friend bringing food was lovely

Comment [J157]: Caring
Happy and lucky I was able to look after him

Comment [J158]: Place of care
Hope more people do it so people in hospital could be at home

Comment [J159]: Helpful
Pleased with support

Comment [J160]: Caring in final stages
Amazing experience, wouldn't have missed it for the world

Comment [J161]: Regrets
Didn't have opportunity with Mum

1 an amazing experience and, and I was glad that I could, that I was able to cope with it and
2 to be there to the end with my dad. And I was surprised at my sister 'cause she's, I didn't
3 think that she would have coped with it but she was with him as well. Yeah. The church
4 people were very good. You know they were phoning and um yeah they were very good.
5 They did the um the food for us. They said don't worry about the food we'll do all that.
6 You don't have to worry. It was absolutely amazing. So they were very good. Everybody's
7 been kind.
8 .
9 JN Good. Well if there's nothing else. I mean you don't have to say any more. You know, I
10 can turn that off.
11
12 B11 That's fine
13
14 JN I'll turn that off now.

Comment [J162]: Caring in final stages
Determined he was going to be with me, amazing experience, glad that I could

Comment [J163]: Coping
Glad I coped with it

Comment [J164]: Being there
Glad to be there to the end

Comment [J165]: Helpful
Church people

Field notes

This interview took place in the evening at her father's bungalow which he has bequeathed to her. She was there on her own – a great contrast to the earlier interview when the bungalow was full of people, noise and activity.

I asked permission to sit on Dad's chair. She had described herself as on a high when I phoned to arrange the interview but said she was feeling down for the first time this evening, maybe because I was coming and she knew she would be going back to her father's illness. She was however happy to talk but seemed to get tired after about twenty minutes. She may also have been hungry as her supper was in the oven – smelling delicious.

I was also tired as it was a 40 minute drive there and back after a full day at work.

Overview:

Main theme: "I was happy and lucky to be able to look after him and I just wanted it to be perfect"

Supporting texts:

I was worried to death that I'd, that am I going to know the signs, that am I going to miss him? 3:14-15

I was a little bit upset because the guy that came to do with the church, he was, he was too loud 3:49-50

I was just trying to make sure that everything was perfect for him 5:34-35

I'd still do it again. I wouldn't have it any (*other*) way. 8:29 and 9:24

He loved having me here and I loved being here with him 8:45-46

I was lucky to be in this position that I could stay at home with him... because, as I said, Dad had money 8:48+50 and 9:4-5

I was just happy and lucky that I was able to look after him 10:22

It was an amazing experience and I wouldn't have missed it for the world 10:27-28

It's an amazing experience and, and I was glad that I could, that I was able to cope with it and to be there to the end with my dad. 10:32-33

Sub-plot: "I coped by being in control, territorial and totally absorbed in his care"

Supporting texts:

I was just on edge obviously all the time, just going backwards and forwards, backwards and forwards and asking if he was comfortable. Did he want anything? Um just being aware that he was in the room. Oh I better go and see dad and see if that bag's blocked up and er is he sleeping? Is he comfortable? Um you know er, just checking everything to see if he was. 5:27-31

I was glad I was in control. I didn't want anybody to see to him 5:39

I didn't want anybody to touch him. 5:47-48

The nurses were supposed to be coming three days a week to wash him and I didn't want them to do it because he was clean and er I didn't want them to disturb him. 5:48-50

I didn't want them to come and move him because it was such an effort to wash in the bathroom. But they came so I was saying no, no he's alright you don't need to he's sleeping. 6:3-5

I didn't want anybody to deal with him except me. Um so I coped with being really territorial ...and in control. 6:8-13

I didn't (*want any space for myself*) because if I, because I was offered that. You know my sister but I didn't, I couldn't cope with going out. I was in the house really, I didn't go out for at least six weeks. 8:4-6

You've just have to take over 8:31-32

You've just got to um organise something 8:33

Appendix 6

A note on reflexivity

Patton (2002:65) states that “reflexivity reminds the qualitative inquirer to be attentive to and conscious of the cultural, political, social, linguistic, and ideological origins of one’s perspective and voice as well as the perspective and voices of those one interviews and those to whom one reports”. The first stage in the reflexive process for me was writing in the first person which I found liberating because it involved finding my voice in the research process. And it is my voice, literally in the interviews I conducted and metaphorically in analysis and writing, and my perspective that I needed to critique in a self reflective way throughout the process. As Holland (2007) stresses, it is important to realise that the researcher’s identity and experiences shape the ideas that go into the field of research, including their political and ideological stance, and that there is an analytical cost if this interplay between person and research is not taken into consideration.

Reflexivity involved constant awareness and examination of my influence upon the methodology, data collection, interpretation and analysis and the way in which I wrote about them, as well as the effect that these processes had upon me which further affected them. In this way, reflexivity offers the researcher the opportunity to unpack their own assumptions and expectations, openly account for the particular interpretations and reflect on their success and failures (Woodthorpe, 2009). However, Marcus (1994:569) warns that “this sort of reflexivity associated with self-critique and personal quest, playing on the subjective, the experiential, and the idea of empathy, can lead to dismissal as dead-end self indulgence, narcissism, and solipsism”. Reflexivity therefore highlights the tensions within qualitative research. It is particularly associated with the ongoing dialectic between the concern for validity and authenticity on the one hand and on the other hand “the sure and certain knowledge that all texts are socially, historically, politically and culturally located” (Lincoln and Denzin, 1994:582).

I chose to research carers in home palliative care because of my concerns for their well-being and I chose a qualitative, grounded theory methodology because I felt it would reveal in-depth understanding of their concerns around the dying process and generate theory to guide practice. My cultural, professional, personal and political attributes shaped these primary decisions. However, reflecting on my early thoughts I realise that it was patronising or even arrogant of me to assume that I could generate new knowledge to help carers. It was the carers who supplied the knowledge, I merely interpreted it. The participants and their accounts shaped and changed the way I felt about carers. This shift in my position from expert to novice influenced not only my interpretation of the findings but my interpretation of myself as practitioner and researcher. It became easier to open my mind to new ways of seeing what was going on, such as the dramaturgical perspective, because I could leave my ‘expert knowledge’ behind. Reflexivity throughout the process concentrated upon my performance and the role of empathy, the emotional impact of doing the research and the implications of the setting of the research.

My performance

Reflecting on my role as a researcher I realised that I too was a performer. When conducting the interviews I developed my ‘front’ when presenting myself to the participants. I felt it was important to have a professional appearance and manner in order to give participants confidence in me and my endeavour. I was making a statement that I was serious about what I was doing and I felt that this showed that I valued the participants’ time and what they had to say. I thought this approach would also give me some protection from the emotional onslaught of the interviews. By creating my front, I used the same defences I would use in my professional work with patients and their carers.

This was just one example of how my professional and cultural values and experience were imposed upon the study.

Throughout the research process I was also working full time as a community palliative care nurse specialist. Some of the interviews were arranged during my working time. I found it difficult to switch directly from a therapeutic visit to one of my patients to a research visit to interview a carer. The textbooks say that the interviewer should remain neutral (Bowling, 2001:382; Patton, 2002:365) but I found it impossible not to give empathetic and affirmative responses to the intensely moving accounts that the participants gave. I challenged Naomi when she repeatedly said that she should have done more for her husband. I congratulated Sharon when she described how she woke her sister at just the right moment before her father died. But as Romanoff (2001) points out, although the explicit purposes of the encounters differ and should be clearly stated, in actual practice narrative therapy is investigative research and interview research is often therapeutic. I am not suggesting that I necessarily had a therapeutic effect but I believe that a number of the carers benefited from having their opportunity to vent their feelings and tell their side of the story. The participants raised many concerns during the interviews which could not be left unattended to. After every interview when I had switched off the audio recorder, there was a period of talking between us. Issues raised in the interview were addressed and aspects of bereavement were acknowledged. Some sort of equilibrium was restored and I felt some reciprocity was achieved between us before I left.

Holland (2007) explores the ethics of empathy in the research process. She presents the feminist critique of the traditional social science interview as a male paradigm and the argument that the feminist interview should be non-hierarchical, with the interviewer investing their own identity in the exchange, even becoming friends with the interviewee. However, as Holland argues, one of the many fears of deploying emotions in this way in the research process is that the feminist interviewer, showing empathy towards the participant, might gain a very good rapport and the interviewee might explore and reveal more of her intimate experiences and emotions than she might have wished. Although some carers may have revealed more than they had anticipated about their experience and their emotions, I do not think that I manipulated them into disclosure by being too intimate or faking friendship. I feel that I trod a fine line between detached professionalism and becoming too intimate with the both male and female participants. Woodthorpe (2009) described a similar conflict in managing a professional detachment and a personal response of empathy when interviewing visitors to a cemetery for her research.

Part of my performance included saying 'Oh that's alright' when a participant had forgotten our appointment for her bereavement interview and was not at home when I arrived. This happened on a day off from work. I had dressed appropriately and driven 20 miles to her home and as far as I was concerned it was not alright. I reminded myself, however, that she was doing me a favour by agreeing to participate. I also had to remind myself constantly that other people's lives did not revolve around my research in the same way that mine did. This applied to my colleagues whom I depended upon to refer potential participants. I felt uncomfortable about nagging them with frequent reminders of my need for participants, but I am immensely grateful to my colleagues for their role in the study. Their on-going interest throughout the process has been tremendously supportive.

There were situations where I questioned whether I was crossing the line into coercion. The carer who forgot our arrangement for her interview also cancelled the next appointment at the last minute. I thought this may have indicated that she did not wish to do the interview. Fortunately it was her sister who phoned to cancel so I was able to ask

her whether she thought her sister wanted to participate or not. She confirmed that she did and felt bad about the cancellations. So we eventually did the interview. However, another carer cancelled two appointments for a bereavement interview by leaving messages with our team secretary. I had a gut feeling that he did not really want to do a second interview and I did not pursue it further with him. Intuition and instinct were just part of the complexity and multiplicity of the qualitative research process (Woodthorpe, 2009) and I had to rely on them from time to time.

Sometimes my performance as interviewer was better than others and it was difficult to listen to the recordings as I transcribed them. This was most acute with carers who were shy or unused to talking about themselves. I seemed to be talking more than them, asking questions in encouraging ways in my attempts to put them at their ease or to probe for responses. My style of interviewing and my interpretation of the data inevitably shaped the findings and the analysis, but I tried to balance my influence to a certain extent by constantly reflecting on my performance. I recorded in my field notes how I felt I had done after each interview and tried to develop my interview techniques as the data collection progressed. It was revealing that the first two participants were the only ones to decline the second interview, suggesting to me that I lacked confidence and expertise at the beginning. With the analysis, I tried to balance my influence with frequent reference to concepts in the literature.

Emotional impact

Holland (2007) argues that understanding emotions is essential to the pursuit of knowledge and that researchers value the extra power in understanding, analysis and interpretation that the emotions they experience in the field can bring to the research. My professional defences against emotional pain are not always effective when I am at work and they were certainly put to the full test during the interviews and while transcribing and coding them. The carers expressed a whole range of feelings - frustration, helplessness, grief, anger, fear and anxiety. Going over and over them was an emotional experience for me. I found I was humbled as a result of the interviews. As Valentine (2007) found when doing qualitative research with the bereaved, the emotional impact of an interactive approach can prove at least as challenging as the intellectual task. On the other hand, there was also humour and some of the participants and I were able to laugh together about aspects of their experiences. I hope Romanoff (2001) is right when he suggests that even the agreement to participate demonstrates therapeutic change, as participants agree to a painful line of questioning because they want to help others or because it's time to give something back. Giving their accounts becomes a means of healing through altruism. Believing that participants may have gained some benefit from expressing their emotions helped me to deal with them.

All of the participants knew my professional role and that I am employed by the hospice. Although it was uncomfortable to hear, I was relieved that some of them felt able to criticise the services of the hospice. In this respect I made a particular effort to remain neutral. I resisted all instincts to defend the hospice or any other health and social services the carers expressed problems with, or indeed to confirm their criticisms. I was left, however, with my own feelings of discomfort and disappointment. There was only one instance where I felt that there might be ethical grounds to pursue the carer's criticisms with the management of the service concerned. I took advice from my colleague who was checking the accuracy of my transcribing and had therefore read the carer's complaints. We agreed that the carer reported in the interview that adequate action had been taken to resolve the problems and that I did not need to take it any further.

The Setting

As well as my performance in the interviews, their location was very relevant. Most of the interviews took place in the patient's home. I found I was drawn into the carers' dramatic setting and this had an impact on my role as a researcher. In the current carer interviews I was always aware of the presence of the patient even though they were generally in another room. Where possible I introduced myself to the patient when I arrived and thanked them afterwards for allowing me into their home and taking their carer away from them for a while. The patient sometimes interrupted the interview or paid carers came to ask for information and throughout the interview some carers remained on the alert for their patient's needs. On one occasion I helped the carer with immediate nursing needs. Another interview had to be suspended and re-arranged because of the patient's needs. I found it was essential ethically and personally to be flexible in this way because of the nature of the research. However, these situations confirmed that my professional nursing stamp was ever present within the research setting and therefore within the whole process.

Most of the bereavement interviews took place in the same location as the previous interviews but the setting had changed. Not only was the patient no longer there, but often the furniture had been re-arranged now that the hospital bed and other equipment had been taken away. A sense of emptiness pervaded the setting. However, I was struck by the way the bereaved carers gestured to where the patient had lain or died when talking about the events around the death, indicating that the drama continued despite the patient's physical absence. The question arose in my mind - do I sit in the patient's empty chair? Gut feeling generally answered this question and permission from the bereaved carer.

Although I have lots of experience of being with the bereaved, the time spent with these bereaved carers had a different impact on me because they were doing the interview for my benefit. The power relations between us were therefore different from when I am a professional visitor offering support and advice. I was more aware of this difference in the bereaved than in the current carer interviews. This may be because I perceived myself and was perceived by current carers as being particularly knowledgeable on my professional speciality of care of the dying, whereas because bereavement is a universal experience, I was no longer seen as having more knowledge or expertise than anyone else. This was confirmation of the enlightening realisation that the carers were the experts and I was learning from them.

Information sheet for research participants 1

An exploration of the expectations and preparedness of carers of terminally ill patients at home: what helps and does not help them.

What is the project about?

There is a lot of research evidence that being a carer for a terminally ill person at home is a very demanding experience, but it can also be a rewarding one. There is less research about what helps and does not help to prepare carers for looking after someone at the end of their life. This research project aims to find out from carers about their experiences and expectations about caring for a terminally ill relative or friend. It will ask carers what helps and does not help them to feel prepared for the final stages and it will ask those same carers later on what helped and did not help them to care and to cope at the end of that person's life. The overall aim is to see if there are ways in which information and services for carers of the terminally ill should be changed and improved.

Who is involved in this project?

Jenny Newbury, a Dorothy House nurse specialist, is doing the research as part of her doctorate studies at the University of Bath. Other members of staff at Dorothy House may be involved in some of the analysis of the data. Carers have been identified by Jenny's Dorothy House colleagues.

What is involved if I do take part?

You will be asked to do two interviews.

- Interview 1 while you are caring
- Interview 2 when you are no longer in the caring role

Initially Jenny will phone you to make an appointment to visit your home (or a mutually convenient place) for the first interview. She would like to spend up to an hour with you to ask questions about your experience as a carer. She will tape record the whole interview if this is acceptable, in order to make an accurate record of your comments. She will also ask your permission to contact you again later on to arrange the second interview which will ask you to look back on your experience as a carer.

Do I have to take part?

No. Taking part in the project is entirely optional. If you choose not to be involved in the project, this will not affect your care or that of the person you care for in any way.

Are there any potential drawbacks for me?

It is recognised that this project covers a very sensitive topic. Talking about caring for someone who is very close to you can be upsetting. If you find it too distressing you can withdraw from the interview at any time. Talking about it can also be helpful, even if you are distressed. Although Jenny will be visiting you as a researcher, if necessary she will use her professional experience as a Dorothy House nurse specialist to support you and, with your permission, she will let your nurse specialist know of any particular concerns that you express.

It is also recognised that caring is very demanding and Jenny does not wish to add to the demands on you. It is important that you do not feel under any pressure to take part and that you only participate if you feel you want to. If you feel that being interviewed is too much for you to take on, you can withdraw and cancel the appointment at any time. Or you may wish to change the appointment. You can contact Jenny Newbury at Dorothy House on 01225 722988 or jenny.newbury@dorothyhouse-hospice.org.uk.

What happens to the information?

All information you give is entirely confidential. The tape recordings are transcribed into written words, and all the comments are analysed together to give a full picture of your experiences, and others like you. All the tapes and documents are kept in a locked cupboard and only the analysis team can see them. At the end of the project all original material will be destroyed. When the research report is written your name will be replaced with a pseudonym and it will include no information that could identify you.

There are rare circumstances, such as instances of abuse, in which a researcher has a duty to disclose information gained during the research. Should a situation like this arise, Jenny would inform you and would seek professional advice, before disclosing any relevant information.

What if I want more information?

Please feel free to contact Jenny for more information. If she is not at Dorothy House when you phone, please leave a message with the nurse specialists' secretary and she will phone you back.

What if I want to complain?

Please raise any concerns or problems with Jenny initially if you feel able to. If you would prefer to speak to someone else please contact Alison Stevens, Director of Nursing, or Sarah Whitfield, Chief Executive, at Dorothy House on 01225 722988.

Appendix 8 Invitation letter – current carers

Date:

Dear

An exploration of the expectations and preparedness of carers of terminally ill patients at home: what helps and does not help them.

Your name has been passed on to me by your Dorothy House nurse specialist, *name of nurse specialist*.

I understand that you are the main carer for *name of patient*. I am writing to you to ask whether you might be willing to take part in a research project looking into the experiences of carers. The attached information sheet explains more about the project and how you might be able to help with it. When you have read it carefully, please return the attached reply slip below in the enclosed pre-paid envelope saying whether I can contact you again about being involved in the project. If you have any questions before making a decision, please phone me on 01225 722988 or e-mail jenny.newbury@dorothyhouse-hospice.org.uk.

I look forward to hearing from you.

Yours sincerely

Jenny Newbury

.....

Reply slip

An exploration of the expectations and preparedness of carers of terminally ill patients at home: what helps and does not help them.

I have read the Information sheet for research participants 1 and I am/am not (*please delete*) willing to be contacted about taking part in the project.

Name:..... Signature:.....

Date:.....

Date:

Dear

An exploration of the expectations and preparedness of carers of terminally ill patients at home: what helps and does not help them.

You may remember being interviewed by me for the above research project. I am sorry to hear that since then *name of patient* has died.

I am now writing to you to ask you to consider taking part again. The attached information sheet reminds you about the project and how you might be able to help with it. In about a week's time I will phone you to find out whether you are willing to be interviewed again. Remember, taking part is entirely optional. Please read the information sheet carefully and if you have any questions before making a decision, you can phone me on 01225 722988 or e-mail jenny.newbury@dorothyhouse-hospice.org.uk.

Yours sincerely

Jenny Newbury

Information sheet for research participants 2

An exploration of the expectations and preparedness of carers of terminally ill patients at home: what helps and does not help them.

A reminder of what the project is about

There is a lot of research evidence that being a carer for a terminally ill person at home is a very demanding experience, but it can also be a rewarding one. There is less research about what helps and does not help to prepare carers for looking after someone at the end of their life. This research project aims to find out from carers about their experiences and expectations about caring for a terminally ill relative or friend. It will ask carers what helps and does not help them to feel prepared for the final stages and it will ask those same carers later on what helped and did not help them to care and to cope at the end of that person's life. The overall aim is to see if there are ways in which information and services for carers of the terminally ill should be changed and improved.

Who is involved in this project?

Jenny Newbury, a Dorothy House nurse specialist, is carrying out the research as part of her doctorate studies at the University of Bath. Other members of staff at Dorothy House may be involved in some of the analysis of the data that Jenny collects.

Carers have been identified by Jenny's Dorothy House nurse specialist colleagues.

What is involved if I do take part?

Jenny will phone you to make an appointment to visit your home (or a mutually convenient place). She would like to spend up to an hour with you to ask questions about your experience as a carer. She will tape record the whole interview if this is acceptable, in order to make an accurate record of your comments.

Do I have to take part again?

No. Taking part in the project is entirely optional. If you choose not to be involved in the project this time, this will not affect your follow up care in any way.

Are there any potential drawbacks for me?

It is recognised that this project covers a very sensitive topic. Talking about caring for someone who was very close to you can be upsetting. If you find it too distressing you can withdraw from the interview at any time. Talking about it can also be helpful, even if you are distressed. Although Jenny will be visiting you as a researcher, if necessary she will use her professional experience as a Dorothy House nurse specialist to support you and she will refer you to the Dorothy House bereavement service if you feel you need further support.

It is also recognised that bereavement can be a very difficult time and Jenny does not wish to add to your difficulties. It is important that you do not feel under any pressure to take part and that you only participate if you feel you want to. If you feel that being interviewed is too much for you to take on, you can withdraw and cancel the appointment at any time. Or you may wish to change the appointment. You can contact Jenny Newbury at Dorothy House on 01225 722988 or jenny.newbury@dorothyhouse-hospice.org.uk.

What happens to the information?

All information you give is entirely confidential. The tape recordings are transcribed into written words, and all the comments are analysed together to give a full picture of your experiences, and others like you. All the tapes and documents are kept in a locked cupboard and only the analysis team can see them. At the end of the project all original material will be destroyed. When the research report is written your name will be replaced with a pseudonym and it will include no information that could identify you.

There are rare circumstances, such as instances of abuse, in which a researcher has a duty to disclose information gained during the research. Should a situation like this arise, Jenny would inform you and would seek professional advice, before disclosing any relevant information.

What if I want more information?

Please feel free to contact Jenny for more information. If she is not at Dorothy House when you phone, please leave a message with the nurse specialists' secretary and she will phone you back.

What if I want to complain?

Please raise any concerns or problems with Jenny initially if you feel able to. If you would prefer to speak to someone else please contact Alison Stevens, Director of Nursing, or Sarah Whitfield, Chief Executive, at Dorothy House on 01225 722988.

CONSENT FORM

An exploration of the expectations and preparedness of carers of terminally ill patients at home: what helps and does not help them.

Lead researcher: Jenny Newbury

- I confirm that I have read and understand the information sheet for research participants 1 for the above project and have had the opportunity to ask questions.
- I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without my care or that of the person I care for or my legal rights being affected.
- I agree to take part in an interview in relation to the above project.

Name of participant

Date

Signature

Name of interviewer

Date

Signature

1 copy for participant
1 copy for interviewer
1 copy for Dorothy House records

Appendix 13 Thank you letter to participants

Date:

Dear

Re: An exploration of the expectations and preparedness of terminally ill patients at home: what helps and does not help them.

Thank you very much for taking part in the above project by being interviewed yesterday. The time and thought that you gave to the interview are greatly appreciated.

The recording of the interview will now be transcribed and anonymised. If you wish to discuss any aspects of the interview or your involvement in the project please do not hesitate to contact me.

Please find enclosed a copy of your consent form.

Yours sincerely

Jenny Newbury
jenny.newbury@dorothyhouse-hospice.org.uk