UNIVERSITY OF SOUTHAMPTON

Family Caregivers in Palliative Care:
Perception of Their Role and Sources of Support

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ABSTRACT

FACULTY OF MEDICINE HEALTH AND BIOLOGICAL SCIENCES
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Doctor of Philosophy

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Although previous literature has examined family caregiving in a number of environments, there has been a lack of information and understanding of the nature of family caregiving within palliative care.

Two studies were undertaken to establish the expected and actual role and position of family caregivers in palliative care, from a health professional and a lay person perspective. In the first study health professionals from a range of backgrounds in both primary care and specialist palliative care were approached to discover their perception of family caregiving and their role in palliative care. Secondly the family caregiver's perspective of their role and position in palliative care was examined using a case study methodology. In addition, this second study also sought to understand the nature of the relationship of family caregivers with visiting health professionals and other sources of social support.

The findings revealed that family caregivers in palliative care settings are frequently in an ambiguous position. Whilst they are considered essential to the well being of a palliative care patient, there are little or no guidelines for health professionals as to the role of these individuals within a total package of care. Family caregivers themselves are often equivocal about their role, and many do not identify with the term 'carer' at all. Because of the ambiguity, family caregivers often assume a subservient role to that of the patient and ignore or deny their own needs for emotional support. Their relationship with health professionals is often limited to discussions of care and management of the ill person, rather than their own needs. In addition they often act as co-ordinators of information between health professionals. Family caregivers seek emotional and practical help from other family members first and foremost, and friends and neighbours generally in the absence of close family support.

The role and position of family caregivers in palliative care needs to be clarified so that appropriate support and assistance can be directed to both the needs of the patient and those close to them. The appropriateness of using the term 'carer' to represent family members of the ill person needs to be carefully considered. This would help to reduce the ambiguity experienced by family caregivers, especially in circumstances where they do not identify with the term carer.

The contribution of both studies to the understanding of family caregivers in palliative care is discussed, as are the implications for policy and practice.

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Glossary of Terms

Throughout this thesis, a number of references will be made to terms and definitions that are outlined here for clarity. Many of these terms may be used in different ways throughout the general literature. For this reason, I will outline my use of the term. Where there is some debate about the use and extent of a particular term, I will make clear the reason for my choice of definition and use within this thesis.

'Cared for person' is the individual receiving care, whether social, psychological, personal, nursing or medical, from either health professionals or family caregivers.

'Carer' refers to someone who provides care and assistance to another individual. This may be during the course of paid professional employment, or as a result of a pre-existing relationship with the cared for person. The interchangeable use of the term "carer" may cause problems in distinguishing between these two groups of carers. An important distinction between the two groups is the level of formal training and qualifications. Issues of pay for providing this care may also differ between the two groups. Someone who undertakes the carer role as a result of a pre-existing relationship does not generally receive financial remuneration, however, they may be able to claim the carers' allowance if they are providing assistance over a certain number of hours a week. Another distinction between the two groups of carer referred to here is that the first is provided by statutory or private sector organisations. Organisational carers of this type have clear guidelines and policy about the nature and extent of caregiving that will be provided, and the times such care will be available. The second type of carer, those who undertake the role as a result of pre-existing relationship, do not generally have such guidelines to work to, and the nature and extent of caregiving within this group may therefore be seen as unreliable and variable. For this reason, individuals who provide care as a result of pre-existing relationships are often referred to in the literature as informal or lay carers (see below).

'Family caregiver' is an individual who is viewed by health professionals and occasionally by the cared for person as being the person primarily responsible for delivering the majority of care and support at home. The family caregiver provides unpaid assistance to the cared for person as a result of their kin relationship. Occasionally, the family caregiver may be in receipt of the carer allowance as a result of their caring activities. The range and extent of the assistance given is variable and dependent on the needs of the cared for person, and the resources and ability of the family caregiver. Informal or lay carers are also terms used to represent close kin within palliative care, hence the reason for the use of the term 'family caregiver' within this thesis. The relationship connection is a significant factor in the decision and willingness to undertake this form of care. For this reason, the term 'family caregiver' appears to be a more accurate reflection of the role than 'informal' or 'lay carer' both of which fail to openly acknowledge the family commitment and willingness to be involved in this type of care.

'Health Professionals' are trained individuals from either a medical or nursing background or professions allied to medicine (PAMs). For the purpose of this thesis they are employed to provide generic or specialist palliative care services.

Hospice is the term used to describe the nursing, medical, social and spiritual care provided within a hospice building or organisation. Such care would generally be perceived as being specialist palliative care; nevertheless there is also a large proportion of care given in a hospice setting that is provided by volunteers who may or may not have any formal training and support in such a role.

'Informal Carer' or 'Lay Carer' generally refers to the unpaid and voluntary support that undertaken due to pre-established relationships. The term 'informal carer' is a broad definition for individuals who may be providing unpaid care, that is not provided by other statutory or private sector organisation. Often, though not always, family or kin members are thought to undertake this type of caring. Occasionally, friends or neighbours may also be involved in giving this type of care. The care provided by these informal carers might be social, personal, financial or nursing. Furthermore, this care and support might be demonstrated by either instrumental or emotional concern for the ill person's well being. Due to the confusion and ambiguity with the use of the term I have chosen to refer to the main participants in the study as family caregivers (see definition above). The informal carers referred to in this thesis are generally not expected to have received formal training, although they may have acquired skills and expertise relating to the specific care of the person for whom they are caring.

Macmillan/Home Care Nurse is a specialist palliative care nurse who visits the patient and family caregiver at home. The reason for the distinction between the two terms is due to the different ways in which the centres through whom the family caregivers were contacted referred to their staff. These nurses act in an advisory capacity and do not deliver hands on nursing care. They are part of the specialist palliative care service, and have direct links with the hospice and associated medical and support team. They often provide advice and assistance to the individual patient and their family and the associated team of primary care professionals who may be involved in a situation.

Palliative Care has been defined by the World Health Organisation (WHO 1990) as "the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount". Higginson (1990) has also defined palliative care as "a person centred approach concerned with physical, psychosocial and spiritual care in progressive disease". Palliative care aims to support both people with advanced disease and their immediate family. Palliative care may be generic or specialist. Generic providers include members of the primary health care team or hospital teams. Specialist providers are often found in a hospice or hospital setting (see Specialist Palliative Care Services below). Within this thesis the term 'palliative care' has been used to represent care given to someone with a progressive disease, where treatment is no longer curative but aimed at the relief of symptoms.

Primary Care is used to refer to all services provided in the community by statutory health and social care professionals. This will included General Practitioners (GPs), District Nurses, Social Workers, Occupational Therapists (OTs), Physiotherapists (PTs), and social care workers such as home care workers. All these services are provided on a professional paid basis.

Specialist Palliative Care Services (SPCS) are specialist services focusing on palliative care to individuals whose deaths are anticipated (NCHSPCS 1995). As a result, SPCS differs from generic palliative care in the degree of expert knowledge and skills that are brought to a situation. A range of health professionals provide SPCS either directly to the ill person, or indirectly by providing advice and information to generic palliative care providers and family caregivers. Historically, there has been a concentration on the provision of SPCS to patients suffering from Cancer, Motor Neuron Disease (MND), and HIV/AIDS; however, this is now being challenged (NCHSPCS 1998).

Chapter One

Introduction

1.1 Origin of the Thesis

This thesis had its origins in my previous professional background of district nursing. When working with those who were terminally ill, I often found that a large part of my time was spent supporting the family members who were caring for that person on a day to day basis. My desire therefore was to better understand their perception of the situation in order to provide more effective care and support to them.

As a start to this I first wanted to determine who these caregivers were, and what they perceived to be their needs. As I began my literature search it became clear to me that whilst there was an abundance of literature on "carers", there was very little that related specifically to those in a palliative care setting. It is my contention that although there may be many similarities between carers of different groups, a particular disease trajectory and the certain process of dying acknowledged within palliative care will have a consequent impact on the situation that can not be accounted for in a general literature. Therefore I proceeded to undertake a specific study designed to explore the perception and role of family caregivers within a community palliative care setting.

First I needed to consider the process by which I would be able to answer the questions that my investigation into the literature had raised. Who were the informal carers in palliative care, what did they actually do, how did they themselves see what they were doing, where did they gain emotional and practical support, what was the best way for service providers to support them in this role, and, most importantly, in what ways do these things change over time? I began to explore the qualitative methodology literature and was heavily influenced by Jennifer Mason's book entitled "Qualitative Researching" (Mason 1996). Also, the work of Jonathan Smith and Interpretative Phenomenological Analysis (Smith 1996, Smith et al 1999) appeared to offer the opportunity to attempt to

understand the individual perspective within an interpretative approach. I used the principles of this process for the first study where I explored the health professional's interpretation of the role of "carer". Finally, I was also influenced by Yin's "Case Study Methodology" (Yin 1994) which allowed me to understand the contextual situation which appeared to be so important for the family caregivers in this situation.

The thesis therefore began by trying to understand the perspective of health professionals within palliative care and primary care. My desire was to be explicit about the term "informal carer", its use by these groups of health professionals, and the expectations that might ensue as a result of its use. What emerged was a sense of the difficulty in defining such a term, and the recognition that whilst the term was used, there was a desire not to force individuals into a role that they did not feel comfortable in or were unable to perform. Despite these difficulties, the term was used in a general way to represent family caregivers who were either closely connected to the patient by kinship relationships or by geographical distance. It was necessary for me to understand the process by which a family member might be considered an "informal carer" for two reasons. The first was that my access to this group for the second study was going to be via health professionals, and although I was very explicit about who I wished to be included within the study, the choice about who to approach was left with the health professionals. Secondly, I wished to understand how health professionals interpreted their relationship with this group, in order to compare this with the way that family caregivers understood their relationship with health professionals.

The thesis then moved on to explore the family caregiver's perception of their role within community palliative care. I wished to move away from the traditional caregiver literature that had focused on the burden that this group experienced, and explore their interpretations of the situation, and their relationship with health professionals and other sources of social support. I explored these issues with 16 family caregivers, identified by the health professionals who worked within Specialist Palliative Care Services (SPCS). What emerged was the variety of the experiences of this group. However, a number of similarities can also be extracted from the stories, which I believe can be of assistance to us

in understanding firstly the family caregiver's perspective, and also the ways in which health professionals may be of assistance to them in this role.

1.2 Structure of the Thesis

The thesis has been divided into a number of chapters that will explore in more detail each aspect of the process of this investigation into the family caregivers' world within palliative care. In chapter two I will review the literature in relation to informal or family caregivers, the development of the use of the term informal carer and the implications this has for its use in the literature relating to family caregivers in palliative care. Next I will begin to explore the way family relationships and a sense of kinship may influence an individual, and the support and expectations that these relationships may engender. Finally in this chapter I will critically examine the problems with the literature and gaps in knowledge about this group.

In chapter three I will discuss the methodological issues and approaches adopted within the thesis. Included in this will be a critical examination of the issues of reliability and validity within qualitative approaches, and a discussion of how this may be addressed within the current study. Ethical issues relating to research in sensitive areas, and in particular relating to palliative care will also be considered

Chapter four will present the health professional study. This sought to examine health professionals' perspectives of the position and role of informal or family caregivers within palliative care.

Chapter five will introduce the family caregivers study. In this chapter, the design and methodology used during the study will be introduced.

Chapter six will present the statistical and demographic details of the participants in the family caregiver study. Analysis of the standardised quantitative questionnaires used will be discussed, and the implications for the study explored.

Chapter seven will begin to present some of the qualitative findings, relating the main themes to the individual participants' stories and experiences. In this chapter I shall explore the family caregivers' perceptions of the role of carer, and how this may influence their adoption of a particular position within the situation and subsequent experiences.

Chapter eight will continue to explore the family caregivers' perceptions of their role and relationship with visiting health professionals, and other sources of social support. In this chapter I shall seek to understand the complex nature of the interaction between family caregiver and health professional, and how the understanding of the role of carer may influence this. In addition I shall begin to explore the meaning and interaction that the family caregivers held of perceived social support. The influence this may have on their perception of the situation will also be considered.

Finally, the last chapter will begin to examine the implications, both theoretical and practical, of the findings of the study and the way in which this research may be taken forward in the future.

Chapter Two

Family Caregivers in Palliative Care

2.1 Chapter Overview

This chapter will explore the background literature relating to family caregivers in palliative care, which formed part of the impetus for the thesis. Principally the chapter will focus on the definition of family caregiving, its role and consequences. In addition it will critically examine the research about family caregivers within palliative care.

The chapter will begin with an exploration of the term informal carer, its development and use in the general literature. This will be followed with a reflection on the role of informal carers, their relationship with service provision and their needs. The lack of clear analytical definition of the term informal carer, or carers as they are often referred to, will be considered.

Next the nature of family caregiving will be examined. The context of family caregiving and the implicit expectations associated with this role will be explored. The negative impact of caregiving will be challenged by alternative approaches.

The following section will continue with a discussion of palliative care. Current philosophies of palliative care and the role of specialist palliative care will be considered. The needs and role of family caregivers within palliative care will be explored.

Finally the chapter will conclude with a critique of the literature and methodologies used within family caregiving and palliative care. The lack of research within palliative care in relation to family caregivers' perceptions and experiences will be discussed.

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2.2 Who is a "Carer"?

2.2.1 Defining the term carer

The term carer was not used until the 1970s (Heaton 1999). Since then the literature relating to this group of individuals has mushroomed. Despite this explosion in the literature, definitions of the term carer remain ambiguous (Twigg 1989 & Spackman 1991). Pitkeathly suggested that a carer was someone whose own life was in some way restricted by the need to be responsible for another (Pitkeathley 1989). This is differentiated from 'normal' caring, for example child rearing, which is usually time limited in some way and involves an expectation of reciprocity and expressions of warmth and affection.

The Carers National Association (1996) defines a caregiver as anyone who "is looking after a friend or relative, who because of disability, illness or the effects of old age, cannot manage at home without help". Neale and Clark (1992) propose that informal care is usually defined as "that provided by spouses or other relatives, friends and neighbours to the chronically focusing around the tasks performed for the dependent person, some definitions have also focused on the number of hours spent giving care, and a few on the restrictions imposed on the carers (Twigg et al 1990).

The sample of definitions above reflects the implicit assumptions and expectations surrounding the term. Although there is some acknowledgement that a carer will be supporting another person in some way, the extent, level and degree of such support is unclear. Few of the definitions focus on the understanding and perception of the individual carer, and those that do tend to concentrate on the negative rather than the positive aspects of the role.

Twigg et al (1990), suggest that the origin of the term 'carer' stems from a professional service orientation, and is therefore interpreted by many as referring to somebody whose paid employment is within the caring field. Many individuals who are giving care in a voluntary or informal capacity do not perceive themselves as carers, and see their role more as a continuation or extension of the relationship with the individual who is being cared for. Twigg et al therefore suggest that the concept of a 'carer' lacks

clear analytical definition and often centres on the performance of supportive 'tasks', whilst ignoring the social and familial relationships with which it is bound.

2.2.2 Informal and Formal Carers

By dividing the term carer into informal and formal categories there is an assumption that there are differences in the level and type of care provided by each group. Formal carers are also referred to as professional carers, as they are paid to provide professional or specialist knowledge and expertise to a particular group of clients or patients. Informal carers on the other hand are generally unpaid and untrained and providing care as the result of a pre-existing relationship with the cared for person. Informal carers are also referred to as lay carers, home carers, and unpaid or untrained carers. The distinction between the two terms surrounding training and expertise implies that formal or professional care is more desirable than informal or unpaid care. However, this fails to take account of the acquired experience and expertise developed by informal carers, particularly if they have been caring for a long time (Nolan et al 1996a).

The term "carer" is increasingly being used in political debate and in policy development (Twigg & Atkin 1994). Indeed Heaton (1999) argues that there has been a polarisation of informal and formal roles in social policy that has conceptualised the informal carers as primary providers of care in the community and formal care as a sustainor of the informal network providers. Heaton goes on to suggest that the fact the Carers (Recognition and Services) Act (HMSO 1995), is not called the Informal Carers Act demonstrates the synonymous use of the term carer with informal carers rather than formal carers.

Understanding how the definition of the term informal carer has been developed within social policy is important due to the changing nature of the National Health Service (NHS). This has resulted in an increasing dependence on the informal carer network to provide a high and reliable standard of care to chronically ill and dependent individuals. Whilst many informal carers may wish to look after dependent or disabled relatives, and see such care as part of their duty, there are those who neither wish nor have the skills or resources to be able to undertake such care. In addition, for many of

those individuals who do undertake to care for their relative in an informal community setting, the constant responsibility and lack of appropriate support can result in physical, emotional, and financial strain (Neale 1993). Unlike statutory care, there is no governing body or established support network to sustain this resource. Thus, caregiving situations may break down, and as a result increased input from statutory services may be required.

Informal care therefore represents that care carried out by unpaid and untrained individuals who are already known to the ill person. Due to these pre-established social relationships, informal care is often unevenly distributed (Twigg 1989). Alternatively, formal care is not dependent upon previous relationships, is available to all on a basis of need and is effectively neutral (Neale & Clark 1992) However, the changing nature of the NHS and social policy definitions of informal care have significant social consequences for family caregivers (Heaton 1999).

2.2.3 Carers and Service Provision

The General Household Survey (OPCS 1988) asked, for the first time for details of the numbers of carers and the number of hours that were spent giving care. A conservative estimate of 6 million individuals were thought to be involved in informal caring. In the 1990 survey, it was believed that 6.8 million individuals or 1 in 7 people were undertaking some kind of caring role (OPCS 1990). The range of tasks may vary from simply providing company to catering for the needs of a severely disabled person who is dependent on help to perform all personal, domestic, and social requirements (Spackman 1991)

Changing patterns of health care are placing increasing reliance on family members to provide care for their sick and disabled relatives. Government policy has placed increasing pressure on family caregivers in recent years by explicitly stating that care in the community should be provided by the community (Heaton 1999).

Informal caring may cease, or be withdrawn, if a breakdown occurs in the carer's own health or social circumstances (Hinton 1994a). Not only is this particularly distressing for the carer and the patient, but it also creates a significant problem for health

professionals and statutory services that may be required to fill the gap. Prevention of such a breakdown should therefore be addressed as a matter of urgency. Identification of those carers who are likely to become distressed or overwhelmed by their caring responsibilities enables them to be offered appropriate support and encouragement in order for them to be able to continue in their role, if this is what they desire. The NHS Community Care Act 1990 recognised the importance of identifying the needs of these carers, although it failed to provide a means by which these needs might be addressed (NHS Community Care Act 1990).

The Carers (Recognition and Services) Act 1995 finally provided a means of recognising the work and commitment of informal carers by the statutory services (HMSO 1995). Whilst this move was welcomed by many carers groups, it has limited ability to provide significant services to informal carers, and continues to concentrate on the instrumental aspects of caring. In addition, Nolan et al (1996b) suggest that the implementation of the Carers Act has a number of difficulties associated with it, particularly the use of pre-defined 'heavily involved' carers. Nolan et al believe this will result in a concentration on those carers providing tangible heavy nursing type care, and ignore those who are acting in a monitoring 'invisible' capacity.

Twigg et al (1990) proposed a model that placed carers within a professional service orientation. In this model, carers could be identified as a resource, co-worker, co-client, or superseded carer. Carers as a resource reflect the predominant reality of social care. Informal care represents the 'given' or 'taken for granted' background to professional service care. As a result, informal carers are often relied on by professional service providers to form the basis underpinning additional support. Within this context carer welfare is marginal or non-existent. Nolan et al (1996b) believe this situation is neither morally nor ethically acceptable.

Carers as co-workers are viewed as partners in care. Within this model, professional service providers aim to link with informal carers to provide the support and assistance required by the cared for person. However, informal and formal services are not always in accord with regard to the emphasis of care required. Informal carers' interests and well being may be acknowledged, although not always acted on, in this model, and the primary emphasis remains the cared for person.

Carers as co-clients is perhaps the most useful way to view informal carers' own service need. Within this model, informal carers are regarded as service users in their own right. By limiting the extent of responsibility and reliance on the informal carer to provide care, service providers are able to concentrate on the caregivers' needs. This in turn should lead to a reduction in the level of burden experienced by the informal carer.

In Twigg's model, the term superseded client is used to refer to someone who is withdrawing from acting as the main carer, and where other services are taking on this role. Twigg et al suggest that carers in this model are referred to as 'relatives' or 'family', which is seen to be more neutral and imply less obligation or responsibility for certain tasks.

An alternative typology has been proposed by Nolan et al (1995), whereby informal carers are seen as 'experts' in caring. Within this framework carers acquire experience and expertise which may be supplemented or enhanced by professional carers. Services would work with the informal carer to provide optimum care and support to the cared for person.

Whilst many of these approaches to informal carers are commonly found in community settings, they fail to identify the carer's perspective and influence on the interaction between service providers. In addition, the service approaches to informal carers have failed to accommodate the non-instrumental care given by family caregivers.

2.3 The Role of Carers

Much of the literature relating to informal carers has concentrated on the tangible and instrumental aspects of the role. However, Bowers (1987) and Nolan et al (1995) suggest that other 'invisible' aspects of the role may in fact be more difficult for an informal carer to deal with.

Bowers' work highlighted the importance of protective care, which sought to maintain the self-esteem of the cared for person. However, maintaining protective care could be in conflict with instrumental care if doing something for someone reduces their perception of independence.

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Whilst Nolan et al (1995) acknowledge the contribution of Bowers' work they suggest it is limited in a number of ways. Firstly, it was developed from intergenerational data, which excludes spouse caregivers. Secondly, it was specifically related to caregivers of dementia patients, and therefore excludes other disease trajectories. Thirdly, it failed to account for the reciprocity that occurs within family caregiving. And fourthly, it was based on cross-sectional data, which fails to elucidate the impact of caregiving over time.

Nolan et al (1995) therefore reconceptualised Bowers' model to account for a more diverse set of caregiving experiences. They proposed a new typology of caregiving that includes some of the original features of Bowers' models and an expansion of other features not accounted for in the earlier model. These include:

- Anticipatory care

- Preventative care

- Supervisory care

- Instrumental care

- Protective care

- Preservative care

- (Re)constructive care

- Reciprocal care

In particular, Nolan et al (1995) redefined Bowers' conceptualisation of anticipatory care, which they see as extending throughout the caring experience rather than as a prelude to instrumental care. Nolan et al suggest that prior to overt forms of care being required, anticipatory care may raise questions such as 'what would I do if ?'.

Anticipatory care at this time is largely invisible. If more overt forms of care are required anticipatory care may change to 'what would I do when ?'.

Overt anticipatory care of this type can be either speculative or informed anticipation (Nolan et al 1995). Speculative anticipation is characterised by a lack of information or knowledge about the situation, and can result in over or under anticipating future needs. This will obviously have a detrimental effect on family plans. Informed anticipation on the other hand, can result in greater shared care and planning. By recognising and acknowledging anticipatory care, health professionals and service providers can reduce the invisibility of speculative anticipation. However, within palliative care it is the very uncertainty of the disease trajectory and potential deterioration in the cared for persons condition which make anticipating future needs even more difficult. Furthermore, the uncertainty, particularly within cancer care, relating to fluctuations in recurrence, remission, treatment and the cyclical nature of these interactions which can have a negative impact on the family caregiver and their ability to cope with the situation.

Finally, Nolan et al suggest that reciprocal care is an important factor in understanding the caregiving relationship (Nolan et al 1995). Reciprocity for care given may be found in a number of ways, as the literature on caregiver satisfaction with caregiving demonstrates (Grant and Nolan 1993).

2.3.1 Needs of Informal Carers
There is now a plethora of information concerning the characteristics of informal carers, such as the tasks of caregiving, and the impact of caregiving on the caregiver (Hull 1990). However, little attention has been paid to the specific circumstances relating to a particular illness or medical diagnosis, except in the case of elderly people and those who are cognitively impaired. This represents a major flaw in the caregiving literature, as it would seem reasonable to expect that different disease trajectories and levels of support would have a major impact on the level of stress that a caregiver may be subject to. For example a diagnosis of cancer is often presumed to result in an imminent death. Caring is then seen as requiring intensive involvement for a short period of time. It is therefore often a shock for some carers to find that with modern treatment and therapy a patient may survive for months or even years without further

deterioration. Throughout this time, however, the responsibility and anticipation of the eventual death may prove difficult to cope with.

Understanding the needs of informal carers requires regular reassessment as need may change over time. Hileman et al (1992) used an explicit definition of 'caregiver' and 'need' in a United States Study. Caregivers were defined as "the unpaid person, identified by the patient with cancer, who helps the patient with physical care or coping with the disease process" (p772). 'Need' was defined as "a condition that is important to the subject and that is not being satisfied in the subject's present environment" (p772). A combination of standardised measures was used to assess the needs of carers, and the importance and satisfaction of each need. Furthermore, level of patient activity was examined. A convenience sample of 492 caregivers, from four settings, were recruited and participated in the survey. Factor analysis of the results revealed six categories; psychological, informational, patient care, personal, spiritual and household. There were significant correlations between caregiver characteristics and caregiver need, and caregiver need and patient activity. Both importance and need changed over time, and therefore frequent reassessment of the caregiver appeared to be necessary.

2.4 Family Caregiving

2.4.1 Defining "Family"

The family is a somewhat elusive and yet enduring concept. It is talked about and referred to at both public and private levels, and yet defining what is meant by the term is difficult due to the variability of its composition and nature. The traditional view of the family as comprising of two adults (one male and one female) and a number of children does not account for other types of relationships that may be considered a family. For example single parent families, reconstituted families, families with kinship ties that do not reside together and unrelated individuals who voluntarily combine resources and residence (Kane and Penrod 1995). Aldous (1994) defined a family as a "cohabiting group of some duration composed of persons in intimate relations based on biology, law, custom or choice and usually economically interdependent" (p43).

The family may be thought of as a system, where each individual has a role in ensuring the well being of the whole group (Frude 1990). When one member is sick, the others may choose to support the sick member by undertaking their role and activities within the family in order to maintain the cohesiveness of the group. Families also change over time as they pass through a number of life stages. The life cycle or stage of a particular family may have an impact on its ability to sustain the individual members within the group.

Keating et al (1994) argue that the concept of family caregiving really refers to one person and fails to explore or identify the dynamics of relationships among other people involved. As women have traditionally assumed the role of family caregiver, Neale & Clark (1992) suggest that such care is closely bound to family obligation and perceptions surrounding the woman's role. Arber and Gilbert (1989) however, highlighted the large numbers of men who participate in caring, particularly if they are the spouse of the cared for person. In addition, elderly men and women have been found to provide equal amounts of co-resident care which suggests that there are few gender inequalities amongst older spouses (Arber and Ginn 1990).

Although each family structure and organisation is different, societal norms and obligations do affect the conduct of family members. Within the UK, there has been increasing pressure on families to provide care for sick or disabled members within the community (DoHSS 1981). Individual expectations within the family also affect the degree to which the family caregiving will be expressed. A sense of obligation and duty to their family members is a strong motivation for caregiving if someone is diagnosed with a chronic illness or disability. Likewise, reciprocity for actual or anticipated need is a factor in an individual's decision to become a family caregiver (Neufeld and Harrison 1998).

There has been an assumption that family caregivers will be available and willing to fulfil such roles. These assumptions have been made despite changing demographic and work patterns that have resulted in increasing numbers of women (traditionally thought to provide such care) now being employed in the work force, and therefore being unavailable to undertake other roles (Clark 1995).

2.4.2 Duty Obligation and Reciprocity

Families are viewed as an important source of support in times of crisis, and there are implicit expectations that the family will be available to fulfil this role. Finch suggests that family relationships are fundamentally a social construct, and that a core unifying notion is that of obligation (Finch 1989). The extent to which such obligations are fixed is a matter for some debate, particularly in relation to care provided by children. Finch has suggested that in practice there is little consensus as to the extent, type or degree of obligation of children towards their elderly parents (Finch 1995). Rather she suggests that care given by children to their ageing parents is based upon a sense of commitment. Such commitment is built up over time between the parent and child through shared activities and mutual support as required. Finch argues that it is the level of reciprocity between the individuals that drives the process of developing commitments within family relationships. Thus, it is possible for different children within the same family to develop differing levels of commitment towards their parent, which in turn would make them more or less likely to engage in caregiving should it be required. Finch also argues that care provided by a spouse is much more likely to be provided on the basis of fixed obligations. This could be as a result of the marriage which is based on a legal contract and involves making promises to care for each other. Thus, caring for a spouse could be seen as an inherent aspect of marriage.

If, as Finch suggests, family caregiving is based upon commitment and fixed obligations, this could present difficulties in the future, given the changing nature of family life. Marriage and divorce are now more common, as are reconstructed families. One would suppose that this might lead to a reduction in family caregiving. However, Finch suggests that in times of difficulty, individuals are more likely to rely on their family of origin for support and that relationships with kin therefore become stronger. This in turn increases the probability of an individual engaging in family caregiving at a later date.

2.4.3 Impact of Family Caregiving

Whilst caring for a close family member can be a satisfying and rewarding experience (Thorpe 1993, Grant & Nolan 1993), if care is extended over a long period of time it can become costly physically, emotionally and economically (Neale 1993). In the

General Household Survey (OPCS 1988) one third of carers reported having an illness that limited their activities, and of those over 45 years of age who reported caring for more than twenty hours per week, over half had a long standing illness. Spackman (1991) found that many carers complained of back problems, which may have been exacerbated by poor lifting techniques, or lack of adequate equipment. Addington-Hall et al (1991), found that the most common reason for admission to hospital or hospice was a breakdown in the ability of the carer to continue providing the level of help required to allow the individual patient to remain at home.

One of the major problems for informal carers arises from the lack of long term preparation or understanding of the difficulties that may be encountered. Often caregiving is entered into at a time of crisis with little or no planning and understanding of the problems that may be encountered. These factors may combine with previous kinship relationship patterns, resulting in perceived differences in levels of burden experienced within caregiving (Seltzer 1996). Difficulties may be encountered because of problems in gaining adequate support from outside agencies, such as help with physical care (eg bathing) or financial support (eg attendance allowance or the carers' allowance). Changing behaviour and abilities of the patient (particularly if there are personality changes) and isolation for the carer if they feel unable to leave the patient may also prove difficult. In a study commissioned by the Rowntree Foundation, Healy and Yarrow (1997) found caring was often entered into at a time of crisis. Once involved, it was almost impossible for the carer to withdraw, or receive help from other sources.

2.4.5 Caregiver Burden

Caregiver burden has been used to account for the distress, (physical, emotional and financial) that some family caregivers experience in the process of caring. However, due to the lack of clear definition of burden and the variety of different measures used to assess such levels, it is virtually impossible to compare the findings in a particular group of carers, let alone in a group with different characteristics and needs from the ones studied.

The concept of caregiver burden has been used extensively in the mental health field, although Jones and Jones (1994) suggest that such findings are equivocal due to varying definitions and sampling procedures employed in the studies. It is common, however, for two types of burden to be described in the literature: objective and subjective burden. Maurin and Boyd (1990) attempted to define each of these concepts by suggesting that objective burden relates to observable, tangible costs to the caregiver, whereas subjective burden is the personal appraisal of the situation by the carer. In addition, there may be a number of other social or situational factors that influence the degree to which an individual may experience carer burden.

Several quantitative measures have been developed to identify the factors associated with burden. These are usually questionnaire based appraisals of strain in informal carers and difficulty experienced with caregiving tasks such as disturbed sleep, restrictions on free time, physical strain and family adjustments (Robinson 1983, Oberst et al 1989). However, such measures fail to account for the non instrumental aspects of caring or the complex dynamic nature of the role.

In addition to quantitative methods, there have been a number of qualitative approaches that have attempted to capture the nature and extent of burden experienced within a particular group of carers. Qualitative measures have used both structured and semi-structured interviews, and participant observation. Very often, such studies have concentrated on particular aspects of support received and specific types of physical or emotional distress experienced.

Few studies have attempted to link specific medical diagnosis and caregiver burden, except those focusing on caring for the cognitively impaired (Hull 1990). Whilst there may be some degree of overlap between medical conditions, for example in the type of role changes and adaptation that carers are required to make, it seems likely that some characteristics and situations are unique to each group of carers. For example, caregiving in palliative care is perceived to be a relatively short term commitment, and in addition the support offered by the hospice movement may well influence the type and degree of burden experienced by the carer in this area.

2.5 Palliative Care

2.5.1 What is Palliative Care?

Palliative care has been defined in a number of ways. For example, the European Association for Palliative Care has defined palliative care as "the active, total care of the terminally ill at a time when the disease is no longer responsive to curative treatment and when the control of pain, of other physical symptoms, and of social, psychological and spiritual problems is paramount". Within this definition there is an implicit assumption that "cure" of the illness is no longer an option and that therefore maximising the comfort of the patient is the priority. This is also reflected in the World Health Organisation (WHO), definition of palliative care as the "active care of individuals whose disease is no longer responsive to curative treatment" (NCHSPCS 1997). Johnston (1995) suggests that there are several principles inherent within this statement, namely:

- To affirm life and regard dying as a normal process

- To provide relief from pain and distressing symptoms

- To integrate psychological and spiritual aspects of care

- To offer a support system to help patients live as actively as possible until death

- To offer a support system to help the family cope.

Quite how or when such support should be offered however is unclear.

Over 90% of patients now spend the majority of their last year of life at home (Seale and Cartwright 1994). Care in the community is viewed as the ideal, and patients and carers often express a preference for the death to occur at home (Addington-Hall et al 1991, Hinton 1994b). Thorpe has suggested that the challenge to palliative care services is to facilitate dying in the community (Thorpe 1993). However, demographic changes within the UK (Midwinter 1991, Clark 1995), and the geographical mobility of the population have resulted in changing patterns of family groups, and an ageing

population. Field and James (1993) suggest that families are smaller, and changing household structures, with increasing numbers of women involved in the labour market, have resulted in less availability of informal carers.

2.5.2 The Hospice Movement

The modern hospice movement within the United Kingdom originated with the founding of St. Christopher's Hospice in 1967 by Dame Cicely Saunders (NCHSPCS 1997). Hospice care aims to provide Specialist Palliative Care Services (SPCS see operational definitions at the beginning of the thesis) to alleviate the distress and suffering of patients and their relatives. Over the years, individual hospices have developed throughout the country. These are largely independent, and funded through local or national donations. They are often organised and run as a charity and may or may not be attached to a particular hospice building. As a result, the services provided are variable throughout the country and may include any combination of inpatient, home care, day care, bereavement services and social care. As resources are often limited, service provision is generally aimed at those patients with a cancer diagnosis, HIV/AIDS, or Motor Neurone Disease (MND). Patients with other incurable and chronic diseases are generally accepted by a hospice for care and treatment, only after local consultation. The vast majority of non-malignant illnesses are not able to access SPCS, although they may receive advice and support from both primary and secondary care at some stage. Due to the development of SPCS within hospices and their focus on palliative care, the terms are often used interchangeably.

Since the emergence of the modern hospice movement, informal carers, in the form of family members, have always held an important place in palliative care. The hospice movement views the family as an integral part of the patient's care, including them in the help, support and information provided to the patient (Seale 1989). Despite this focus, Hinds found that as many as 31% of her sample were coping poorly with the physical caregiving they were required to do, and the most frequently expressed need was for a place that they could turn to in order to discuss their fears (Hinds 1985).

2.6 Family Caregivers in Palliative Care

Although family caregivers have been acknowledged as an important group within palliative care, understanding their needs and perceptions has, until recently, been relatively ignored. With increasing dependence on family caregivers to provide and sustain a patient in the community, attention to this group's needs and access to support is important for service providers to be able to implement appropriate assistance to prevent a breakdown in the caring situation.

As SPCS has developed, changing patterns of care and treatment have resulted in a prolonged need for a period of care, particularly for many cancers. Expectations that death will be immediate and caring may only be necessary for a short time span could be responsible for individual family members preparing to take on a caring role that often extends far beyond their expectations.

A review of the literature was carried out to determine current research relating to family caregiving within palliative care. The review covered three databases, CINAHL (Cumulative Index to Nursing and Allied Health Literature), EMBASE, and MEDLINE. These databases were selected as being those most likely to produce a broad spectrum of biomedical and social science literature in the area. The databases were searched from 1980 to 2000. In addition, articles recommended by colleagues, fellow researchers within the area of palliative care, and key articles cited in the literature were also included. It is acknowledged that this does not represent all research within the area. Rather this concentrates on those articles relating to research that represents the way family caregivers have been presented in palliative care. The search was limited to articles in English and keywords used were Family Caregivers, Informal Caregivers, Palliative Care and Hospice Care.

Articles have been divided into those presenting family caregivers as a proxy for patients' views and satisfaction with services, family caregivers' quality of life and experience of burden, family caregivers' needs and family caregivers' perceptions and expectations of the caring role.

2.6.1 Family Caregiver Satisfaction with Services

Often carers have been asked to act as a proxy in determining satisfaction with services for the patient, due to the difficulty of undertaking research with patients who are terminally ill. When family caregivers have been asked to assess patients' symptoms variability has been found amongst studies. Some studies have found patient and family caregiver rating to be different (Nekolaichuk et al 1999) whilst others have found agreement. Field suggests that discrepancies between patient and caregiver usually arose from accounts of psychological symptoms, degree of distress caused by the symptoms and the main symptoms experienced by the patient on admission to hospice care (Field 1995). However, Field concludes that accounts of patients' experiences, as given by their carers, are legitimate sources of information. Robbins suggests that differences between patient and family caregivers may reflect different versions of the 'story', rather than various degrees of accuracy (Robbins 1998).

There is broad agreement between family caregiver and patient perspective for clear cut symptoms and problems. However, there is more likely to be a discrepancy in reporting of levels of anxiety and distress between the family caregiver and the patient themselves. Following bereavement Hinton found retrospective reports less reliable, particularly those relating to pain, anorexia and depression (Hinton 1996). Higginson et al suggest such changes may be the result of variations during bereavement such as grief, coping and mood in addition to recall bias (Higginson et al 1994).

Table 2.1 (which can be found at the end of this chapter) summarises a selection of studies relating to family caregivers' satisfaction with services burden and needs. The range of methods used within the studies highlights the lack of synthesis between studies.

Pottinger (1991) in a United Kingdom study, asked 40 self-appointed primary caregivers to complete a questionnaire regarding the services typically offered by hospice staff. The questionnaire was compiled from a number of standardised scales that were specifically adapted for this particular group. Measures used included the General Health Questionnaire, Bereavement Index, perceived satisfaction with social support, the nature of the relationship between primary caregivers and patients, and sociodemographic information. The study sought to assess whether needs were

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associated with adjustment to loss. The findings suggest that those services meeting the emotional needs of the primary caregivers were the most sought after and used, although these did not necessarily alleviate the distress experienced. Pottinger recommends the use of a routine check on caregiver needs following this study.

Fakhoury et al (1996), dealt with the satisfaction of family caregivers with services for the dying cancer patient. Fakhoury et al used a retrospective approach to ascertain bereaved family caregivers' satisfaction between services delivered by district nurses, general practitioners, hospital doctors, and various service and non-service variables. 1858 carers (defined as close friends, neighbours or relatives) were interviewed ten months following bereavement. Multiple logistic regression was used to gain an odds ratio with service and non-service variables. Both service and non-service variables were found to be associated with high satisfaction with district nurses and general practitioners. It was concluded that post bereavement evaluation of services was largely determined by service characteristics. Attitudes of both patient and informal carer also had an effect.

The studies have concentrated on the satisfaction with services provided for the patient and their carers, rather than looking at whether or not such services were required or helpful to family caregivers. In many cases the studies examined in this literature only referred to family caregivers as a means of identifying the needs of the patient, even though some studies suggested that family caregivers were likely to perceive the situation as more difficult than either the patient or the medical personnel involved.

2.6.2 Family Caregiving Burden within Palliative Care

A number of studies have highlighted the burden experienced by family caregivers in palliative care (Addington-Hall & McCarthy 1995, Carey 1991, Theis & Deitrick 1987). Despite increasing SPCS, the effect of caring for a terminally ill relative or friend can result in the family caregiver becoming exhausted both emotionally and physically. Family caregivers have been found to suffer greater levels of anxiety than the patient (Hinton 1994b) and therefore may require improved support from formal services.

Addington-Hall and McCarthy (1995) completed a retrospective study of 2074 family members or others interviewed to ascertain the symptom control and communication between health professionals during the last year of life. The study found that relatives bore the brunt of caring (81%), and that for those caring in this way 65% experienced restricted activities, although 53% also found it rewarding. More help with activities of daily living was required by 31% of the sample, whilst 25% needed financial help, 24% domestic help, and 29% wanted more help from district nurses. Social services concentrated on helping those individuals living alone such that 47% received home help and 25% meals on wheels as compared to 11% and 4% of those living with another person. This would indicate that living with someone automatically renders that person a carer whether or not they are able/wish to perform such a task. Addington-Hall and McCarthy found that 1 in 3 carers had health problems of their own.

Carey found that burden was predicted by patient's level of dependency (Carey 1991). As with the research conducted in the Alzheimer's disease field, there appears to be a lack of clarity relating to operational definitions of carer burden, and even whether this term should be applied to one individual or the whole family. Such lack of definition adds to the confusion in understanding the exact nature of carer burden in this particular field.

Caregiving in palliative care may result in a number of role changes or restrictions in the life of the carer, for example by their becoming house bound as the patient's condition deteriorates (Theis & Deitrick 1987). When caregivers' perceived needs go unmet stress may be created, and if this is great enough and sufficiently prolonged the family's ability to act as a buffer for its members may be impaired or destroyed. Hull (1990) found that family caregivers were able to identify three sources of stress: the patient's symptoms, interactions with others and concerns for self.

2.6.3 Family Caregivers' Needs within Palliative Care

In a major United Kingdom survey, Seale and Cartwright (1994) compared the last year of life of patients in 1987 with a similar study conducted in 1967. All deaths were investigated, including those resulting from accidents and those from illness. They

found that the majority of the last year of life was spent at home, and therefore the burden of care fell primarily to the family caregiver. Since then, several studies have investigated the needs of caregivers with the terminally ill, but none have looked at the process of becoming a caregiver and the impact such care has on the individual caregiver.

It is possible, however, to outline some of the characteristics of a family caregiver in palliative care that may differ from caregivers generally (Seale 1989). A high proportion of family caregivers are spouses within palliative care (Jones et al 1993, Addington-Hall et al 1991). Overall, around 66-75 per cent are likely to be female (Jones et al 1993, Given 1993). Under half of all family caregivers are under 60 and only 4 per cent are likely to be over 80 (Robbins 1998). Jones et al (1993) suggest that family caregivers may experience sleep problems and weight loss. Furthermore, some cancers are more common in particular age groups, which may present particular difficulties for family caregiving, due to the nature of the family life cycle. For example, the family caregiver of a young mother with breast cancer is likely to be her partner. Not only would the family caregiver have to deal with caring for his partner, but he may also have to juggle the responsibilities of supporting young or teenage children. Similarly, an adult daughter who is caring for her elderly parent, may also have her own family responsibilities. Therefore, family caregiving is often more complex and dynamic than a simple one to one relationship would predict.

Decker and Young (1991) used a convenience sample of 19 caregivers of home-hospice patients in the United States of America and an interview schedule to elicit intra, inter, and extrapersonal stressors identified by the caregivers. The result was used to identify community nursing diagnoses that could be applied to identify potential problems of carers. By attending to such stressors as early as possible, Decker et al suggest that this might improve the caregiver's ability to care for the hospice client.

Hileman & Lackey (1990) recruited 15 patients and their carers to produce statements of their own and their partner's needs. An object content test was then used to identify need statements of both patient and carers, which were subsequently Q-Sorted by oncology experts and nurse researchers into previously established categories.

Caregiver's greatest needs were found to be psychological, informational (relating to both the disease process and the delivery of home care), and household tasks. Decreased social contacts were also noted. Furthermore, it was found that caregivers and patients did not accurately report each others needs.

2.6.4 Family Caregivers' Perceptions and Expectations of Palliative Care

Recently, the caregiving literature has begun to explore the experience of caregiving from the family caregiver's perspective rather than concentrating on their satisfaction with services or perception of burden. These studies have tended to use qualitative approaches with small numbers and therefore need to be interpreted with some caution. They do, however, give an insight into the relatively complex and evolving nature of the family caregiving experience within palliative care.

In a series of articles based on her doctoral research Rose used a Heideggerian Phenomenological approach to elicit the experience of 21 family caregivers of terminally ill cancer patients (Rose 1998, 1999, Rose et al 1997). She found that family caregivers reported caregiving as a time consuming activity relating to practical and emotional tasks of caring in addition to outside demands of work and family commitments. Managing time and being assisted to manage time appeared to afford the family caregiver the opportunity to maintain a sense of equilibrium within the situation. Rose suggests that assisting family caregivers to manage time, and appreciating the hidden demands on them is an important aspect of the health professional support to this group of individuals. In addition to the time constraints noted above, Rose found family caregivers expressed a need for information relating to the illness itself. Most importantly, the individual character of carers' needs regarding access to information about the illness and disease progression was highlighted by Rose.

Duke (1998) conducted a retrospective study of the experience of anticipatory grief and its effects on four spouses. All participants had been caring for a partner with a malignant disease and were in their second year of bereavement. Also, they had been assessed as a low risk of poor bereavement outcome at the time of their bereavement. Using a Heideggerian Phenomenological approach, Duke found that participants

reported changes to a number of aspects to their lives as a result of their experiences. Duke also found that participants' experiences were characterised by continual change. In particular, the juxtaposition of role change from spouse to caregiver and the loss of both these roles during bereavement was noted. Changes to role and subsequent strain have been shown to have negative psychological effects when there is an absence of reciprocation or a discrepancy between role expectation (Chowanec and Binik 1989). Duke speculates that an effect of multiple role change associated with caregiving may result in subsequent ill health.

2.6.5 Family Caregiving and Support within Palliative Care

Several authors have found that a lack of support for the carer can account for the breakdown in caring in certain situations (Addington-Hall et al 1991, Townsend et al 1990, Wilkes 1984). This lack of support is made worse by the informal carer's reluctance to acknowledge problems or ask for help (Blyth 1990). In addition, there may be a mismatch between professional carers' assessment of burden and those of the informal caregiver (Carey 1991).

Addington-Hall et al (1991) called for improvements in symptom control and availability of district nurses and general practitioners in supporting patients and caregivers during the terminal stage of the illness. Jones et al (1993) also pointed to the need to improve the availability and instruction to caregivers from trained professional sources in simple nursing techniques and symptom control during the terminal stage. Hinton (1994b) discovered that, as death approached the percentage of family caregivers with psychopathology rose in carers above that experienced by patients. This demonstrated that family caregivers come under increasing strain as death approaches. This in turn resulted in an increased difficulty in maintaining their relative at home, which resulted in a lower preference for home care from 100% initially to 45% for caregivers, and 54% for patients, during the terminal stages of care. If support had been greater and caregivers given adequate time for rest, both the patient and the family caregiver might be able to realise their original desire to remain at home during the dying trajectory.

Grande et al (1997) in a study with patients, the family caregiver and associated GPs, found there was a need for more help with transport, personal care and housework. Furthermore, Grande et al discus the family caregiver's need for reassurance from health professionals, and a reluctance to seek assistance due to a perceived lack of resources and professionals' time.

There is a dearth of literature regarding the effects of social support for the family caregiver in palliative care, which may provide valuable assistance with the caring role. Ell (1996) however, suggests that social support provided by family members may also be a source of stress as well as a resource. Understanding the nature and extent of social support for family caregivers in palliative care is an area that requires further investigation.

2.7 Critique of the Literature

Whilst examining the literature in relation to family caregivers in palliative care a number of limitations and methodological problems have been observed. There is an abundance of research relating to family or informal caregivers in relation to Alzheimer's disease and elderly care, however, there has been little exploration within the field of palliative care, or other disease trajectories. This is important, as it is suggested there may be specific problems associated with the nature and course of chronic illnesses such as those represented in a palliative care setting. Furthermore, within palliative care there has been a concentration on delivering care to people with cancer. This has resulted in the development of SPCS, which may have an impact on the perceived support available to individuals with cancer and their family caregivers, whilst largely ignoring those individuals with a terminal, yet non-malignant disease.

Research within the family caregiving literature has also tended to concentrate on the negative effects of burden that have been associated with family caregiving for some people. This sense of burden has focused on the instrumental or 'doing for' activities of caregiving. These assumptions have recently been challenged, and more positive perceptions of family caregiving and satisfaction with such roles are being explored (Nolan et al 1996a). Furthermore, it has been suggested that there may be more

involvement by family caregivers in anticipatory care and responsibility related to family caregiving than previously assumed.

Within palliative care there is a scarcity of research relating to family caregivers' perceptions. Where studies do exist they generally seek to use the family caregivers perspective as a proxy for the patient. Rarely do they concentrate on the needs of the individual family caregiver. In addition, many studies that do exist have originated from the USA and Canada, which have different health care organisations and cultural expectations from the United Kingdom.

Furthermore, studies relating to informal carers have often been cross sectional in nature and have therefore failed to account for changes over time within a particular disease trajectory (Plant 1996). This has resulted in little knowledge of the changing nature of the family caregiving process with the anticipated changing disease trajectory in palliative care. If, as with carers of the cognitively impaired, distress increases with symptoms, it would be useful to identify the extent that carers in palliative care also cope with exacerbations of symptomatology or the approaching terminal stage of the illness. Emotional problems may be compounded by distress over the impending death and the high levels of dependency many patients exhibit at this time (Seale 1991).

Palliative care research is also particularly prone to bias in sample size and composition due to the nature of the patient's disease trajectory. Thus, research has tended to concentrate on the relatively well patients and their families, as more seriously ill patients are unable to participate. Furthermore, health professionals often act as gatekeepers, protecting their patients and associated family members from the perceived distress and discomfort of being asked to participate in research towards the end of life.

In addition, many of the studies have been retrospective, particularly in the case of family caregivers' satisfaction with services. This may result in problems associated with memory recall and subjective experience relating to the actual death of the cared for person. There may also be a need for the family caregiver to remember the event of the cared for persons death positively, which may result in an altered perception of events.

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2.8 Conclusions

Family caregivers would appear to maintain a particularly ambiguous position within formal service provision. Whilst many concepts of caring and carers have been identified, there appears to be no unifying concept applicable to all informal carers. Despite this, the position of family caregivers continues to be critical to the delivery of health care, particularly in the light of recent changes within the NHS.

Within palliative care, a number of special difficulties present themselves to the family caregiver. For example, the level of support offered to family caregivers is important in maintaining terminally ill patients with a cancer diagnosis in the community. Whilst it is perhaps unrealistic to expect formal care to provide all the support needed by a patient, it is apparent that much can still be done to improve the situation of family caregivers in the community. For example, education and needs assessment can be provided to enable the informal sector to provide adequate and appropriate care. Neale and Clark (1992) suggest that helping people to maintain their contribution to the spectrum of care will prove a sound investment.

A number of questions arise from the literature, in particular the nature of the role of the informal carer within palliative care. Many family caregivers, particularly in palliative care, fail to recognise themselves as carers and this may have an effect on the strain they experience. They may be reluctant to seek advice or help, particularly from outside professional sources, if they do not feel that they have a legitimate right to such assistance. Information about the perceptions of individual caregivers throughout their caring experience of the terminally ill may enable health professionals to identify the most appropriate point of intervention and assistance to this group, thus, helping to maintain the quality of care that will enable an individual patient to die peacefully at home. It is clear that in order to explore further the meaning of the caregiving experience of family caregivers in palliative care, a more detailed exploration of their perception of the role needs to be undertaken. It is these aspects of family caregiving within palliative care that the present thesis sought to explore.

Table 2.1 Family Caregiver satisfaction with services, carer burden and needs reviewed in sections 2.6.1, 2.6.2, and 2.6.3.

Authors	Country	Year	Participants	Design
Carey et al	USA	1991	49 family caregivers of patients receiving chemotherapy	Questionnaire based study using several standardised measures including the Caregiver Burden Scale, Appraisal of caregiving scale, Family Hardiness Index, Profile of mood states
Decker et al	USA	1991	15 Patients and their carers	Interview based study examining statements of patient and carer needs
Pottinger	U.K	1991	40 self appointed primary caregivers	Questionnaire based study including a range of measures: GHQ, Bereavement Index, Social Support, Relationship to patient and sociodemographic characteristics.
Hileman & Lackey	USA	1992	15 sample of convenience	Interview schedule
Addington-Hall and McCarthy	U.K	1995	2074	Retrospective study
Fakhoury et al	U.K	1996	1858 relatives or close friends	Retrospective interview based study 10 months following bereavement

Chapter Three

Research Within Palliative Care: Methodological Consideration

3.1 Chapter Overview

The purpose of this chapter is to establish the methodological rationale for the thesis. To do this I will begin by outlining the epistemological rationale underpinning the study. Secondly I will discuss the methodological approaches that guided the research and the reason for these choices. Thirdly I shall explore some of the ways that qualitative research can be evaluated. Fourthly I shall move on to consider the principal methods of data collection to be adopted during the study. Fifthly I will consider some of the particular problems associated with undertaking research in palliative care. Finally I shall discuss some of the ethical issues surrounding research interviews in relation to palliative care.

3.2. Epistemological Foundation of the Thesis

Guba and Lincoln (1998) suggest that there are a number of paradigms within qualitative research that are used by researchers to guide the understanding of knowledge. Such paradigms comprise three elements; epistemology, ontology, and methodology. Epistemology refers to what is regarded as knowledge or evidence in the social world (Mason 1996). Ontology refers to the nature or essence of reality. Methodology reflects the way we gain knowledge of the world.

The epistemological stance being taken in this thesis is that of social constructionisim. Social constructionisim focuses on language as a functional system which does more than reflect reality but creates social reality through social exchange and shared meanings (Gergen 1985). That is what people say is a reflection of their understanding and experience within a social context. The focus on the use of language not only reflects the reality of the individual but also the construction of that reality by both the researcher and the researched.

During my reading and growing understanding of the ontological and epistemological foundations of research two qualitative methodologies presented themselves as particularly appealing to my own sense of what can be considered knowledge and how this might be investigated within a palliative care setting. I shall now briefly discuss these methodologies, and the reasons for my choice of these methods.

3.2.1 Methodological Approach Chosen for the Thesis

Palliative care lends itself to an individual approach to understanding the perspective of patients and their family caregivers who are encountering the situation, often for the first time. The use of interviews as a research tool offers a suitable way to explore the understandings and perceptions of participants' worlds and experiences. Skilfully interpreting and understanding the individuals' perspective can result in a personalised approach to the provision of services and support for this group of people. As this thesis is concerned with the meaning and understandings that individual family caregivers attribute to caring, the use of a largely qualitative approach, and in particular interviews, appeared to be a useful way of investigating these issues.

3.2.2 Interpretative Phenomenological Analysis (IPA)

Smith has used this term to identify the approach, which combines both phenomenology and symbolic interaction (Smith J.A., 1996, Smith et al 1999). A range of methods may be used to represent this type of work but most common are phenomenology and grounded theory. The aim of IPA is to explore the participant's view of the world and to adopt, as far as is possible, an 'insider's perspective' of the phenomenon under study. Thus, the approach is phenomenological in that it attempts to capture the individuals account of an object or event rather than an objective statement about the event itself (Smith et al 1999). Furthermore IPA attempts to make explicit the cognitions or beliefs behind an individuals statement about an event. That is working from a social cognitive paradigm there would be an assumption that what someone says reflect an underlying cognition or belief about an event. At the same time IPA acknowledges the dynamic nature of the research process, and the interpretative activity through which the researcher attempts to understand the perceptions of the participant.

IPA is particularly suited to answering questions about topics that involve complex social circumstances and personal interpretations, as it attempts to combine the individuals perception of a situation with the effects of social interactions, whilst at the same time taking account of the interpretative nature of this type of research. Furthermore, some of the methods employed by researchers using this approach, such as interviews are well established within social science.

For the purpose of this thesis IPA was felt to be an appropriate choice of methodology for the health professional study, as an understanding of the health professional perspective and relationship with the family caregiver was sought. Also in this study a mainly qualitative methodology was utilised involving semi-structured interviews.

3.2.3 Case Study Methodology

The use of case studies has a long and varied history. Anthropology, sociology, psychology, medicine, nursing and education have all used case studies as a research tool. However, the term has been applied inconsistently and this has caused confusion and ambiguity regarding the value of both the process of conducting and reporting case studies and the conclusions drawn from such work. Within this section I shall give a brief description of the way case studies have been conducted and reported. I shall then move on to discuss a proposal by Yin for case study research (Yin 1994). Finally I will consider some of the advantages and disadvantages of applying case study research to the present thesis.

Case studies have been defined as "A strategy for doing research which involves an empirical investigation of a particular contemporary phenomenon within its real life context using multiple sources of evidence" (Robson 1993) p146. The use of case studies has been strongest within the qualitative tradition, which is dominated by a naturalistic, holistic, cultural and phenomenological interest (Stake 1998). For this reason case studies may be seen as 'soft' research, that has generally avoided tight pre-specified designs (Robson 1993). Although for some it is the very fact that case studies are more flexible and less prescriptive that makes them an attractive proposition for certain types of research.

A lack of clear definition of the term 'case', has also increased the confusion found in the applicability of case studies (Bergen & While 2000). An individual, group or institution within a particular context or situation can represent the 'case', but this does not necessarily explain what is understood by case study method. Furthermore there have been differences in emphasis of the nature of the 'case' boundaries. Stake (1998) suggests that the bounded nature and behaviour patterns of the system are key factors in understanding the case. Whereas Yin (1994) suggests that:

"A case study is an empirical enquiry that:

- investigates a contemporary phenomenon within its real life context, especially when

- the boundaries between phenomenon and context are not clearly evident" (Yin 1994 p13).

This suggests a difference in interpretation of the definition of what constitutes a 'case', and the level of interpretation and analysis that can be drawn from this.

The way case studies have been used to present information within disciplines has also been a source of confusion. For example within a medical perspective case reports and case series have been used to highlight a potential new disease or refinement of an existing disease (Vandenbroucke 1999). In this way case studies can provide a valuable source of evidence of new and previously undocumented problems. In addition, case studies of pathological forms have also been used to theorise on normal functioning, for example in neuropsychology (Sharp 1998). Unless clear guidelines are given to the reader as to the reason for the different use of case studies to promote different understanding this could add confusion to the situation.

A major criticism of case study research has been its lack of ability to generalise to larger populations, due to its concentration on an in depth, detailed exploration of a particular phenomenon. However, this view fails to acknowledge the uniqueness of the information provided by case study research (Stake 1988). Also generalisations in this

sense are usually based on an assumption of statistical probability rather than non-statistical generalisations such as direct demonstration or making a case (Robson 1993). Sharp suggests case study may however, be able to make a valuable contribution to theoretical generalisation of the relationships between variables as opposed to empirical generalisation of the characteristics of a population (Sharp1998).

Case studies may be used as a descriptive tool, emphasising the particular or common. More commonly case studies are used as an exploratory tool, as in the case of an unknown phenomenon, in order to gain greater insight into the situation. In addition case studies can be used as an explanatory tool, where analytical induction may be used to modify theories or thinking in the light of new evidence presented by the case which may be either confirmatory or contradictory (Smith et al 1999). Thus, case studies are useful in highlighting complexities requiring further investigation, refining theory, and establishing limits to generalisability of theories (Stake 1998).

Having established that case studies can offer a legitimate source of information, it is important to establish how the process of data generation can be relied on. Bromley (1986) suggests that the case study can be legitimately used for more than exploratory work, but that evaluation of such studies requires different judgement criteria than traditional quantitative research would suggest. (See section 3.3 for a more detailed outline of methods for evaluating qualitative research.)

To date there has been little systematic documentation guiding the process of case studies. Yin (1994), however, has proposed the use of Case Study Research as a methodology in its own right. As mentioned above Yin sees a case study as an empirical enquiry. As phenomenon and context are not always distinguishable in real world situations Yin elaborates the technical characteristics of his definition of case study to include data collection and analysis strategies. Thus, Yin states that case study inquiry:

- cope with the technically distinctive situation in which there will be many more variables of interest than data points, and as one result

- relies on multiple sources of evidence, with data needing to converge in a triangulating fashion, and as another result

- benefits from the prior development of theoretical propositions to guide data collection and analysis. (Yin 1994 p13).

Within this focus the case study becomes an all-encompassing method, including specific approaches to data collection and analysis, focusing on the phenomenon in context.

The case study is most appropriate for questions revolving around 'how' and 'why'. Thus, how and why do health professionals and family caregivers co-operate to provide joint care to a terminally ill person? Yin suggests that the use of propositions during the design phase will enable the purpose of the study to be clearly defined. If the propositions are clear it will be possible to examine the nature of the relationship between the two positions.

According to Yin case study research is able to be generalised to theory through the use of replication logic, whereby generalisation to some preformulated theory is performed. In this respect Yin's approach to case study is strongly aligned to a positivist approach (Bergan &While 2000). This is in contrast to the popular notion that case study is in line with a naturalistic paradigm. Furthermore Sharp (1999) suggests that to use case studies, as a means of replicating previous instances of a case, does not alter the probability that future cases will be falsifying.

As with all research it is important to be able to judge its quality (see section 3.3). In evaluating case study research Yin (1994) suggests a number of strategies that may assist the researcher to evaluate their research throughout the conduct of the case study. These suggestions are heavily influenced by the quantitative paradigm and focus on construct validity, internal validity, external validity and reliability. Whilst acknowledging the importance of a clear evaluation of qualitative research I would argue that the use of evaluations based upon different assumptions fails to acknowledge the unique contribution that qualitative research has to offer.

Within the thesis, a major objective was to understand the position of the family caregiver's view of their role and relationships with health professionals and other forms of social support within the context of a palliative care setting. Yin's concentration on the use of propositions appears to be strongly aligned to a quantitative paradigm. However, the ability to explore the contextual issues was considered an important and valuable factor to include in the choice of research methods, as this aspect of family caregiving in palliative care is unclear. Therefore an approach based on Yin's case study research was adopted for the second study involving family caregivers. The use of propositions was omitted from the design as it was not clear what the study would reveal and therefore it was not considered appropriate to pre-determine the focus by the use of propositions. The family caregiver study was therefore designed as a triangulated study with data collected from both semi-structured interviews, demographic details and standardised questionnaires. The aim of this was to produce a complete picture of the nature of the family caregiver experience within palliative care. Thus, this study sought completeness from the triangulated data and not confirmation. It was hoped that clarifying the positions of family caregivers, both from a health professional perspective and the family caregiver perspective would help develop theory relating to family caregivers in palliative care.

3.3 Evaluating Qualitative Research

Although qualitative research is premised upon a number of assumptions and beliefs that are different from those found in the quantitative paradigm, it is still required to be rigorous and trustworthy. Clark (1997) believes this can be achieved through following a set of recognisable procedures when designing and carrying out a research study. However, within qualitative research this can sometimes be problematical due to the disparate nature of the methodologies employed. It is therefore essential that qualitative researchers be specific about the epistemological assumptions that their research is based upon.

Evaluating qualitative research, particularly within psychology, has until recently been poorly defined. This has resulted in qualitative research being evaluated using criteria that is unsympathetic to the underlying principles and methods adopted. This situation

is aggravated by the vast range of traditions and procedures representing qualitative methods which increases the difficulty of demonstrating intellectual integrity (Yardley 2000). In addition, Yardley suggests that some qualitative methods are incompatible with fixed universal procedures and standards. Nevertheless evaluating qualitative studies is necessary if the interpretation derived from such findings are to be given credence.

Yardley (2000) proposes a number of ways that qualitative research might be evaluated. Sensitivity to the context of the research; commitment, rigour, transparency, and coherence of the research; and impact and importance of the research. Sensitivity to the context refers to a sensitivity towards theory and previous investigations which allow a link to be drawn between the particular phenomenon, the abstract and the work of others (Yardley2000). Johnson calls this particular form of theory building 'vertical generalisation' (Johnson 1997). Yardley suggests that being sensitive to the context in this way involves the researcher corroborating theoretical predictions with empirical evidence, seeking out conflicting evidence and examining and accounting for these findings (Yardley 2000).

Commitment, rigour, transparency and coherence are also important aspect of qualitative research that relate to the thoroughness of data collection, analysis and reporting (Yardley 2000). Commitment is demonstrated through prolonged engagement with the topic and development of competence and skills in methods used. Rigour refers to completeness of data collection and analysis, which may be assessed in different ways depending upon the epistemological and ontological assumptions underpinning the research. However, one way of demonstrating rigour is through the use of triangulation of data, which involves applying data gathered from various sources such as interviews and other records that taken together can present a more complete picture of a phenomenon (Banister et al 1994).

Transparency and Coherence are used within qualitative methods to demonstrate the clarity and cogency of an argument, which is in turn reflected in the persuasiveness of the description of an argument (Yardely 2000). Demonstrating transparency can be achieved by detailed openness regarding data collection, coding and direct access to

textual data for the reader to be able to identify and analyse the information (Peräkylä 1997). In addition the use of reflectivity regarding choices made along the research path will help to clarify for the reader both the external and internal pressures which may have influenced the research process and conclusions.

Finally Yardley suggests that the decisive criterion by which any piece of research is judged is the impact it has (Yardley 2000). Much qualitative work is concerned not only with the theoretical impact of a study but its socio-cultural and economic impact. Understanding the socio-cultural impact of a situation can help to challenge prevailing practice. Yardley believes that combining research and outcome in the way of participatory or action research is an important development for qualitative methods (Yardley 2000). This Yardley suggests is a real challenge to traditional criteria for validation as it may be used to seek to make positive change for all participants and solve practical solutions to local problems.

3.4 Palliative Care Research

3.4.1 Purpose of Research in Palliative Care

Corner, has suggested that "health service research is now driven by cost containment, evidenced based delivery, and indicators of outcome performance" (Corner 1996 p202). She goes on to argue that it is important for palliative care to be clear of its own research agenda. Palliative care is a relatively new and developing field of care. Despite this much of the research in the area has been carried out within the prevailing bio-medical model, which relies heavily on the quantitative paradigm, and has ignored the social and cultural aspects involved in this area. However, alternative approaches are available that reflect the diversity of meaning and truth as perceived by post-positivist and postmodern perspectives. These alternative approaches are able to overcome some of the deficiencies of the quantitative paradigm, whilst at the same time eliciting and interpreting a further dimension within palliative care.

Clark (1997) suggests that qualitative research within palliative care may have relevance in four areas:

- Health needs assessment, concentrating on perceptions and experiences of palliative care services by the public. Such information could then be used to identify particular health needs in an area.

- Policy formulation, and the dynamics of how policy is formulated at local levels.

- Service evaluation, and the opportunity to study palliative care from a wider perspective than a mere audit of services might provide.

- Sociological, cultural, historical and ethical issues, in order to understand the place of palliative care within wider social circumstances and changes.

Developing palliative care research therefore needs to take account of differing methodologies and ontological assumptions upon which such research may be based.

3.4.2 Difficulties of Research in Palliative Care

Palliative Care, and in particular SPCS, have traditionally been associated with cancer care. The term cancer can be applied to a number of different forms of malignancy, each of which has its own disease trajectory. In this respect the differing forms of cancer each act as a separate illness, and for this reason research with one particular cancer type, for example breast cancer, may not necessarily be applicable to other types of cancer. This situation is complicated still further by the differing treatments available, so that one person may receive a completely different treatment regime from another with apparently the same disease. Such individual differences, with the nature of the disease and varying treatments, pose serious problems for research aimed at establishing similarities and generalisations. Differences are likely to include;

- Intra-individual differences, for example coping styles.

- Inter-personal differences, for example in their interactions with professionals.

- Disease differences such as site of cancer and type of cancer.

- Treatments differences.

- Disease trajectory or stage of disease.

- Social differences with type and extent of family or carer availability.

Another significant difficulty faced by researchers in palliative care concerns the ethical and moral considerations of research with a group of individuals who are dying. Issues relating to the individual participant, such as disease trajectory, multiple pathologies, and a deteriorating condition, may make research extremely difficult, especially if conducted over a prolonged period of time. The rapidly deteriorating state of the patient and their increased vulnerability need to be carefully considered prior to undertaking research with this group. Particular attention therefore needs to be paid to the appropriateness of both the research question and approach in order to minimise any undue distress being placed on individuals who are already experiencing a difficult situation. Despite the increased difficulties of participating in research during the terminal phase however, patients and relatives often express a desire for their experiences to benefit others, and this desire to be helpful can overcome feelings of fatigue and discomfort that may accompany participation in a study (Davies 1995).

Traditional medical research has concentrated on the use of randomised control trials (RCT's) and large sample sizes. Randomisation may be unsuitable for this field of study (Corner 1996), due to the nature of the disease process that occurs prior to involvement in palliative care. For many individuals palliative care is the last stage in a long line of treatments and experience of cancer. With multiple pathologies and differing treatments applying randomisation, for example in an evaluation of a specific intervention, is often impracticable or even impossible due to the difficulty of achieving similar controls. Placebo RCT's also raise ethical issues for palliative care research as it is considered unacceptable to prevent individuals from receiving care by the use of placebo treatments. In addition health professionals involved in such a randomisation may find it impossible to apply such a procedure to individuals who are very ill. Whilst it is not

necessarily inappropriate for randomisation trials to occur in palliative care, their use may be limited and restricted to specific situations.

The difficulties outlined above would cause some people to argue that these considerations make any meaningful research impossible. However, this view has been challenged by the need to deliver the best quality care, thus making research a moral imperative (Speck 1996). An alternative approach to RCT's is to apply a qualitative paradigm, which does allow some measure of understanding about a particular situation to be made. This in turn can be useful in improving knowledge about and appropriateness of certain interventions.

3.4.3 Qualitative Research and Palliative Care

Clark suggests that qualitative research is more than just a set of techniques and methods, and should be viewed more as a framework in which the subjective experiences of the individual are acknowledged and applied (Clark 1997). Thus, rather than searching for the incidence of a particular event or circumstance, differences, meanings and understandings are sought. This unique way of exploring the world can challenge previously held assumptions and knowledge, which will ultimately increase our understandings of palliative care.

The term qualitative research is used to account for a number of different methodologies that come from a variety of academic backgrounds (Denzin and Lincoln 1998). Henwood and Pidgeon (1994) have identified three epistemological foundations: empiricism, contextualism, and constructivism upon which various methodologies and methods have been developed. Methodologies refer to the theoretical analysis defining both what a research problem should be, and how such research should be addressed. In this context methods are the related strategies and techniques that have developed to support a methodology.

Nevertheless, Tesch (1990) suggests that there are at least 26 approaches to qualitative research, with no one to one correspondence between research interests and analysis.

Tesch therefore subdivides qualitative analysis into four categories, according to research interest:

- The characteristics of language.

- The discovery of regularities.

- The comprehension of meaning.

- Reflection.

In order to simplify the understanding of the analysis of these approaches, Tesch (1990) further subdivides the approaches into two: interpretative analysis and structural analysis. These terms are similar to the two perspectives ethnographic and ethnomethodological. Ethnographic research aims to identify what people mean, whereas an ethnomethodological perspective is concerned with understanding how people use talk (Payne 1999). Thus, in an ethnographic study what people say in the interview would be viewed as reflective of the way people interpret and make sense of their world. The inferences drawn from these statements would be held to have some basis in the underlying beliefs and understandings of the individuals involved. Alternatively an ethnomethodological approach concentrates on the way individuals use talk to construct particular situations. This approach makes no assumptions about the meanings individuals may infer from such a situation, rather it seeks to elicit how people respond to certain situations.

Although numbers of participants involved in qualitative research may be relatively small, this does not diminish the value of the findings. Qualitative research is based upon the premise that it is the interpretations that are important and not necessarily the number of similarities. This does not mean that small numbers can not be useful in predicting future behaviour or opinion. Rather qualitative research can usefully describe the variety of experience that can have a place in the explanations of a particular phenomenon.

The numbers of participants involved in research in palliative care are generally small as a result of the progress and severity of a particular disease trajectory. However, by applying theoretical or purposive sampling (Mason 1996, Clark 1997), it is possible to produce meaningful results. Purposive sampling allows a selection of participants to be made on the basis of their relevance to the research question, theoretical position, analytical framework and analysis, and the explanation that is being developed (Mason 1996).

3.5 Research Interviews within Palliative Care

Interviews are an important source of gathering information in qualitative research. Through interviews the researcher attempts to gain access to the meaning and interpretation of a particular event for the individual. There are many advantages to using interviews when collecting verbal information from participants. However, there are also a number of difficulties which need to be considered if such an approach is to be used.

To understand and make sense of human interactions social scientists have sought to use interviews in a variety of ways to explain and comment on the topic of investigation. Interviewing provides a way of generating empirical data about the social world by asking people to talk about their lives. In this respect interviews are said to be special forms of conversation, or conversations with a purpose (Holstein and Gubrium 1997). How such 'conversations' are generated and interpreted will depend upon the underlying epistemology of the researcher, and the purpose of the research.

It is also important to recognise the expectations that each participant may have about the interaction that occurs within an interview. Both the participant and the researcher may hope to gain something from an interview. The researcher hopes to gain a fresh or deeper understanding of the situation, whilst the participant may wish to put forward their own views in the hope that it will be acted on at some higher level. Alternatively it may be that the participant has not had the opportunity of discussing their own situation with anyone in the past and this is particularly important in palliative care when there is often little or no focus on the perceptions of family caregivers. As a result the

participant may find it difficult not to discuss in detail everything that has been part of their experience. The researcher therefore needs to be sensitive to the vulnerability of the family caregiver in this situation and ensure that only the information relevant to the research agreed to by the participant is included in subsequent analysis.

3.5.1 Advantages of Using an Interview Approach

One of the advantages of adopting an interview approach in palliative care research is the flexibility that this allows the process. It could be argued that asking people what they think or believe would give a more direct response than observing behaviour and interpreting actions. In addition interviews give the researcher the opportunity to follow up interesting lines of inquiry as they occur, which is not possible with other methods such as the use of survey or questionnaires. This is particularly important where the research is of an exploratory nature and it is not clear exactly what the issues and problems may be.

Interviews also offer a personal method of gaining data that may be more acceptable to participants than a questionnaire received through the post. Where small numbers of potential participants are available, as in palliative care, interview data can reveal substantial amounts of rich information. Interviews allow the researcher to be reflexive rather than neutral, which is in direct contrast to a more positivist tradition that seeks to reduce bias and exclude the researcher affecting the research

3.5.2 Cathartic Nature of Interviews

Interviews may also be found to be a cathartic process for the participant. For some it may be the first opportunity they have had to express their fears and worries to an interested listener. This in turn may make them more likely than normal to reveal feelings or emotions that they may later regret. It is therefore important that the researcher is sensitive to these points and makes every attempt to protect the participant from revealing more than they feel comfortable with, and at the same time respecting their accounts and acting non-judgementally about any information that is shared. For some participants the prospect of being able to help others through their involvement with the study is a way of making sense of the situation they find themselves in. This in

turn can be beneficial to the participant, and enables the research to be useful to both the researcher and the researched (Oakley 1981).

However, it is important to make clear that a research interview is not a counselling session (Coyle and Wright 1996). In such situations the nature and purpose of the interview should be highlighted prior to the start of the interview, and if necessary referral to appropriate support services made at the end. This may be a particularly difficult issue for a researcher who has previously been a health professional, and may possess skills and expertise within a particular field. For example there may be a feeling of responsibility towards a participant that extends beyond the nature of the research interview and is more closely aligned to the therapeutic relationship between health professional and client. If interviews are conducted over a period of time there may also be a desire to intervene in a situation, particularly if the participant raises an issue that the health professional would normally have dealt with within their health care role. It is helpful to address these issues prior to beginning a research study so that guidelines can be agreed and limits set as to the extent of professional involvement the researcher should extend to the participant. This is not to say that the participant should be left with unanswered questions or concerns about a situation, but rather that the researcher should acknowledge the limits of their new role in providing such answers. By anticipating the possibility of these issues arising the researcher can be prepared to refer the participant to the most appropriate source of support.

3.5.3 Disadvantages of Using an Interview Approach

Whilst interviews offer a number of advantages to conducting research in sensitive areas, there are also a number of disadvantages. Interpreting the context and meaning of the interview is one such problem. However, Mason suggests that understanding the epistemological and ontological assumptions underlying the use of an interview technique can assist the reader to evaluate the research (Mason 1996). Therefore to accept the findings of an interview approach Mason suggests that people's knowledge, views, understandings, interpretations, experiences and interactions must be viewed as meaningful properties of social reality. Thus, the contextual, situational, and

interactional nature of knowledge can result from the construction of social explanations.

However, interviews are only able to access and interpret recounted experience and interpretations. It is not possible to understand or interpret information that is not revealed in the interview (Mason 1996). Therefore the information gained may not be reliable, for example as a result of the way an individual may choose to present themselves during an interview. From a positivistic perspective what people say is not necessarily an accurate representation of what they believe or will do. However, a social constructionist perspective would suggest that as all interactions are constructed an interview is both useful and reliable. For this reasons interviews can prove to be as problematical as other forms of investigation.

Interviews may be particularly prone to issues of bias. Both researcher and participant may be inclined to discuss issues not relevant to the research problem, or only one aspect of the problem. This is particularly important for some traditional approaches, where it is considered essential for the researcher to remain detached from the researched and the topic under investigation. However, Oakley (1981) would suggest that to be so detached is in fact untruthful and representative of the power differential within the research context. Thus, it may be felt to be essential to interact and empathise with the interviewee as an individual, particularly if they are sharing sensitive and emotional information. A middle line can be found when sharing of such information is acknowledged and responded to in a sympathetic manner.

Interviewing is time consuming, and can be emotionally stressful for both the researcher and the interviewee. Time may also limit those able to participate, particularly in a situation such as palliative care where time is perceived to be limited. This can lead to bias in the sample of the population able to participate.

It is not only after the interview has taken place that problems can emerge with interviews. Transcribing and analysis of interview data can be time consuming. Robson (1993) recommends that a factor of ten be allowed for transcribing unless the person is highly skilled at the task.

3.5.4 Practical Issues in Interview Research

Interviews represent a face to face contact with researcher and researched. For this reason it is important that the interviewer is able to put the interviewee at their ease and build rapport. Interviewing is an active process of asking, listening and responding to the individual. Whilst this can result in a degree of flexibility that a questionnaire may be unable to achieve, it can also result in a mass of data and information that may be overwhelming. For this reason it is important that the purpose of the research, and the underlying assumptions about the nature and interpretation of the data it produces, be addressed prior to the interviews being conducted.

The style of interview adopted depends upon the purpose, analysis, time and financial constraints associated with a particular study. Three main styles of interview can be identified:

- Fully structured, where predetermined questions, are recorded via a standardised schedule

- Semi-structured, where questions are open to modification if necessary

- Unstructured, which are completely informal and of general interest, thus allowing 'conversation' to develop naturally (Robson 1993).

Thus, the style of interview chosen may be viewed as part of a continuum ranging from very formal and structured to completely informal (Smith 1995). In some cases very formal styles may be almost representative of a quantitative approach (Tesch 1990), allowing little room for the participant to express their perspective. Alternatively, interviews that are completely unstructured may run the risk of failing to identify pertinent issues. The use of a semi-structured interview approach accommodates both a sense of structure and a degree of freedom to explore and follow up relevant and interesting issues.

Robson (1993) recommends a sequence of questions arranged so that there is a clear introduction, a series of warm up questions followed by the main research questions and

finishing with straightforward question and closure comments at the end. Open rather than closed questions allow the individual to respond as they desire rather than restricting the choice of reply. This also allows the researcher to follow up interesting comments or respond as appropriate during the interviews. Probes are suggested as a useful way of encouraging a participant to expand on a response that was unclear or ambiguous.

The safety of the researcher and the participant are also practical and important issues to consider during the preparation of the interview process. In situations where a researcher may be visiting participants in their own home, possibly in the evenings, it is important that some mechanism is established to ensure that at least one other individual is aware of the location and expected return time (Keynon &Hawker 1999). In addition, it is important that the emotional safety of the researcher is considered, particularly if it is likely that the interview will raise sensitive and emotional issues. Often it is advisable for the researcher to have access to supervision or emotional support from a qualified professional (Payne 1999).

3.6 Ethical Issues in Palliative Care Research Interviews

Ethical issues are always important in interview research, especially where respondents may be particularly vulnerable as in palliative care. Interviewees may be extremely susceptible to providing information that they think the interviewer wants to hear. Harré argues that the objectivity of research is compromised by the interview technique (Harré 1981). For this reason some researchers would contend that information provided during interviews is merely a reflection of the particular situation, and that further inferences as to underlying meanings or understandings of interviewees are not possible. Qualitative research however, acknowledges the dyadic relationship between the participant and the interviewer, and the effect this might have on the situation. To ignore these dynamics is to fail to adequately understand the situation as the individuals involved perceive it. Thus, it is important to acknowledge the dynamic nature of the interview approach and be reflexive about the possible consequences (Plant 1996). In doing this I would argue that despite the strangeness of the situation it is possible to draw inferences of the meanings and understandings of the interviewee, whilst at the

same time acknowledging the particular difficulties of the process. That is, the interview situation will have some sense of 'reality' for the individual, and will therefore reflect something of their psychological world (Smith 1995).

3.6.1 Power Relationship in Research Interviews

Research interviews are not the same kind of interactions that we would expect to share with family or friends. There may be a perceived inequality in the relationship due to the researcher being seen in a more powerful position than the participant. Participants may thus wish to present themselves in a way that would be favourable to the researcher (Cornwall 1984). For example they may present a 'face' to the researcher of someone who is coping well with a situation, when in reality they are experiencing great distress. It may be that over a number of interviews, as the participant and the researcher come to know one another better, this effect would be less notable in the interviews. Also, as explanations and clarifications to earlier situations are made, the participants and the researcher may be able to share a common understanding of particular circumstances relating to the interview that will make the 'falseness' of the situation less notable.

3.6.2 Protecting the Participant from Harm

There is debate in nursing about the ethics of research in sensitive areas (Smith 1992). Palliative care is one such sensitive area, and therefore consideration was given to the consequences of the participants' involvement in the research process. Within palliative care it is possible that interviews might raise issues that could be potentially disturbing for participants. The researcher is responsible for ensuring that no harm comes to the participant as a result of taking part in the study. Once issues have been raised it may not be possible for these to be dealt with satisfactorily during the interview. Should issues arise within the interview that are outside the experience and qualifications of the researcher, provision should be made available for referral to appropriate services for support, such as referring health professionals, other suitably qualified professionals or local or national support groups. In addition to ensure that participants are not left with unresolved issues as a result of the interview, the opportunity to discuss the effect of any issues raised should be offered at the end of the session as a form of de-briefing.

3.6.3 Consent and Confidentiality

Gaining consent from the participant, and ensuring confidentiality are important aspects of any research. In situations where it is likely that verbatim quotes are to be used in any report it is essential that the participant's anonymity be protected, by replacing real names with pseudonyms, identification codes or removing any identification from the final script. For this reason it is important that participants be made fully and explicitly aware of the nature and purpose of the interview, and provided with written information that is clear and easy to understand. To prevent unnecessary distress to the participants careful discussion about the nature and purpose of the interview should be undertaken prior to the individual agreeing to sign a consent form and take part in the study. In this way participants are able to give informed consent.

3.7 Summary

Within this chapter I have outlined the methodological approach guiding the research and the reason this was adopted. I have considered ways that qualitative research might be evaluated and the particular difficulties faced in palliative care research. Finally, I considered some of the issues surrounding the use of interviews in palliative care research.

Chapter Four

Health Professionals' Perceptions of Informal Carers in Palliative Care

4.1 Introduction

Within the literature it was found that little attention had been paid to the perception of the position of family caregivers within palliative care. As one aspect of palliative care philosophy is to support the family it is important to understand how this can be satisfactorily achieved from both a health professional and family caregiver perspective. Previous research (Smith P.C., 1996, Payne et al 1999) had demonstrated a degree of ambiguity about the definition and status of family caregivers within palliative care. The thesis therefore sought to explore the perceptions of both health professionals and family caregivers regarding the definition, status and support offered to family caregivers in this situation. It was decided to begin this exploration with a detailed investigation of health professionals' perceptions, definitions and experience of working with family caregivers in a palliative care setting.

4.2 Aims

This chapter will provide details of a study which sought to identify the perspectives of health professionals regarding who becomes an informal carer in palliative care situations, and the type of activities they may be undertaking. In particular two questions were considered:

1. How do health professionals perceive informal carers in a palliative care setting?

2. What is the nature of the relationship between health professional and informal carers within palliative care?

Firstly I shall describe the design and method used to collect the data, and outline the nature of the analysis undertaken. Secondly I will concentrate on some of the issues

arising from the interviews. Finally this chapter will conclude with a discussion of some implications and conclusions that can be drawn from the investigation. Questions arising from the study will also be considered, and their implications for further research explored.

4.3 Method

The study applied a cross-sectional qualitative approach, involving an interview and a brief demographic questionnaire.

4.3.1 Participants

In order to elicit the perceptions of health care professionals who come into contact with terminally ill patients and their carers, a sample of convenience of twenty health care professionals in primary care and twenty health care professionals in SPCS were contacted.

Permission was sought from the Local Research Ethics Committee to approach a number of health professionals in a community trust within Southern England and an associated independent hospice, where the researcher had previous professional contact. In addition, to access a larger sample of SPCS professionals a number of individual practitioners from a variety of backgrounds, who were members of the South and West Palliative Care Research Network, were contacted. All had previously indicated their willingness to participate in other members research. Letters of introduction (appendix 1), were sent to 47 individuals: 17 District Nurses, 10 General Practitioners, 11 Macmillan Nurses, 7 Doctors specialising in palliative care, 2 Social Workers, 1 Clinical Psychologist working in palliative care.

Response rates were high, and ranged from 60% for General Practitioners to 100% for Doctors, Social Workers and Clinical Psychologists working in SPCS. Final interviews were conducted with 14 District Nurses (82%), 6 General Practitioners (60%), 10 Macmillan Nurses and Home Care Nurses (91%), 7 Doctors specialising in palliative care (100%), 2 Social Workers (100%) and 1 Clinical Psychologist (100%) all working

in SPCS. Reasons for non-participation were due to sickness or pressure of work. All participants had been working in their professional field for at least six months, and all had experience of the care of a terminally ill patient during that time.

4.3.2 Development of the Semi-Structured Interview

The interview used a semi-structured format (appendix 2), and covered topics developed from the previous literature, consultation with health professionals and other researchers in the field. Topics were designed to elicit the perceptions of health professionals with regard to informal carers, and their relationship with this group.

The results of three interviews acting as a pilot study informed the structure and content of the final interview schedule. Some of the early study questions were altered. In particular, the question concerning what a health professional would 'typically expect' an informal carer to do was altered to 'typically find', as the word 'expect' had obvious value attached for the health professionals. An attempt was made to ensure that all the questions included in the schedule followed a logical sequence and were not value laden or used closed questioning.

In addition during the interview process emerging areas of concern or interest were incorporated into the schedule. For example it became apparent that informal carers proximity to the patient was identified by many of the health professionals to be important in the definition and understanding of who became an informal carer. A question reflecting this position was therefore added to later interviews, particularly if the individual health professional did not independently raise this notion. In this way the research process was able to inform subsequent data collection and refinement of the questions. Questions were deliberately kept general in an attempt not to lead the participants' responses.

4.3.3 The Pilot Study

A pilot study was undertaken to determine whether the topics and organisation of the interview schedule were appropriate, understandable and elicited the perception of the

health professionals. The pilot study also offered the opportunity to gain interview experience, (especially the use of opening and closing statements) and to become acquainted with the tape recording equipment and the interview schedule itself.

Following the development of the main areas of interest for the interview, three members of a primary health care team were interviewed; two district nurses and one general practitioner. No apparent problems emerged from the style or nature of the questions, and so they remained unchanged for the study. In addition to the interview, participants were requested to fill in a short demographic questionnaire (appendix 3), which recorded their professional qualifications and expertise.

4.3.4 Procedure

Following the letter of introduction participants were contacted by telephone and asked if they wished to participate. If they agreed, a time and place that was convenient to them was arranged.

Prior to the interview, participants were given a brief outline of the study aims and reminded that all information was confidential and that any names or places would be changed in the final text to preserve anonymity. They were also reminded that they were free to halt the interview at any time should they wish. The interviews were tape recorded and lasted between 20-40 minutes.

4.3.5 Transcribing

Transcription of the audio tape into written text is an initial part of the analysis of qualitative data. For this reason it is important that the purpose and process of the transcription are made explicit. For the purpose of this study the transcriptions of the audio tapes were undertaken by the researcher, with the intention of analysing them according to the principles of Interpretative Phenomenological Analysis (IPA). This approach holds that what an individual says in an interview has some significance for him or her, and that there is some relationship between this and their beliefs or psychological constructs (Smith 1995). Thus, the meaning and not the content of the

talk produced in an interview are of interest in this study. The transcripts therefore reflected all speech of both the participant and the researcher, including non-language utterances such as 'umm'. However, for the purpose of this analysis it was not considered necessary to record the prosodic, paralinguistic or extralinguistic elements included in some forms of transcription, such as the intonation and meanings inferred from a tone of voice or accompanying gestures (O'Connell and Kowal 1995).

4.4 Analysis

Analysis of the interviews was undertaken using an approach based on IPA (see section 3.2.2 in chapter 3). Analysis of the data began whilst data collection continued as outlined in 4.3.1. In this way the data were able to inform the process of data collection. Demographic details of the health professionals interviewed were used to provide a profile of participants qualifications and experience within either primary care or SPCS.

4.4.1 Coding and Interpretation

Once the first few interviews had been fully transcribed a detailed analysis of the information was undertaken. On the first reading of the transcripts, items were highlighted and notes made in the margin about sentences or words that appeared to be of significance. This included the type and nature of the response the participants were making to the interview questions. These items formed the basis of the coding of the emerging themes. All the emerging themes were recorded and an attempt was made to uncover connections and links between the themes. Codes relating to similar constructs were grouped together into themes. For example codes relating to who informal carers were, what they were likely to do and why they were likely to do it became emerging themes. Once a list of themes had been identified, a master list of themes was produced, and the sub themes that had been combined to characterise the master theme were identified underneath (appendix 4). This list became the master list of themes and reflected the underlying concerns of the participants.

As the process continued with further transcripts, new and emerging themes as well as further instances of original themes were recorded. Furthermore, each reading of the

transcripts revealed some differences in the understanding and interpretation of the original themes. This resulted in some themes that were originally thought useful being superseded by other more encompassing themes. Initially the themes focused on the format of the interview questions, however it soon became clear that these questions revealed a number of inconsistencies and conflicts between what was being discussed at various stages throughout the interview. The relationship that health professionals had with informal carers, and the tensions this caused became an important theme that was incorporated in the final list of themes.

Fifteen interviews representing a cross-section of the participants were fully transcribed and analysed. The subsequent interviews were partially transcribed using a thematic approach representing the themes that had emerged in the original 15 transcripts. Once this had been completed the transcribed data were then subjected to a further coding process and refinement of the master themes and sub themes. Also the portions of data coded with the theme identifier were then joined into one document so that a comparison across all cases could be made.

4.5 Results

The results can be divided into three sections. The first explores the participant profile and the level of experience and expertise within the two specialist fields; primary care and SPCS. The second section explores the health professionals' perspectives of the nature and activities of the informal carer. The final section considers the relationship between the health professional and the informal carer and the difficulties that might be posed.

4.5.1 Participant Profile

Six male and thirty four female participants were interviewed. Total years of experience within their specialist field ranged from six months to thirty two years, with a mean of 8.3 years. Table 4.1 shows the level of experience between the two groups of professionals. Total years since original qualification and experience within the specialist field (primary care or SPCS) remain fairly similar for both groups.

Participants from primary care had a mean of 17.5 years since qualifying and 10.1 years in the specialist field, whilst those from SPCS had a mean of 16.9 years since qualifying and 6.4 years in the specialist field.

Table 4.1 Years of Experience by Professional Field

Professional Group	Years since Qualifying			Years in Specialist Field		
	Minimum	*Maximum*	*Mean*	*Minimum*	*Maximum*	*Mean*
Primary Care	5	32	17.5	0.6	32	10.1
SPCS	3	34	16.9	2.75	18	6.4
Total	3	34	17.4	0.6	32	8.3

Level of qualification are also similar for both groups, with a slightly higher number of SPCS health professionals holding three or more professional qualifications (Table 4.2).

Table 4.2 Qualifications Held and Estimated Number of Palliative Care Patients Seen Per Year.

Professional Group	Qualifications Held		Estimated number of Palliative Care Patients seen per year		
	1-2	*3+*	*Minimum*	*Maximum*	*Mean*
Primary Care	10	10	5	60	25.9
Specialist Palliative Care	6	14	48	400	180
Total	16	24	5	400	102.9

The largest difference between the two groups, as was expected, was to be found in the number of terminal patients visited on average in a year (Table 4.2). These estimates are very rough, and indeed a number of health professionals found it impossible to estimate how many patients they would typically see. Although the range for the SPCS group is large (48-400), this can be partly accounted for by the differing orientation and expertise found within this area. Despite this there was remarkable similarity with the mean

number of estimated palliative care patients seen per year within each group of health professionals.

The study revealed a number of dimensions reflecting the characteristics of an informal carer as perceived by the health professionals. These dimensions were premised by the nature of the relationship of the informal carer to the patient and various implicit assumptions about the informal carer generally.

4.5.2 Health Professional Perceptions of an Informal Carer

Health professionals identified a number of factors that related to their perceptions of an informal carer. These perceptions have been classified as; Credentials, Readiness, Motive. Each perception can be thought of as part of a dimension relating to the identity and definition of an informal carer (Table 4.3).

Table 4.3 Dimensions Relating to Identification of an Informal Carer

Dimension of Carer	Most Likely Aspects of the Dimension to Represent an Informal Carer	Least Likely Aspects of the Dimension to Represent an Informal Carer
Credentials	Unpaid	Paid
	Untrained	Trained
	Non-professional	Professional
	Informal	Formal
Readiness	Close	Distant
	Available	Not available
Motive	Positive Emotion	Negative Emotion

Each dimension was associated with aspects seen as most likely and least likely to represent an informal carer. Thus, within the credential dimensions an informal carer was felt most likely to be unpaid and least likely to be paid. However, whilst individual carers may be present at one end of the dimension on any one day, this did not mean that they were fixed in that position, and could move along the dimension at any time. In other words there was seen to be a great deal of flexibility within each dimension for

individuals to move between the most likely and least likely aspects of the dimension. Furthermore, health professionals perceived that the location of an informal carer within any dimension was due to a complex relationship between the informal carer, the ill person, and the process of negotiation of roles and tasks between the patient, carer and health professional. Despite this most health professionals referred to informal carers as being found at the most likely end of each dimension.

Underpinning the dimensions relating to the identification of an informal carer was the ability to care. This was seen most clearly in the caring activities undertaken by the informal carer. Activities ranged from personal intimate care tasks such as assisting the ill person with personal hygiene, and general household and social tasks such as assistance with house work, shopping or providing company. In order to be able to provide such care it was necessary for informal carers to have the appropriate credentials, readiness and motivation to care. Thus, ability to care was essential to the role of informal care and cut across each dimension in the identification and definition of an informal carer.

4.5.3 Relationship to the Patient

Relationship to the patient was the most frequently cited reason for involvement in this type of caring. Seventy seven and a half per cent (n=31) of the health professionals, representing all groups, identified the informal carer as being a relation or member of the family.

> *"It's most likely to be family. Spouse, brother, sister, children." District Nurse*

> *"A member of the family or a friend." Palliative Care Doctor.*

However, health professionals were also keen to point out that informal carers were not always members of a patient's family. Neighbours and friends also featured strongly in definitions of informal carers, particularly for those health professionals working in SPCS.

"It doesn't necessarily have to be a member of the family, I mean quite often for us neighbours do a lot of informal caring." Social Worker

"Mainly it's family members yes, but for those that are living on their own neighbours can be relied on quite heavily." Macmillan Nurse

Thus, the importance of pre-established relationships with the patient prior to the illness developing, was commonly associated with kin or family members being identified as the informal carer. Non-kin individuals were presented as similar to close family members, with the exception of the type of activities they were likely to undertake. In this area non-kin were often implicitly seen to be more likely to be involved in social type activities, such as visiting, shopping, and providing meals for the ill person, rather than close intimate activities such as assisting with washing, toileting and dressing.

"It's almost as though there's sort of levels of expectation. A neighbour would be expected just to keep an eye and perhaps you know do the odd thing, empty a dust bin, maybe go to the shops. Family members perhaps a bit more, deals with bodily functions and so on." General Practitioner

Few differences were identified between kin and non-kin informal carers except in the area of personal care. In this respect non-kin were thought less likely to be involved in giving personal care than kin, although it was stressed by many health professionals that informal carers would not be expected to undertake more caring than had been negotiated and agreed.

Credentials of family caregivers related primarily to the definition of a carer. As such it concerns the pay, training and professionalism of the individual. Nearly a half of the health professionals (42.5%, n=14), mentioned the fact that informal carers were generally untrained, whilst 35% commented on their lack of pay.

"They're non-professional, they probably haven't had any training in caring." Macmillan Nurse

The difficulty of distinguishing what was understood by 'informal' and 'formal' was problematical. A few of the nursing health professionals thought of immediate family as providing more 'formal care' whilst 'informal' was seen to be delivered by people who 'pop in and out'. This contrasts with the literature that tends to identify informal care as that provided by family and friends, rather than 'formal' health services.

"I think of the carers as being the people that live with them and care for them every day whereas the informal carers are the people that are in and out such as the district nurses, the physios, um the Macmillan nurse something like that." District Nurse

The place of volunteers also caused some tension for a number of health professionals. This group of individuals, whilst conforming to many of the dimensions in the same way as kin and non-kin, were seen as different because they had often received training, were occasionally given out of pocket expenses, and were organised in a similar way to professional carers. However, these people did not generally have a pre-established relationship with the patient and were therefore considered by most health professionals to represent more formal rather than informal carers.

"And the grey area would be people like volunteers who are not paid as such but are actually organised carers if you like from our setting."
Doctor in Palliative Care

The dimension of 'Readiness' referred to the geographical distance from the patient and the perceived willingness of the individual to be involved in caring for the ill person. Consequently the majority of informal carers were thought to be either resident with the ill person or living very close by. Geographical proximity to the patient and being a family member were both mentioned by 65% (n=26) of the health professionals as a reason that informal carers engaged in this role, although four health professionals suggested a distant informal carer could be involved in providing psychological and social support rather than practical hands on care.

"Well it's normally the person that's there isn't it, the person, if it's a married couple, it's the person who's doing the care." District Nurse

One reason for the perceived importance of geographical closeness were the practical considerations of caring. Two health professionals suggested that they had known carers, who normally lived away, to come and stay with the patient should more intensive practical care be required.

"I would say a proportion either um moved to the patient's home or take the patient to their own home, and that's more common when it's like children caring for parents." Doctor in Palliative Care.

The reasons individuals agreed to participate in caring were thought to relate to a number of personal qualities. Positive feelings included compassion and a desire to help (37.5%, n=15), love for the person (22.5%, n=9), and fulfilling a personal need (10%, n=4).

The act of compassion and a desire to help generally centred around the pre-existing relationship between the ill person and the informal carer, and was often implicit within the relationship. Love also appeared to be understood as a 'given' or taken for granted reason for caring and was therefore often summarily commented upon by the health professionals.

"and love of course, um, that goes without saying of course, but I suppose one ought to mention it." Social Worker

For a small percentage of health professionals (10%, n=4), undertaking the role of an informal carer was perceived to be a way of fulfilling a personal need within the carer to be needed. This act also allowed the individual to fulfil certain 'roles' that they saw as their responsibility.

Besides the positive factors that were described, a number of negative reasons for undertaking care were also mentioned by the health professionals, although these were

more likely to be applicable to kin carers than non-kin. These included a sense of duty (37.5%, n=15), obligation (27.5%, n=11), no other option (27.5%, n=22), responsibility (20%, n=8), and guilt (10%, n=4).

Duty was perceived to be directly related to the relationship between patient and carer, particularly family relationships. Obligation was also implicitly related to past behaviours of the ill person, or expectations that they would act in a similar way if the situation were reversed. Again this was seen to be particularly relevant to familial relationships, expectations, and patterns of behaviour.

> *"they perceive it to be their duty because they are wife, husband, daughter, nearest relative available." General Practitioner*

There was an awareness among the health professionals that some carers felt they had no option in undertaking the caring role. This was in part thought to relate to the carers' own expectations about themselves, and in part concerned the availability of statutory or voluntary services.

> *"I think sometimes it's almost a fait accompli by professional organisations that well if you don't look after them there isn't the care'. I very much see them as filling the gaps between the statutory carers that are available." Macmillan Nurse*

Responsibility was mentioned by 20% (n=8) of health professionals as a reason someone was likely to undertake informal care, as were perceived feelings of guilt (10%, n=4). In most cases this sense of responsibility was limited to the duty of an individual towards the ill person. Guilt was seen to be expressed by carers only if they were unable or unwilling to undertake informal caring, which was implicitly understood to be their 'role'.

> *"I think women do hold that in their heads (a model of what they should do) and many feel guilty if they for whatever reason they can not or will not do it (care)." Social Worker*

Indeed a sense of expectation that certain individuals would be identified and volunteer for the role of informal carer, stemmed not only from the caring individual, but also from the patient, other family members, society and the health professionals. Despite this, most health professionals reported no explicit 'expectation' of carers undertaking more than the most basic familial responsibilities.

"I think sometimes when somebody is designated as a carer by the patient or by other family member, or by themselves, we have an expectation that they're selfless about it, and I think we don't know what relationship they've had, you know, we don't know what's in the background, um, so I think sometimes our expectations are unrealistic" Doctor in Palliative Care

Whilst the subject of gender was not specifically raised during the interviews, it became clear that many implicit referrals were made towards female carers. Although most health professionals were careful not to identify informal caring as a woman's role, within families it was usually perceived that a female rather than a male relative would be chosen as a carer.

"Well they're most likely to be a wife or a partner or a daughter or son or in-law, you know the younger generation in-laws." District Nurse

Finally the health professionals identified a number of activities that an informal carer would typically be found doing. The range of activities varied from very infrequent help such as popping in to see how the ill person was to full nursing care. All the health professionals perceived these activities to be open to negotiation between the ill person, the carer and the health professional.

Housework, shopping, cooking, social care, organising and supervising the patient's medication were generally seen to be tasks and activities that most carers would be able to undertake without problems. More personal care required by the patient, and any increase in responsibility for their well being was thought to be undertaken only after negotiation with both the patient and the carer.

In reality, some health professionals expressed the notion that whilst this was the ideal, when no-one else was available the carer would have to manage some tasks that they may not be totally happy to undertake. For some carers this had resulted in a pleasant surprise that they were able to undertake such tasks successfully.

"I've seen it happen before somebody who physically and mentally feels they're not able to care for somebody, um, and possibly hands on care, ends up by caring for that person at home till they die" Macmillan Nurse

4.5.4 Responsibility and Conflict Arising for the Health Professional

Most health professionals identified a strong sense of responsibility towards the informal carer. However, this was perceived to be qualitatively different from that directed towards the patient. This resulted in conflict and tension when there was seen to be friction between the patient and carer, doubts about the provision of medical treatment, and a need to provide differing support to both the carer and the patient. Table 4.4 indicates how a perceived sense of responsibility on the part of the health professional resulted in a degree of tension or conflict.

Table 4.4 Perceived Responsibility and Conflict Arising for the Health Professional

Perceived Responsibility	Conflict Arising From:
Towards the carer	Differing patient and carer needs
For medical treatment of the patient	Practical limitations of the situation.
For support of the patient and the carer	Acting as a mediator between the patient and the carer

Responsibility Towards the Carer

When asked if they felt a sense of responsibility towards the informal carer the health professionals overwhelmingly (87%, n=35), replied that they did.

"Yes a huge responsibility, just as much as the patients almost." Macmillan Nurse

However, this responsibility was seen to be qualitatively different from that of the patient. Few health professionals reported instances when the informal carer was perceived to be the primary responsibility. This was typically because it was the patient who had been referred to a particular service for assessment. In some cases the health professional was almost apologetic about not considering the carer as the primary responsibility, and appeared to have difficulty in determining whose needs should be met.

"Um, not so much as the patient, wrongly probably" District Nurse

The result of the differing responsibilities towards both the patient and the carer was particularly highlighted when there was a conflict in the needs and desires of the patient and the carer. Such situations were compounded when the carer was perceived by the health professional to be influential to the realisation of the patient's desire.

"the only time it (determining professionals' responsibility), would become a problem if you like is when there's a big difference between what the patient wants and what the family says" Doctor in Palliative Care.

Conflict between the patient and carer was not always caused by the patient making unreasonable demands upon the carer. Occasionally the carer was cited as the reason for the conflict.

"but there are circumstances too when carers' demands for care for the patient may not coincide with what the patient wants anyway, and so there becomes a conflict." District Nurse

Responsibility for Medical Procedures

A second tension was found between the responsibility most health professionals felt towards any medical procedures undertaken for the patient and the practicalities of carrying through such requirements. Whilst most health professionals felt responsible for any medical procedure, they often had to relinquish this task to the informal carer due to practical requirements, or because the carer and patient preferred to undertake

these tasks themselves. This dilemma was most often commented on by the nurses in the study. Doctors rarely commented on this issue except in connection with informal carers administering control drugs and using syringe drivers.

"I mean I'm not giving those tasks away easily but some people want the independence and the, you know, they're happy with the responsibility, and I suppose you just have to get to know them and weigh up what you think is reasonable." District Nurse

Many of the health professionals were concerned about relinquishing what they saw as essentially medical procedures such as dealing with syringe drivers or adjusting medication particularly of opioid related drugs. One specialist palliative care professional commented that they had come across a number of patients who were quite severely opioid overdosed by well meaning carers.

"We do occasionally see patients who are quite badly opioid overdosed simply because the carer um has taken upon themselves to give you know more and more." Doctor in Palliative Care.

Of particular concern when 'sharing' medical responsibilities with informal carers, was the legal situation. Both nurses and doctors who were fairly new to primary care questioned the legal position of allowing informal carers control of the administration of opioid drugs via a syringe driver.

"The legal responsibility I guess has got to lie with the health professional."
District Nurse

Interestingly no one in specialist palliative care found the idea of allowing informal carers to perform 'medical' type tasks unacceptable, provided they had been appropriately trained, supported and all parties were willing to pursue this path.

"Um, it doesn't happen very often but I mean I have had situations where carers have changed syringe drivers, not many, but for some that's all right

and perhaps they are finding it very intrusive all the professionals coming in
they don't want that." Macmillan Nurse

When this occurred the health professionals were keen to emphasise their involvement in a supervisory and monitoring capacity that ensured they maintained control of the medical procedures being undertaken in the home. This also prevented the health professional from feeling that they were abandoning their responsibility in the situation.

In fact some informal carers had been known to undertake essentially medical tasks that visiting health professionals were not qualified to do, such as epidural administration of medicine.

"I've certainly seen informal carers do things that trained nurses won't do
because of their rules and regulations and lack of certificates and things."
Doctor in Palliative Care

Responsibility for Support of Patient and Carer

Tensions were often noted when attempts were made to resolve some of the conflict between the patient and carer. Again this was seen to be particularly important if there was a difference in the patient's and carer's needs, and the carer was considered influential in achieving the patient's desire. Generally, resolution of conflict was achieved by encouraging open communication, training in practical nursing care if necessary, offering extra help, and assisting both the patient and the carer to recognise the carer's needs.

"I think it's part of my role and other people's to make quite sure they
realise early on that we are there to ask. There's an awful lot of things we
can do, but we wouldn't want to tell them at day one every single service
available, but the more that comes up they must keep asking, I think it comes
back to the dialogue which I think we need to keep open."
General Practitioner

A lack of clear communication and openness between the patient and carer regarding diagnosis and/or knowledge of treatment regimes caused concern for some of the health professionals. In these situations the health professional was left trying to juggle the needs of both the carer and the patient without betraying confidentiality or professional responsibility.

> *"if you've got say a family member who's adamant that they don't want their wife or husband to know or whatever, um in a way it's got to be worked with because you can't have a, if they want to stay at home or they're needing this care, you cannot have a carer that's hyped up, doesn't know what's going on, seeing somebody getting progressively less well, frightened, that you cannot start to include, do you know what I mean?" Macmillan Nurse*

Often a desire for open communication on the part of the health professional was in order to minimise a perceived fear of the patient that people were talking behind their back, unless the patient had specifically requested that information not be passed onto their carer.

> *"I think it's best to talk things over with both of them, unless of course the person that's ill says 'I don't want you to discuss this with my daughter' or something like that" District Nurse*

Psychological and emotional support for the informal carer was provided on an ad-hoc basis, and was usually said to be initiated by the carer themselves either at the end or the beginning of a visit with the patient. Some carers had been known to request time alone with the health professional, and were usually seen at the health professional's workplace or sometimes at the carer's place of work. Phone calls and time in the other rooms of the house were also sometimes used.

> *"I have had patient um carers ask if they can come and see me here, I've had that on a few occasions, ... and I've said well you can come here or I'll come to where you work whatever." Macmillan Nurse*

Occasionally the health professional would deliberately manipulate a situation to discuss issues that were known, or suspected, of causing difficulties for the informal carer, although this was sometimes resisted by the carer. If informal carers did not want to discuss their own needs they would sometimes achieve this by leaving the room when the health professional arrived, or concentrating all their efforts on the ill person, thus limiting the time spent with health professionals on their own.

"If you try and encroach on a rather painful area and they don't want to it's pretty obvious they either physically go away or they mentally try to change the subject or cut you off or whatever." Macmillan Nurse

Some health professionals reported the need to reassure informal carers that they were doing a 'good job'. This was perceived to enable the informal carer to continue with the caring role. When offered support was refused by the carer, health professionals were often able to offer little in the way of alternative support.

"I remember we had an Indian gentleman who's severely disabled by a stroke, and his wife used to care almost to the point of physical breakdown, washing him, getting him on and off the toilet, and neither of them were very old I think they were both in their sixties, but for cultural reasons she would not allow anybody else to do anything else to him, ... despite our at least four case conferences we were never able to improve that situation and then well he's dead now." General Practitioner

4.6 Discussion

The study sought to explore the perception of health professionals regarding informal carers in a palliative care setting. In addition the nature of the relationship between the informal carers and health professionals was explored. Health professionals from both primary care and specialist palliative care participated in the study, and the results suggest health professionals perceive a number of dimensions relating to an informal carer. The nature of the association between health professionals and informal carers

was particularly ambiguous resulting in both tensions and conflict within the relationship.

Generally, informal carers were divided into kin or family members and non-kin. Family members were represented by immediate kin such as spouse, partner and children (usually adult children). Occasionally siblings, parents (of adult children), and grandparents were also involved. Non-kin were usually found to be friends, neighbours and occasionally work colleagues. Some differences were found between kin and non-kin particularly in relation to the type and level of activity the carer may become involved in. Voluntary, private or statutory services were generally perceived to be formal rather than informal due to the organised service nature of their contact with the ill person.

4.6.1 Health Professionals' Perception of Informal Carers

The dimensions identified by the health professionals were generally based on their experience and implicitly held assumptions and expectations. Four dimensions defining the informal carer and their actions emerged from the accounts provided by the health professionals: Credentials, Readiness, Motive. Each aspect of the dimension was viewed as ranging from most likely to least likely. Whilst informal carers were thought by the health professionals to be found at the 'most likely' end of the dimension, it was acknowledged that other possibilities could, and indeed in their experience had, occurred. For example it was thought unlikely that informal carers received any payment for participating in this type of caring, although some were known to receive a 'carers' allowance' if they had given up work to look after a relative. Health professionals continued to perceive these individuals as an informal carer because they did not fulfil all the 'least likely' end of the dimensions identified. Underpinning the dimensions was the ability of the informal carer to perform the caring activities relating to the role of carer.

Credentials

Credentials related to the pay, training, professionalism and consequent formality or informality of the service provided. Informal carers, whether they were kin or non-kin, were generally perceived to be unlikely to have received any pay or training at the

commencement of undertaking the caring role. However, both pay and training were often provided by social services and visiting health professionals. Nolan et al (1996a) suggest that for this reason, informal carers should be regarded as 'experts', and given appropriate assistance in maintaining this role. Thus, whilst informal carers may have entered caring with little or no experience or expertise, it is possible that they may gain this over time. Similarly, informal carers could be a trained health professional in their working life, but be considered an informal carer if they were looking after a relative or neighbour outside of their professional role. These evident contradictions in the credentials of the informal carer did not apparently concern the health professionals, as they were still identified as an informal carer due to their relationship with the ill person. It would therefore appear that an underlying assumption about an informal carer is related to the relationship prior to the illness developing. This would support the findings of Twigg (1989) who suggested that informal care is not provided on a basis of need but in response to pre-established social relationships.

It is perhaps not surprising that the health professionals identified pay and training as part of the dimension relating to a 'carer' as this term has been used in the past to refer to 'professional caring', usually within the health and social services field. Twigg & Atkin (1994) suggest the origin of the term 'carer' stems from a professional service orientation, and is associated with someone who is in paid employment. Therefore the development of the concept 'carer' in terms of professional carers, could be the basis for the implicit assumptions relating to the nature of who and what carers do, and how health professionals relate to them.

Whilst identifying with the term "carer" as someone who provides care and assistance to an ill or disabled person, the use of the term informal caused some confusion for a number of health professionals. This was particularly noticeable when considering the place of volunteers, who had usually received some training, were organised by a particular service and were not therefore known to the ill person and family prior to the illness developing.

Readiness

Proximity and availability were perceived as important factors in the health professional's identification of informal carers. Availability of the informal carer, particularly during the health professional's visit, increased the probability that an individual would be identified as an informal carer. This could perhaps explain why precedence appeared to be given to family members over non-kin.

Motive

Motivation was seen by the health professionals to relate to either positive or negative emotions. Although there is rarely one single reason why an individual becomes involved in informal care, expectations from friends, family and the individual themselves may result in someone participating in a caring role with less enthusiasm than is perhaps desirable. Whilst the health professionals were able to recognise this, they were often unable to offer any alternative for those individuals who did not really wish to become an informal carer.

The duty and obligation that carers sometimes experience, were seen as part of the natural relationship bond, particularly a familial one. Previous research has found that informal care in the community is still predominately undertaken by female relatives of the ill person (Payne et al 1999, Smith P.C., 1996), despite changing demographic and work practices. Such expectations were particularly heightened within a palliative care context, where it is acknowledged that the ill person has a limited time left.

Although few explicit references were made to gender, there were many implicit assumptions that gave preference to female carers. For example, female kin were frequently cited as carers before male kin. A number of reasons could account for this. Firstly the nature of the interview schedule did not specifically aim to identify gender difference. The few instances of female gender role mentioned were therefore implicitly assumed within the relationship bond. Secondly for these health professionals the gendered nature of caring may have little impact as their primary responsibility and concern was felt to be the patient. In addition there may be little they felt they could do to alter individual situations within their own professional role. Finally, it is important to recognise the situational and cultural context within which palliative care occurs.

Specialist palliative care in this country is generally linked to cancer care. Thus, the age of the population served is likely to be elderly. For this generation the notion that women fulfil 'caring' roles will often be adhered to, resulting in a higher instance of female carers.

Activities

There appeared to be a difference in the type of tasks that informal carers would be likely to undertake if they were kin or non-kin. Kin were more frequently perceived to be involved in more personal and intimate care tasks than non-kin. Although health professionals were keen to emphasise that they would not ask or 'expect' an informal carer to take on tasks that they were unhappy with.

Ungerson (1990) suggests that more intimate personal care is mediated by the relationship and gender of the ill person and the carer. Breaching these boundaries may cause embarrassment and social difficulties. Therefore, whilst it is perfectly possible for an adult daughter to help her mother with bathing it is less likely to occur if a daughter was caring for her father or a son was caring for his mother. Similarly it is unlikely that a non-kin or neighbourly relationship would extend to such intimate care tasks.

4.6.2 The Nature of the Relationship Between the Informal Carer and the Health Professional.

All the health professionals acknowledged a sense of responsibility towards the informal carer. However, this sense of responsibility resulted in a degree of conflict for the health professionals, particularly when there was a tension between the patient and carer needs.

Responsibility and Tension

Informal carers have only recently been openly acknowledged and their needs considered by service providers when implementing care in the community. Whilst the hospice movement has always maintained as one of its principles to care for the family of the ill person, they were not apparently viewed as equal to the patient. Such a situation caused considerable conflict for the health professionals because they were torn

between their desire to help, and their professional responsibilities, which were generally directed towards the patient.

It is possible that part of the reason for this difficulty is the nature of the health professionals' experience and expertise. Most of the health professionals came from a medical oriented background. That is, they possessed medical skills and knowledge such as those relating to drug control of symptoms and nursing care. In this context, psychological or social care is often difficult to identify, particularly if it is not acknowledged as a primary function of this group of health professionals. As some of the health professionals commented during the study, the patients' needs are clear and often well defined, whereas the informal carers' needs are much less easy to identify and resolve. For this reason it is perhaps easier for the health professional to concentrate on those needs and symptoms which they do have the knowledge and skills to resolve or improve.

Within the study the social worker and clinical psychologist appeared to be particularly well placed to be able to devote time to addressing the needs of the informal carer. This may be due to the differing emphasis and training of these two groups of health professionals, and demonstrates the importance of a multidisciplinary approach to palliative care. Therefore, it would appear that different health professionals may be accessed for different types of advice and support. Consequently, an informal carer may approach the social worker or clinical psychologist for help with their own personal issues and difficulties. If, however, the carer wished to gain assistance with aspects of care for the patient, the primary and specialist palliative care health professionals are perhaps more appropriate sources of support. What remains unclear is the extent to which the informal carers themselves can distinguish between these different sources of support, and if in fact they are viewed as legitimate and appropriate services to access.

The health professional/informal carer relationship is not a one way street with the health professionals doing all the giving. The carers themselves have an influence on the situation, by bringing their own expectations and norms of behaviour which will influence the amount and type of help they receive from statutory services (Twigg et al 1990). Twigg suggests that informal carers can be viewed as clients in their own right,

co-workers, resources or a superseded client. Many of the health professionals in this study appeared to think of informal carers as co-workers or, if difficulties arise, as a superseded client, and only a few saw them as individual clients. Thus, if a carer is seen as a co-worker, the support offered will be more likely to reflect the caring and 'medical' roles that the carer is engaging in. If, however, the carer is seen as a client in their own right, then the health professional will be able to concentrate their contact to dealing with issues and concerns of the carer alone.

Resolution of Conflict

Although health professionals often saw their primary responsibility lying with the patient they were aware that the informal carer was often crucial to the delivery of the patient's desires. For this reason, they often sought to resolve the conflict and tension arising between the differing needs through mediation and open communication. This enabled them to attempt to help both the ill person and the informal carer to understand each other's perspective.

If health professionals see their role as providing a service to the patient first and the carer second, conflict will naturally arise when opposing needs occur between the patient's desire and the carer's ability. Resolution of these issues may occur if the informal carer was given the same priority as the patient in terms of service provision.

4.6.3 Effect of the Palliative Care Situation

It is interesting to note that specific difficulties which informal carers in a palliative care situation might experience were rarely mentioned by the health professionals. Thus, many of the dimensions and responsibilities relating to informal carers, identified by the health professionals in this study, could be applicable to any long term caring situation. This could be for a number of reasons. Firstly there is the possibility that the wording of the interview schedule prevented the health professionals from acknowledging the particular difficulties faced by informal carers in this setting. However, whilst this could account for much of the apparent lack of awareness of the special difficulties faced by this group, all the health professionals were specifically asked to think about informal carers in a palliative care setting. Therefore, a general assumption relating to informal

carers would appear to be very pervasive, resulting in no perceived difference between informal carers in a palliative care setting and any other long term caring situation. Alternatively, the special difficulties associated with a palliative care situation, such as anticipatory grief, differing disease trajectories, or the emotional impact of coping with a disease that is often stigmatised and feared, may be so taken for granted and implicit, that they were not mentioned by the health professionals.

4.7 Further Research

A number of questions have emerged as a result of this study. These focus on the way informal carers themselves understand the caring situation that they are engaged in. Of particular concern is the way they view their relationship with health professionals.

4.7.1 Informal Carers' Perceptions of Their Role

How do informal carers perceive their role/identity within the caring situation?

- What factors influence the development of this role within palliative care?

- What are the implications of subscribing to this identity?

How does the adoption of the 'carer role', affect the carers' access to sources of support and help?

What is the extent of the difference between non-kin and kin?

- in terms of what they are expected/willing to undertake

- what are the influences/implicit explicit assumptions about these relationships?

4.7.2 Informal Carers' Perceptions of the Relationship with Health Professionals

How much do the carers' own expectations and behaviours influence the health professionals' response to them?

- do they have problems explaining or communicating their own issues because they are unsure how legitimate it is to explore these issues with the health professional?

Do informal carers perceive different health professionals as providing different services?
- is this helpful/unhelpful for them?

The questions arising from the first study were followed through to a second longitudinal study that will be discussed in the following chapters of the thesis.

4.8 Conclusions

An informal carer was thought most likely to be a member of the immediate family. Occasionally, non-kin carers such as neighbours or friends were identified as an informal carer. A number of dimensions could be found to be related to the identification of an informal carer notably: Credentials, Readiness, Motive, and Activities. Whilst it was emphasised that informal carers would not be expected to undertake caring, it was acknowledged that they may become more involved than they desired.

The relationship of the health professionals and informal carers was ambiguous. Health professionals felt a level of responsibility towards an informal carer that was qualitatively different from that expressed towards the patient. This ambiguity often resulted in tension when conflicts arose between the needs of informal caregivers and the ill person.

What continues to be unclear is how informal carers themselves view their position within this context, and the influence they might have on the situation. If the position of informal carers in palliative care was clearly stated and defined this may help to avoid the confusion and difficulties relating to the ambiguity of the role for both the carer and the health professional.

Chapter Five

The Family Caregiver in Palliative Care

5.1 Introduction

The first study revealed that although health professionals perceived a number of people as possible informal carers the vast majority were close kin to the cared for person. Furthermore, many of these individuals were perceived to be willing to undertake a caregiving role due to their desire to support the cared for person. As individuals were therefore most likely to be kin relations, and were perceived to be willingly engaging in caregiving in palliative care settings, further reference to this group will be as family caregivers rather than informal caregivers. Having considered the position of family caregivers from a health professional perspective the second study sought to explore the family caregiver's view.

This chapter will describe the purpose of the longitudinal study of family caregivers perceptions' of their role and sources of support. The methods and procedures used will also be outlined in this chapter.

5.2 Focus of the Study

The position of the family caregiver in palliative care is vague and poorly reported in the literature. For this reason an exploratory study was undertaken to highlight this particular group of caregivers' perceptions in relation to their role and sources of support. The aims of the study were:

1. To explore the definition and role of the family caregiver from the individual's perspective;

2. To gain a deeper understanding of the relationship between the family caregiver and health professionals;

3. To explore other sources of support that may be available to the family caregiver in this situation.

5.3 Context of the Study

For many people there is a desire to remain at home during the dying phase (Hinton 1994a). As a result the impact on the family caregiver may be felt most strongly at home within a community palliative care setting, where over 90% of patients spend the majority of their last year of life (Seale and Cartwright 1994). For this reason the study was conducted with family caregivers in their 'normal' or 'daily' environment, within the community. Each family caregiver was caring for someone who was currently receiving SPCS, and had a prognosis of six months or less.

Initially it was hoped to recruit from one area in the south of England. However, recruitment difficulties and high attrition rates, resulted in the study being extended to a second area in the south of England. The two areas were matched for similarities, with both areas being medium to large urban centres. However, one area was classified as an expanding fairly new town with a low unemployment figure, whilst the other was considered to be an established city with high unemployment and poverty rates.

Access to family caregivers was gained through the visiting Macmillan/home care nurses for the local hospice to the area. The hospice in Area One was a 10-bedded unit with capacity for 16 beds when fully opened, and an attached day care centre. In Area Two the hospice was a 15-bedded unit, with a capacity of 18 beds when fully opened, and attached day care centre. Both centres admitted people with a diagnosis of cancer, motor neurone disease and HIV/AIDS patients, although for the purpose of this study only those family caregivers of a person with a diagnosis of cancer were included.

5.4 The Researcher

The researcher was not known to the family caregivers prior to the study. The researcher had a background in district nursing. Some family caregivers were directly informed of this by the referring Macmillan/home care nurse, and some appeared to

assume the researcher had some form of nursing or medical background, which had a direct influence on the type of information provided during the study. A previous professional background was found to be particularly useful in understanding some of the medical terminology and processes that the family caregivers reported. However, Mason (1996) believes that qualitative research should involve 'active reflexivity' (p6-7). That is, being aware of any actions taken within the research and how this might affect the situation under investigation. Therefore the way in which the researcher might influence the process and findings of the research must also be taken into consideration. A research diary was completed to record the way that decisions were reached with regard to the data collection and analysis process, and that sought to understand the influence of the previous professional background on the information provided by the family caregivers during the study.

5.5 Design

The study followed a Longitudinal Case Study design. Multiple methods were used including a semi-structured interview and a range of standardised quantitative questionnaires. Family caregivers were identified as 'carers' for someone who was receiving SPCS, and who had a prognosis of six months or less. Each family caregiver was visited up to four times over a four-month period:

- Time One   At introduction to the study

- Time Two   2 weeks from entry to the study

- Time Three   6 weeks from entry to the study

- Time Four   12 weeks from entry to the study

Longitudinal design studies in palliative care are particularly prone to high attrition rates, as a direct result of the nature of the situation being studied. Time points were selected in line with a study by Jarrett et al (1999) that found a considerable attrition of terminally ill people within the first two weeks of a study. It was therefore proposed

that the second visit should be within a short time span of entry to the study in order to capture as much data as possible from participants who might otherwise decline to be further involved in the study. Initial assessment was within two weeks of referral into the study. Remaining time points were spaced at longer time periods as it was believed that, should the situation remain relatively unchanged during the first two weeks after entry to the study, a longer time period before visits would allow for greater diversity in the experience to be discussed.

Family caregivers were interviewed using a semi-structured interview schedule (appendix 5) about their perception of their role, and relationship with visiting health professionals and other sources of support. In addition questionnaires were used to ascertain the level of activity related to caring for their loved one, the amount of social support available, and the degree of anxiety and stress experienced. Both the development of the schedule and measures are described in greater detail below.

5.6 Ethical Issues

The selection criteria for inclusion in the study raised a number of ethical issues, some of which are transferable to other studies in palliative care. This is a particularly sensitive time for the family caregiver and for the person who is cared for. Difficult emotional issues need to be addressed and there is often a sense of loss associated with this situation.

5.6.1 Ethical Approval

Ethical approval for the study was obtained from the local ethics committee in each area. Confidentiality was assured throughout the study by adhering to the principals of Good Clinical Practice guidelines, and maintaining all records in locked cabinets or code locked computer files. In addition, the study sought to conform to the Data Protection Act 1984. Furthermore, all real names were deleted from the transcripts and substituted with false names.

In Area One, ethical approval was given by the Hospital Research Ethics Committee, once an agreed protocol dealing with possible distress in any of the participants had been more fully explained. The committee in Area One considered no further alterations to the protocol necessary. Protection of the participant from harm is an essential requirement of any study involving human participants. Research within palliative care is of necessity likely to involve highly charged emotional situations. For this reason it was necessary to be explicit with the participants about the purpose of the research and the interviews, to prevent unrealistic expectations of the research as a counselling session for the participant. However, time was allowed for participants to express their concerns and worries if they wished to do so. Where individual participants had concerns or worries relating to their situation, and not to the research study, they were advised to contact their visiting health professional for further counselling or clarification of the issues raised. If a situation was to arise where the researcher felt the participant was potentially suicidal, it was agreed that the referring health professional would be contacted immediately by the researcher. During the study no such situation arose, and there were very few instances of the participant becoming obviously distressed during the interviews. As far as could be ascertained no participant was left in a distressed state at the end of the interview.

In Area Two the local ethics committee was concerned that the family caregiver's GP and the patient's GP should be informed of the decision of the family caregiver to participate in the study, in case this affected their relationship with the visiting GP. However, it was not possible to contact the family caregiver's GP prior to the study commencing, as the referring Macmillan/home care nurse would not have these details available to them at the point of introduction to the study. Therefore, it was not possible to know who the family caregiver's GP was, or how to contact him/her. In addition, it was questionable if the family caregiver was in contact with their own GP, and, if they were, if this was as a direct result of the caregiving situation. Consequently, in order to reduce any unnecessary communication with overworked GPs, it was agreed that only the patient's GP would be contacted prior to the inclusion of any family caregiver in the study. Thus, each patient's GP was contacted by letter (appendix 6), explaining the purpose of the study and the involvement of a family caregiver of one of their patient's. This gave each of the patients GPs in Area Two an opportunity to

contact the researcher for more detailed information about the study prior to commencement of the family caregiver's participation. No GPs contacted the researcher for more information about the study.

This situation does raise the issue of the power relationship in the community, with the GP being seen as a gatekeeper to all services received by his/her patient. It is possible that the family caregiver was not in contact with their GP, and it is therefore open to question whether or not there was a need to contact them about the research. For example, there were likely to be cases relating to adult children as the main family caregiver. In these situations, there may have been no connection between the patient and the family caregiver's GP. In many cases, however, the family caregiver and the ill person may have had the same GP, and it would be considered a courtesy to inform them of the ongoing research.

5.6.2 Consent

Written consent was obtained from the participants at the first interview (appendix 7). In all subsequent interviews, verbal consent was again agreed with all participants prior to the interviews commencing. At each time point, participants were advised of their right to stop the interview at any time without prejudicing the treatment or care received by the patient or themselves. Of the participants visited by the researcher for an interview, only one requested that the interview be delayed due to the deterioration of the patient's condition. This person subsequently withdrew from the study. All other participants (n=9) who withdrew from the study did so between visits by the researcher.

5.6.3 Interviews in Palliative Care

A general discussion on ethical issues relating to interviews in research can be found in chapter 3 (section 3.5 and 3.6). However, within the study, consideration was also given to the welfare of the family caregiver in relation to maintaining confidentiality of information divulged from both the referring health professional and the cared for person. This was felt to be important, so that family caregivers could feel free to discuss

issues concerning their position within palliative care that may have been either positive or negative.

It was also considered important that, should issues arise as a result of the interview that the researcher was unable to deal with, appropriate provision was made for family caregivers to be given details of other agencies or support that might be able to assist them. General details relating to protecting the participant from harm within interview research, particularly if those issues are of a sensitive nature, have been discussed in chapter 3 section 3.6.2. If someone was considered potentially suicidal it was agreed that the researcher would contact the referring nurse immediately, and take appropriate steps to ensure the immediate safety of the family caregiver.

5.7 Selection Criteria

It was decided to recruit family caregivers via the visiting Macmillan/home care nurses for a number of reasons. Firstly the aim of the study was to explore the perception of family caregivers during the terminal stage of the cared for person's illness. As this is recognised as a potentially stressful and emotionally difficult situation it was felt that it would be inappropriate to contact potential family caregivers without prior warning from someone they knew and trusted. Previous studies undertaken by the researcher had also used the visiting Macmillan/home care nurse as the point of access with good results (Payne, et al 1999). In addition, a second aim of the study was to explore the perceived relationship of family caregivers with visiting health professionals. In order to achieve this it was felt necessary to contact family caregivers who had access to a similar range of visiting health professionals. By accessing potential family caregivers receiving SPCS it was felt that all participants would be likely to be in contact with at least two distinct groups of health professionals: primary care services in the form of GPs and district nurses, and SPCS via the local hospice and visiting Macmillan/home care nurses.

Eligibility for inclusion in the study also included:

- Each participant being aware of the diagnosis of the person for whom they were caring;

- Caring taking place in the patient's home or in the home of the caregiver;

- Caregivers being able to understand English;

- Participants were excluded if the person they were caring for had been admitted to an institution prior to the commencement of the study and were not expected to return home, or had died.

In order to recruit via the Macmillan/home care nurses it was necessary to involve them in the management of the data collection strategy to be employed during the study. Hence, prior to the commencement of the study, the Macmillan/home care teams were visited and the study aims and objectives explained. The visiting Macmillan/home care nurses were asked to select a caregiver if they were considered to be the primary carer of a patient with a terminal diagnosis of cancer, and who fulfilled the other eligibility criteria outlined above. Advice was sought from these teams as to the best way to communicate with them in regard to obtaining referrals of potential participants. It was felt important that regular contact was maintained with both teams during the data collection phase to ensure that family caregivers who had agreed to participate were contacted promptly following introduction to the study. This was for two reasons: The first was to ensure that there had been no major changes in circumstances that the researcher needed to be aware of prior to contacting the participants, for example the death or deterioration of the patient's condition. The second was to reduce the attrition rate of participants prior to entry to the study. In both areas the nurses preferred to be contacted by telephone in the morning which was their usual time for conducting office work before visiting patients and their families. The researcher therefore agreed to contact each group of nurses at least once a week to collect details of any family caregivers willing to participate. In addition, the nurses were able to contact the researcher at any time with information about participants already included in the study, for example if the person they were caring for had been admitted to hospital or hospice or had died, and with new referrals.

Recruitment of participants from the visiting health professional has a number of advantages and disadvantages. One advantage of the Macmillan/home care nurse referral was that a current assessment of the circumstances of both the family caregiver and the person being cared for could be given to the researcher. This is particularly useful in a situation such as palliative care where there is the possibility of an unpredictable and rapidly changing set of circumstances. By reducing delay between the time the Macmillan/home care nurse introduced the study to the family caregiver and contact by the researcher it was hoped that no individual would be contacted at an inappropriate time. Indeed, there was one instance during the study when close contact with the referring nurses prevented a call to a possible participant following the patient's sudden death.

Another advantage of recruiting via the visiting nurses was the way the study was legitimised when it was received from a respected source rather than an unknown researcher. As the family caregiver is in a particularly vulnerable position during this time, access to names and addresses of possible participants need to be protected. By contacting participants only when they had already agreed for their name to be forwarded to the researcher, confidentiality of those family caregivers who did not wish to participate was maintained. Thus, participants were screened by the entry procedure of the study, and only those family caregivers that wished to participate were recruited.

A disadvantage of recruiting in this way could be the possibility that family caregivers felt obliged to participate because their visiting nurse had asked them. It is possible that some family caregivers may have felt their access to services would depend on their participation in the study. To prevent family caregivers participating unwillingly, it was stressed on both the information sheet (appendix 8), and at the time of giving consent that access to any health service was in no way related to participation in the study. Another problem related to introduction of the study by the visiting nurse was that family caregivers might be reluctant to be open and honest with the researcher about dissatisfaction with care provided by professional services, due to a fear that future care may be jeopardised by such comments. Again it was emphasised that all comments were given in strict confidence and that no individual comments would be reported back to the referring nurse, either during, or after completion of the study. However,

participants were made aware that a report of the main findings would be made available to the referring institution and that all names and identities would be concealed to protect confidentiality.

Furthermore, the Macmillan/home care nurses acted as gatekeepers to the family caregivers, and selectively screened some family caregivers before informing them of the study and its aims. For some nurses there was a tension between wanting to refer family caregivers to the study and the need to protect them from any distress they felt might be experienced as a result of participation in the study. The emotional and physical situation of the patient became prominent factors in decisions concerning which participants should be told about the study. In cases where there was obvious distress, there was a great reluctance by the nurses to mention the study in order to protect both the patient and their family caregiver from further distress. Alternatively, a few family caregivers were introduced to the study particularly because the situation was said to be 'difficult', and often involved complex social and emotional factors. There was a sense that participants in these situations were referred to see if any useful information could be returned to the team dealing with the situation. However, there was an agreement that information given during the interview by participants would not be discussed by the researcher with the referring team unless requested by the participant.

It was notable, in both areas, that one or two nurses referred more participants than others, despite each nurse holding similar case loads. When further enquiries into the referral situation was made, it became apparent that some nurses were reluctant to introduce the study to new patients and their families as they felt that this would jeopardise the trust they were building up in a particular situation. Thus, many of the family caregivers referred to within the study were in fact long term carers of a patient in a relatively stable condition. This could explain why there was little apparent deterioration experienced by a number of the family caregivers.

Despite the problems with referral via a visiting health professional, the benefits of retaining confidentiality of this particularly vulnerable group and the advantage of minimising delay of referral and contacting only those individuals who had been forewarned of the study resulted in the procedure being adopted.

As with many other studies in palliative care research it is clear that this sample is not necessarily representative. However, qualitative research does not require representativeness, as it attempts to reveal differences and the unique situation of each individual. Each family caregiver that agreed to participate in the study was able to bring their own particular experiences and viewpoint of the situation, thus improving our understanding of the position of family caregivers in a palliative care setting.

5.8 Participants

Each family caregiver identified by the visiting Macmillan/home care nurse was given a verbal explanation of the project and left an information sheet (appendix 8). If they agreed for their name, address and telephone number to be forwarded to the researcher, they were contacted by phone within a few days by the researcher. At this point a further explanation of the project was given, and any questions arising answered. An appointment was then made for a time and date convenient to the caregiver.

Twenty-three caregivers were contacted. Seven declined to participate at this stage and were thanked for their time and not contacted again. Sixteen caregivers were admitted to the project. An equal number of male (n=8) and female (n=8) family caregivers were recruited into the study.

Ten family caregivers withdrew early because of difficulties with the situation (n=5), or the death of their loved one (n=5). In total six family caregivers were bereaved during the study and one shortly after completion of the fourth interview. Of the family caregivers who were bereaved during the study, three agreed to be interviewed following the death of their loved one. Thus, sixteen family caregivers completed one interview, ten completed two interviews, eleven completed three interviews, and six completed four interviews.

A case history and demographic details were recorded for each family caregiver that entered the study. These details give a contextual background about the family caregivers and their individual circumstances and can be found in appendix 9.

5.9 Data Collection Tools

The main data collection tool used in the study was a semi-structured interview. This was used to elicit the perception of the family caregiver to their role and sources of support. The development and use of this is discussed below. In addition a number of other standardised measures were applied to assess the level of activity, stress, anxiety and social support of the family caregiver. The measures used were:

- A semi-structured interview (compiled by the researcher appendix 5)

- A Caregiving Activity Questionnaire (compiled by the researcher appendix 10)

- The Relative Stress Scale (Green et al 1982 appendix 11)

- The Significant Other Scale (Short form version B) (Powers et al 1988 appendix 12)

- The State-Trait Anxiety Measure (20 item version) (Spielberger et al 1983 appendix 13).

5.9.1 The Semi-structured Interview

The choice of a mainly qualitative approach to the study was taken to allow the participants the greatest opportunity to express their perceptions and view of the situation under investigation. Also, the qualitative framework of a semi-structured interview allows the participants and the researcher to engage in a dialogue that explores contextual information and allows an opportunity to clarify issues and statements in a way that is not possible with questionnaire based approaches.

Purpose

The purpose of the semi-structured interview was to identify the perception of the family caregivers to the role of 'carer' in a palliative care setting, and to identify the perceived sources of support, both practical and emotional, that may be available to them in this situation. A more detailed discussion of the positive and negative aspects of the use of

semi-structured interviews can be found in chapter 3 section 3.4, and will not therefore be discussed again here.

Development of Topics

The interview used a semi-structured format, and covered topics developed from previous literature, consultation with health professionals and other researchers in the field. In addition the results of a small number of interviews (n=4) acted as a pilot study and informed the final structure and content of the semi-structured interview schedule.

A number of issues arose during previous research (Smith P.C., 1996), and in the Health Professional Perspective study:

- Family caregivers did not all identify with the term 'carer'.

- Family caregivers received support from different sources, both professional and informal.

- Family caregivers often expressed ambivalence about their role.

- Health professionals reported feeling a responsibility towards a carer but the position was seen as ambiguous.

- Health professionals identified a range of activities that could be considered the role of a carer.

These findings were incorporated into the main research questions developed for the study. The purpose of the study was to clarify which carers identified with the term and how this affected them, and in addition to identify the nature of the relationship of carers with professional and informal support.

Once the main research questions had been established, a number of issues relating to these questions were written down and categorised into topics. These topics provided

the basis of the interview format. Topics were developed from the literature, previous research undertaken by the researcher and consultation with health professionals and other researchers in the field. Topics were designed to elicit the perception of family members with regard to the role they were undertaking, the amount of support perceived to be available to them, and their relationship with visiting health professionals. Questions were deliberately kept general in an attempt not to lead the participant's response.

The main topics covered were;

How did the family member become involved in caring?
The history of their participation in caring for their relative;
How they saw their participation in caring for their relative;
How their participation in caring affected their relationship with other people;
How caring had changed their normal routine;

What they understood by the term 'carer'
What does the term carer mean to them?
Do they identify with this term?
If yes why? If no why not?

What forms of support were available to them
Other people that might be involved in looking after their relative;
Who had helped them most in caring for their relative?
Why had this been so helpful?

5.9.2 The Questionnaires

Each of the four questionnaires was chosen for a specific purpose, which will be discussed further below.

5.9.2.1 Caregiver Activity Questionnaire

Purpose

The Caregiver Activity Questionnaire (appendix 10) was a scale developed by the researcher for the purpose of this study. The aim was to identify the range and level of activity undertaken by the family caregiver for the ill person, and changes that may occur over time. Items were divided into four categories: household activities, supplying emotional needs, giving personal care and undertaking medical activities for the ill person.

Why Chosen?

The scale acted as an accurate means of identifying specific activities undertaken by the family caregiver that had been identified in previous research as being important to this group of caregivers (Smith P.C., 1996, Payne et al 1999). This study had highlighted the need for a simple method of checking the level of activity across participants. The caregiver activity scale was designed to reflect both the present and the past level of activity undertaken by the family caregiver at baseline. This was an attempt to show how perceptions of activity may be influenced by the circumstances surrounding the patient's care. Furthermore, it was hoped that the scale would be able to highlight whether an increased level of dependency arose for the family caregiver during the course of the study. It was thought that an increased dependency might be reflected in a greater level of burden and anxiety, as expressed by the family caregiver in the caregiver stress scale and the state trait anxiety scale, which were also used during this study.

Alternatives

Appraisal of caregiving scale (Oberst et al 1989) was initially developed for use with family caregivers and clinical experts of Alzheimer's patients. The later version was developed with family caregivers of ambulatory patients receiving radiotherapy, rather than palliative care. Furthermore, as this scale was developed in the USA it was not felt to be compatible with a community palliative care setting in the UK.

Format

The scale was designed to be self-administered and is presented as a written questionnaire with a four point Likert type scale ranging from 'Never' to 'All the time'. The scale records four dimensions of caregiving: household activities, supplying emotional needs, giving personal care and undertaking nursing activities for the ill person. At baseline the scale asks that each question be considered in relation to the present circumstances and those at time of entry to palliative care or one month previously whichever is earlier. At subsequent time points only the present activity is recorded. For example:

For each of the activities mentioned below, please indicate the extent to which you carry out these activities **NOW**. Also please indicate how often you did these activities at the last visit, that is in the **PAST**.

| 2. Washing | **NOW:** Never | Sometimes | Frequently | All the time |
| | **PAST:** Never | Sometimes | Frequently | All the time |

9. Listening to the	**NOW:** Never	Sometimes	Frequently	All the time
person who is now	**PAST:** Never	Sometimes	Frequently	All the time
ill				

Scoring

Each item was scored from 1-4, with 1 representing never and 4 representing all the time. Totals for each group of activities were summed. Thus, each questionnaire had a total of four scores.

Evaluation of the Scale

The scale was evaluated during the course of the study. All participants found the scale easy to understand and took between five and ten minutes to complete the questions. Some participants found the questions repetitive. Only a small number of participants identified activities that they undertook for the patient that were not included in the scale.

Reliability and Validity

The scale was shown to have face validity when shown to a number of health care professionals in the field.

Disadvantages

A major concern with this measure is that it has not been previously validated. That is, there was no evidence prior to this study that the validity of the questions asked or the response produced did reflect the type and level of activity undertaken by the family caregiver for the patient. Also this is a very long scale with up to 22 items, and space recorded for other activities not mentioned in the questionnaire, which at times appeared to be repetitive for the family caregivers to complete.

5.9.2.2 Relative Stress Scale (Green et al 1982)

Purpose

The relative stress scale (appendix 11) was included as a measure of distress experienced by the family caregiver in relation to caring for their loved one. Due to the nature of palliative care, situations can change very rapidly. It was hoped to record any changes over time that the family caregiver may experience in this situation, with regard to distress experienced on both a personal, domestic and emotional level.

Why Chosen

This scale is short and easy to administer and score. It allows three subscales to be distinguished: personal distress, life upset and negative feelings relating to the ill person and the situation.

Alternatives

The Caregiver Strain Index (Robinson 1983), is a short 13 item questionnaire designed to measure the strain experienced by family caregivers or recently discharged hospital patients. However, in a previous study, the items on the questionnaire were found to be too global and relied heavily upon instrumental aspects of caregiving only (Smith P.C., 1996).

Format

The relative stress scale is a 14 item self-complete questionnaire. Each item was scored on a five point Likert scale ranging from Never to Always.

1. Do you ever feel you can no   Never   Rarely   Sometimes   Frequently   Always
   longer cope with the situation?

2. Do you ever feel that you need   Never   Rarely   Sometimes   Frequently   Always
   a break?

Scoring

Items are scored from 0-4, with 0 representing the Never category and 4 the Always. Each of the three subscales is then totalled, giving three separate subscale scores: personal distress, life upset and negative feelings.

Reliability and Validity

Reliability coefficients were reported by Green et al for each subscale of the scores ranging from 0.72-0.88 (Green et al 1982). Construct validity was also found when comparing the scale with other levels of patient functioning.

Disadvantages

This questionnaire was originally developed for use with a group of caregivers of someone with Alzheimer's dementia. Many of the questions were therefore focused on mood disturbance, which was not generally perceived to be a problem for this particular group for caregivers. During the pilot stage one question was found to be unacceptable for family caregivers in a palliative care setting. This question revolved around the caregivers being embarrassed by the patient's behaviour. As a result this question was removed from the version given to the main study participants.

A further question related to the person not being able to see an end to the situation. This did not appear to be a problem during the pilot interviews and was therefore left in the questionnaire. Indeed, most caregivers during the study did not have a problem with answering this question. However, a few caregivers refused to answer this question as

they said they knew there was going to be an end to the situation, but that this would be when the person they were caring for had died. This obviously proved too painful for them to consider, as thinking there would be no end to the situation would be to deny what they knew to be the case. As a result of these comments, this question was deleted during the analysis relating to this measure.

5.9.2.3 State Trait Anxiety Inventory (Spielberger et al 1983)

Purpose

Anxiety in caregivers is often found to be high (Hinton 1994b). It was hoped that this scale (appendix 13) would be able to distinguishing between a naturally high level of anxiety (trait) and that contributed by the situational circumstances of the family caregivers (state).

Why Chosen

This scale gives both a state and trait score that can be used to assess the anxiety state over a period of time.

Alternatives

Hospital Anxiety and Depression Scale (HAD: Zigmond and Snaith 1983), a brief scale used to test for both anxiety and depression. Recently the sensitivity of this scale has been questioned (Lloyd-Williams et al 2000)

Format

The State Trait Anxiety Inventory is a 20 item questionnaire for both the state and trait scales. Each question gives a four point Likert type answer ranging from not at all to very much so.

Example State Questions	Not at all	Somewhat	Moderately	Very Much
1. I feel calm	1	2	3	4
2. I feel secure	1	2	3	4

Example Trait Questions	Not at all	Somewhat	Moderately	Very Much
25. I feel like a failure	1	2	3	4
26. I feel rested	1	2	3	4

Scoring

Each answer is weighted from 1 to 4, with 4 indicating a high level of anxiety. There are ten state and eleven trait items. Weights are reversed for the remaining ten state and nine trait scores according to the author's coding (Spielberger et al 1983). Scores for both scales are then summed.

Reliability and Validity

The Spielberger State Trait inventory has been extensively reviewed for reliability and validity with a number of different groups.

Disadvantages

Some individuals find difficulty with differentiating between general feelings (as on the trait scale) and immediate feelings (as in the state scale).

5.9.2.4 Significant Other Scale (B) (Powers et al 1988)

Purpose

The SOS (B) (appendix 12) was used as a measure of social support available to the family caregiver. The scale seeks to describe the level of received and ideal support available in key individuals selected by the participant.

Why Chosen

One of the main reasons that someone is admitted to a hospital or hospice is due to the inability of the family caregiver to continue with caregiving (Addington-Hall et al 1991). One factor contributing to this may be a breakdown in the support, either emotional or practical, that is available to the family caregiver. It was therefore considered important to identify any perceived factors in the family caregiver's social network that may be

helpful. A loss of such supportive factors could then be identified as a contributory factor in a breakdown of family caregiving.

Identification of a person's social support network was thought to be one way that the emotional and practical support available to an individual could be highlighted. Social support is a complex concept that has been defined in several ways. The term is used to describe the social, emotional and other support provided to an individual by their social contacts (Weinman et al 1995). Social support can be conceptualised by the size and structure of the persons support network. However, this conceptualisation fails to take account of the different support functions provided by various social contacts, or the perceived adequacy of the support received. As the study was particularly interested in the perception of the family caregivers to the support, both emotional, social and practical, it was considered important to include a social support scale that accommodated these factors.

The SOS scale of Powers et al (1988) was chosen as it distinguished between both emotional and practical support as well as the perceived satisfaction with received support. The short version of the scale was chosen as it was considered sufficient for the purpose of the study, and would reduce the fatigue on family caregivers when combined with the other questionnaires and interview. The measure assesses five emotional and five practical social support functions. There are two versions to the scale, A and B. Scale A has seven individuals already chosen, for example spouse or partner, mother, father. Version B is left blank to allow individuals to nominate the person who is significant for them. Version B was chosen so that individuals could identify significant others themselves. For each person identified, the actual and ideal support provided for both emotional and practical support is graded on a seven point Likert scale. It is possible to calculate any discrepancy between perceived and received support.

Alternatives

The Social Network Scale (Stokes 1983) is a measure of social support that does not distinguish between network size and density and level of social support. Many other scales that have been developed are less well tested (Perceived Social Support) or fail to

explore different categories of support such as practical and emotional (Weinman et al 1995).

Format

The SOS (B) is designed so that individuals can nominate a particular key individual who is available to them. Each named individual is then rated on four types of support, two emotional and two practical. The type of support is rated from 1 representing never to 7 representing always, for both ideal and actual level of support.

Person 1........................   *Never*   *Sometimes*   *Always*

1 a) Can you trust, talk to frankly and

    share your feelings with this person 1   2   3   4   5   6   7

b) What rating would your ideal be? 1   2   3   4   5   6   7

3 a) Does he/she give you practical

help?   1   2   3   4   5   6   7

b) What rating would your ideal be? 1   2   3   4   5   6   7

Scoring

Individual scores for each nominated individual are summed, to give separate totals of emotional support and practical support, both actual and ideal. A further discrepancy score can then be calculated between the actual and ideal ratings. The discrepancy score acts as a measure of satisfaction with available support. The number of individuals nominated is divided by the total score. This gives an overall mean score of each type of support.

Reliability and Validity

Power et al (1988) have shown satisfactory reliability and validity. Test-retest reliability was found to range from 0.72 to 0.83 across the summed support scores. Criterion validity was found by comparing scores of non-cases, non-depressed cases and

depressed cases with varying psychopathology as found on the General Health Questionnaire.

Disadvantages

This is a time consuming and repetitive scale and it can be difficult to distinguish between actual and ideal support, particularly for close family and friends. In addition, social norms may be acted upon so that it is not possible for the individual to be completely honest about their perceptions of social support from any one person.

5.10 Pilot Study

A small number of interviews (n=4) acted as a pilot study and informed the final structure and content of the semi-structured interview schedule. Two participants were interviewed; one participant was interviewed once, and one was interviewed three times. Thus, a total of four interviews were conducted.

5. 10.1 Purpose of Pilot Study

The pilot study served as a means of the researcher gaining experience of using both the interview schedule and the questionnaires. Although the number of interviews conducted for the pilot was small, the researcher had conducted similar interviews in previous research, and was therefore already familiar with some general and specific issues surrounding interview technique with this group of participants. For example, it was known that this is a particularly sensitive time for the participants and every effort was made to make the family caregivers feel comfortable with both the research questions and the researcher during the interview. It was hoped that this approach would enable a smooth and fluent interview technique to be developed. As a consequence, the pilot interviews revealed copious rich data on the perceptions of the family caregivers.

The pilot study was also used to test the study design and fitness of both the semi-structured interview and the questionnaire format. In addition, the pilot study gave an indication of the length of time required to cover both the interview and the

questionnaire, and to gain feedback from the participants as to the process of being interviewed and the suitability of the questions.

5.10.2 Development of Interview Schedule Questions

Previous work by the researcher had highlighted the need of the participants to describe how they became involved in the caring situation. It was therefore decided to begin the interview by allowing the participant to describe this process. It was found that this set the scene for the study and gave the researcher the contextual details necessary to understand the wider implications of the situation for the individual family caregiver. The use of a semi-structured format allowed the participants as much opportunity as possible to describe their own experiences and perceptions. Thus the original interview schedule was designed with broad topic areas and few prompt questions.

As the participants guided the interview format, the order of coverage of topics was left to the natural flow of the conversation. In this way, it was possible to determine a logical progression of questions, which began with the family caregiver's involvement in the caring situation, and moved on to consider their role, relationship and access to various forms of support within the situation. The interview schedule format was adjusted to aid the progress of the questions, giving the interview a more natural conversational feel. The question of how the participants defined a carer, and whether they felt this term applied to them, was moved towards the end of the interview. This was because it became clear that this issue was not a priority of the family caregivers but only the researcher. One question was included following the pilot interviews, which related to the part that the participant felt they had in looking after the ill person. This question was found to allow participants an opportunity to discuss their own experience as an issue separate from that of the patient's. Prompt questions were simplified, and made broader to reflect the participant's feelings about the situation rather than seeking factual answers.

During the process of the interviews for the family caregiver study, emerging areas of concern or interest were incorporated into the schedule. In this way, the research process was able to inform subsequent data collection and refinement of the questions.

5.10.3 Benefits of the Pilot Study

A number of changes to the conduct and format of the main study resulted from the pilot study both in the interview format and in the practical issues surrounding referral and data collection procedures. Initial discussion with the district nurses (who assisted with the pilot phase) resulted in an information sheet being produced for the referring health professionals (appendix 14). This helped to clarify the purpose of the study and the referring criteria. It was hoped that this would reduce the ambiguity relating to participants fulfilling the eligibility criteria for the study.

In addition to the changes to the interview format, the pilot interview gave the researcher an opportunity to explore the issues surrounding the difference between a health professional interview and that of a researcher. The researcher found that there was some tension between the previous professional background and the responsibilities of a researcher. Other researchers in this field have also struggled with this issue (Plant 1995). That is, the researcher was unsure how much nursing or medical information should be presented to the participant. In one respect this was resolved by the researcher's previous professional background being in community nursing rather than palliative care. The researcher was not therefore equipped to comment on particular treatment regimes or circumstances. However, it was considered possible that some participants might wish to use the interview as a means of gaining information about their relative's condition, or to seek reassurance about the role that they were playing in the patient's care. It was therefore decided that the researcher would answer questions and give general advice where it was felt there was sufficient expertise to do so. If participants required additional information they would be advised to contact the referring nurse. Identification of the need for such boundaries was incorporated into the main study protocol.

The questionnaire format of the standardised measures was found to be long and cumbersome. Despite this, it was felt that the areas covered by the questionnaire were important aspects of the background information about the participants that could be potentially important in understanding the nature of their position. For this reason, the questionnaire was left largely unchanged, although some questions were removed from

individual scales if they were seen as distressing to the participants. For example, it was found that one of the questions in the caregiver stress scale was inappropriate for this group as it referred to cognitive impairment in the ill person that was considered largely inappropriate by the participants in the pilot study. The social support questionnaire used, required up to seven people to be nominated as an important source of support for the individual. This was found to be too extensive and repetitive for the family caregivers, therefore the number of identified people who were important to them was reduced to a maximum of four.

5.10.4 Referral Criteria during Pilot Study

Participants were recruited from the caseloads of a group of district nurses in Area One in a manner reflecting the recruitment practice for the main study. That is, all participants were identified as the main caregiver of someone who had a diagnosis of cancer. This procedure highlighted the need for good communication with the district nurses in order to act promptly on any referrals made. To streamline the passage of information about potential participants, district nurses were issued with a series of participant detail sheets (appendix 15). These sheets included information about the participant that the researcher required to conduct the study, such as name, address, telephone number and relationship to the person being cared for. It was initially thought that these sheets could be forwarded to the researcher by post. However, this was found to incur some delay and therefore the sheets were used as a guide to the information required during telephone contact with the district nurses and the researcher.

Participation of District Nurses

All district nurses involved in the pilot phase of the study were visited during one of their normal business meetings, where the study proposal and aims were explained. Arrangements were made regarding contact of the district nurses by the researcher and vice versa. A contact telephone number was provided so that the district nurse could contact the researcher urgently if necessary. Time was allowed for any questions or ethical issues raised by the district nurses to be answered. District nurses were given the

information sheet (appendix 14) which contained information about the project proposal, selection criteria of participants, and contact details of the researcher.

If district nurses felt they had a potential participant on their case load they were asked to give a broad outline of the study to the individual and a copy of the participants' information sheet (appendix 8). If the person agreed to participate in the research they were asked whether they agreed for their name to be passed on to the researcher. The district nurse would then pass on the details of the participant to the researcher in the agreed format. When the researcher received the participant details the individual was contacted. At this time, further queries about the project were answered. Only if the participant understood what was involved in the study, and agreed to participate, was a date arranged for a visit to be made by the researcher.

During the pilot phase it was identified that there were potentially a number of problems in recruiting via district nursing teams. Principally, there was perceived to be problem in obtaining sufficient numbers of participants from this method. For the main study therefore, recruitment was made via visiting Macmillan/home care nurses. The procedures and referral sheets developed with the district nursing teams, however, were used during the main study.

5.11 Procedure

Following consideration and changes made in accordance with the pilot interviews the main study was commenced. After referral to the study, telephone contact with the caregiver was made and an interview date and time was agreed. Final telephone contact was made either in the morning or the afternoon prior to the proposed interview to ensure that each caregiver was still willing and able to participate.

On arrival at the participants' home, the researcher would introduce the purpose of the study, give the participant an information sheet if they had not already received one from the referring district nurse, and ask them to fill in a consent form. The visit consisted of two parts. During the first part, a tape-recorded interview, covering items in the semi-structured interview schedule, was conducted. Once this interview had finished, the

tape recorder was turned off and the researcher proceeded to administer the questionnaires. The researcher was available to answer any questions about the questionnaires should the need arise. Finally, a debriefing session gave the participant an opportunity to discuss the interview process and issues raised. Where appropriate, the researcher answered any questions. If the questions related to treatment procedure or aspects of care which the researcher was not able to answer, the participant was advised to contact the referring nurse. Finally, an appointment was made to see the participant again if necessary. Participants were thanked for their time and effort.

Initial interviews and questionnaires took between one and two and a half hours to complete. Subsequent interviews were often completed more quickly. On completion of the study, or following withdrawal, participants were sent a thank you letter for their participation (appendix 16).

5.11.1 Interviews

Each caregiver was interviewed at home. Wherever possible, caregivers were interviewed separately from the person they were caring for, to ensure privacy and the opportunity to respond honestly and openly to the questions. However, a number of couples (n=4) in particular those that had been married for a long time, preferred to be interviewed together. In addition, due to limited space in some homes, four interviews were conducted with the patient sitting nearby, although they were not actively involved in the interview procedure.

For two participants, their spouse was only present for one or two interviews and this led to a qualitatively different feel to the interviews themselves. For example, one family caregiver was able to talk more explicitly about how she handled her own feelings when her husband was not in the same room. Furthermore, she concentrated on very practical and informational topics during the interview when her husband was around and sought to include him by seeking his advice in her decision making about certain situations.

During the interviews when both partners were interviewed together, there were some instances when they would rely on each other to correct details and to make accurate

statements, particularly about the time scale or treatment options. Often during this type of interview the patient was deferred to when an answer was given pertaining to the patient's story or treatment schedule. Interestingly, there was no subsequent space allowed in the conversation for the family caregiver to give his or her side of the story or recall details from their perspective.

5.11.2 Questionnaires

Following the interviews, participants were invited to complete the questionnaires. Most individuals (n= 10) completed these unaided. However, a number (n= 6) requested the researcher to read out the questions and fill in their responses. The researcher remained in the room during completion of the questionnaires, to assist with explanation of any unclear instructions. It was found that the majority of the questionnaires were easily understood by most participants. However, some difficulties were experienced with the SOB questionnaire. In particular, the identification of people who were considered significant to the individual was sometimes difficult. Also, the repetition of responding to both the ideal and actual level of support was difficult for some individuals. In consequence a number of participants identified no more than one or two significant other sources of support (n=10/16 at time one, 4/10 at time two, 5/10 at time three, 4/5 at time four). It is possible that the longer the caregiving situation persisted, the fewer number of people there were available to the family caregiver to call on for support. Equally, it could be that as the family caregivers became familiar with the researcher, the interview and the questionnaire, they were less likely to need to give an account of the numbers of people they were able to seek support from.

5.12 Analysis

Analysis was undertaken in two stages. Initially, all interviews were transferred into written text via transcription. Following this, the transcripts were individually coded and the data transferred to The Ethnograph v4 package for further analysis. Throughout the process of both data collecting and analysis, memos and notes were made about thoughts and questions arising from the analysis process.

5.12.1 Transcribing

A total of 43 interviews were audio taped and fully transcribed. Two experienced secretaries transcribed seven and six of the interviews respectively. The researcher transcribed the remainder. Transcribing is a time consuming activity but can represent part of the analysis of the data. Conversation Analysis has made particular use of the audio tapped interview and has developed particular conventions for undertaking transcribing of the data (Peräkylä 1997). For the purpose of this study, detailed analysis of pauses and intonation were not required as the focus was on understanding and interpreting the meaning behind the respondents interaction rather than the sequencing and turn taking of conversation analysis. Thus, verbal utterances and audible emotional expressions such as laughing, weeping or sighing were recorded, whereas silences were not recorded unless they were of an extended duration.

Every interview was transcribed in full into a word processing package (Word v6). Transcripts were then checked for accuracy against the audiotapes, and corrected accordingly. Real names mentioned by the participants or researcher were replaced with a pseudonym to protect the individual's identity. Copies of the transcripts were made and converted into The Ethnograph text formula as described below. The original word-processed transcripts were kept separate as master copies. Following the detailed analysis of several transcripts as detailed below, all subsequent coding and analysis was done using The Ethnograph transcript copies of the data. At each stage of transcribing and analysis, transcripts were password protected to prevent unauthorised use of the data.

The transcripts were read a number of times and issues that were felt to be interesting or significant were noted on a separate sheet of paper. This allowed the researcher to become familiar with the respondent's accounts, and helped to focus reading and interpretation of the data. Transcripts were re-read several times, which helped to reveal new and interesting issues, and prevented the focus of the interpretation becoming too narrow at an early stage.

After the initial orientation of the transcripts had been completed, an initial coding process began. Notes were added directly to the transcripts in the right hand margin relating to issues seen as significant. Sometimes the issues summarised the words and phrases that the participants had uttered. At other times the issues were initial interpretations of the words and phrases. Interpretations of the words and phrases were often made on the basis of the background information and detail that the researcher had obtained from the individual during the course of the interviews. The summaries and the interpretations represented emerging themes. No attempt was made to omit any part of the transcript at this stage as all information was regarded as possibly interesting to the project. Emerging themes were sometimes repeated during the transcript. These were noted and used to explain in more detail the similarities and differences in the participant's perception of a particular theme.

When the first transcript had been fully coded, a list of the themes and summary interpretations was made. An attempt was then made to look for a clustering of themes and related interpretations. For example, a number of themes, particularly during the first interview, were related to the patient's story. These were then coded into a superordinate code e.g. diagnosis. Within this superordinate code there were three subordinate codes relating to time, emotion reaction and tests (appendix 17).

Subsequent transcripts were treated in a similar way. As each transcript's list of codes was examined, it was compared with previous transcripts, and subsequent codes and themes were incorporated into the major themes, superordinate codes and subordinate codes. After a number of transcripts had been coded in this way there appeared to be few new themes or superordinate codes emerging. At this point a master code list (appendix 18) was formed of all the themes and their related codes. This master list was subsequently used to guide the coding of future transcripts. In addition, earlier transcripts were re-examined in the light of the master code list and recoded where necessary to reflect the final themes and sub-themes. Instances of issues that had been noted but were found to be lacking in evidence in further transcripts were dropped or incorporated into more representative themes. Once a final master list had been developed, coding of the transcripts was undertaken using The Ethnograph V4.0 package as detailed below.

5.12.2 The Ethnograph v4.0

The Ethnograph V4.0 package (Seidel et al 1995) is a qualitative data analysis package designed to be used in conjunction with a Personal Computer (PC). Its main focus is to allow selective searches of the coded data within individual or joint transcripts. Ethnograph is particularly useful for exploring data in depth as it has a special function for modifying coding schemes as interpretation of the data progresses. On completion of the coding scheme, Ethnograph can produce frequencies of a particular code or speaker identifier within a particular transcript or group of documents. The Ethnograph v4.0 analysis package was used for all analysis of the data once the main themes and codes had been identified. This package was particularly useful in allowing easy access to printed code segments of data for further interpretation and analysis.

In order to benefit from the computing advantages provided by The Ethnograph package, it was necessary to convert the original word processed transcripts into a format that could be read by the programme. This involved copying the word processed document into a particular format and saving as a text file. This was completed as described in the Ethnograph manual accompanying the programme. It is possible to set up a template for this purpose so that the word processed documents are created in a format that can be read by the Ethnograph programme without requiring conversion. However, during the early stages of the study it was initially intended to perform the analysis by hand. This proved to be impractical as the number and length of the transcripts relating to each interview grew as the study progressed. For this reason, it was felt necessary to take advantage of the computing facilities provided by the Ethnograph package. Therefore each word processed transcript was converted into an Ethnograph file in the manner described by The Ethnograph manual. Use of a computing package such as Ethnograph does not eliminate the need for the researcher to be immersed in the data during the analysis process. Rather, it requires the researcher to be more explicit about the nature and relationship of various themes as the process could generate many codes that would be difficult to explain.

Following import of the data to The Ethnograph programme, a print-out of each transcript with line numbers was made. This provided a hard copy of the transcripts

which were used to manually code the data. Once final versions of the coding scheme had been made, later versions of the transcripts were coded onto the computer screen in The Ethnograph package.

Code mapping (Tesch 1990) is initially undertaken by hand so that the researcher may become immersed in the data. This allows the organisation of the data to emerge as each transcript is read, coded and reread in the light of other coding undertaken.

Each transcript was initially read through and emerging ideas and impressions given by the transcripts were recorded in memos alongside the text. When final codes had been agreed, the package was able to produce a copy of all codes across transcripts. This allowed the data to be compared across cases. The findings that emerged from the analysis will be discussed in chapter six, seven and eight.

Chapter Six

The Psychological and Social Consequences of Family Caregiving in Palliative Care

6.1 Introduction

In this chapter the results of the quantitative analysis of the questionnaire data and demographic information collected during the study will be reported. The rationale for gathering the questionnaire data was to enable an assessment of both the instrumental, psychological and social consequences of being a family caregiver within a palliative care setting over a period of time. For this reason a number of measures were introduced to allow comparison across the individual participants, and over time. It was hoped that by identifying possible changes in perceived activity, anxiety, stress and social support it would be possible to understand something of the nature of the experience of the family caregiver. The questionnaires were used to fulfil the following aims:

- To determine if there were changes in the perceived levels of caregiving activities, caregiver stress, caregiver anxiety and social support identified by the family caregiver over time.

- To assess the usefulness of the caregiver activity scale as a means of gathering information about the activities of family caregivers in palliative care.

The chapter will be presented in several sections. The first section will report baseline demographic details and sample characteristics of the participants. Following this each of the measures will be presented in three sections. First descriptive statistics of baseline data for all participants will be presented giving a cross sectional view of each measure. Second changing levels of each measure over time will be explored using descriptive statistics. Thirdly the implications of the data for each measure will be considered. Finally in this chapter there will be a brief discussion of the main findings from the quantitative data.

6.2 Description of the Sample

6.2.1 Relationship of the family caregivers to the patient

Recruitment for the study was taken from two geographical areas. Equal numbers of both male and female participants from both areas were recruited. The relationship of the family caregivers to the patient can be seen in Table 6.1.

Table 6.1 Number of Participants, Gender and Relationship of Family Caregivers to the Patient in both Area One and Area Two

	Number of Participants	Gender	Total	Relationship to Patient	Total
Area	8	Female	4	Wife	4
One		Male	4	Husband	4
Area	8	Female	4	Wife	2
Two				Daughter	2
		Male	4	Husband	4

Table 6.1 demonstrates that all the men in both areas (n=8) were the husbands of the patients. Of the female family caregivers, in Area One all were the wife (n=4), and in Area Two half were wives (n=2) and half daughters (n=2) of the patients.

6.2.2 Age of the family caregivers

At baseline the age range in Area One was 51-72 years, and 37-77 years in Area Two. The mean for Area One was 59.3 years and 53.8 years for Area Two. Combined area age range was 37-77 years, and the mean was 56.8 years which can be seen in Table 6.2.

Table 6.2 Range, Mean and Median of Family Caregivers Age from Area One and Area Two

	Age Range in Years	Mean Years	Median Years
Area One	51-72	59.3	60
Area Two	37-77	53.8	53.5
Combined	37-77	56.8	58

Table 6.2 demonstrates that there is a slightly larger age range in Area Two than Area One. This could account for the slightly lower mean in Area Two than Area One. Overall the combined mean and median are similar to both areas.

For subsequent analysis age distribution of the two areas was combined due to the small sample size, and can be seen in Table 6.3.

Table 6.3 Combined Range, Mean and Median Age in Years of Family Caregivers over Time

	Number of Participants	Age Range in Years	Mean Years	Median Years
Baseline	16	37-77 years	56.8	58
Time Two	11	37-77 years	53.2	52
Time Three	9	40-77 years	55.8	54
Time Four	5	37-77 years	55.0	52

Table 6.3 reveals that despite the large attrition rates that occurred during the course of the study (see section 6.2.3), the mean age remained relatively similar across time (56.8, 53.2, 55.8, 55.0 years at baseline, time two, time three, and time four respectively.)

6.2.3 Number of bereavements during the course of the study.

During the course of the study six family caregivers (37.5%) were bereaved. Table 6.4 shows the number of bereavements occurring after each time point in the study. In addition one family caregiver experienced a bereavement one week after completing the study.

Table 6.4 Number of Bereavements Experienced at Each Time Point

	Baseline	Time Two	Time Three	Time Four	Total
Area One	1	1	2	0	4
Area Two	1	1	0	1	3
Combined Area Bereavements	2	2	2	1	7

Table 6.4 shows that four deaths occurred in Area One and three deaths in Area Two during the course of the study. The greater number of deaths following the time three interviews in Area One could be a reason why there were less time four interviews within this group.

Three people (2 from Area One and one from Area Two) who were bereaved during the study agreed to be interviewed about their experiences following the death of their loved one. Two of these interviews took place at time three and one at time four. In each case the bereavement interview occurred between two and four weeks following the death. These family caregivers were not asked to complete questionnaire data at this interview, as this was considered inappropriate due to the sensitive nature of the interview. These interviews will therefore not be included in any quantitative analysis of the questionnaire data.

For all three participants it would appear that because a relationship had been built up between the family caregiver and the researcher prior to the death, there was a desire to share that experience with someone who was familiar with the situation and person involved. As information arising from the bereavement interviews were qualitatively different from the original study questions and were not anticipated as part of the research design they will not be reported within the thesis.

6.2.4 Attrition Rates

Participant attrition from studies in palliative care research are well-documented (Jordhøy et al 1999), particularly in randomised controlled trials and studies taking a longitudinal approach. Participant attrition occurs for a number of reasons, but is principally due to the deterioration or death of the patient. This poses a number of implications for research in this field, notably the possibility that only the most well participants are able to be involved in palliative care research. Furthermore, large attrition rates can have significant effects on final numbers of participants involved in a particular study, which will have implications for any conclusions drawn. Jordhøy et al (1999), suggest that careful consideration of entry criteria should include an estimation of survival rates for participants that will be sufficient for an effect to occur and be

assessed. In addition the possibility of large attrition rates should be included in calculations of potential numbers of participants to be recruited into a study.

Although it is important to acknowledge the limitations imposed by high attrition rates in palliative care, this should not overwhelm the contribution to knowledge and understanding that is provided by those participants who are able to be involved in research in this field. Furthermore, a clear understanding of the time at which participants are unable to continue to be involved in research in palliative care could potentially indicate a time when an intervention may be most required. For this reason the combined area data on the number of interviews with family caregivers at each time point, excluding bereavement interviews, has been documented and can be seen in Table 6.5. Some family caregivers were interviewed four times, others only once.

Table 6.5 shows that both areas had similar numbers of interviews and attrition rates at each time point with the exception of time four. At this time point the cumulative attrition rate in Area One was higher than in Area Two (n = 7 and n = 4 respectively). One explanation of this difference is that individuals being cared for in Area One were at a later stage in their illness progression than those in Area Two. Alternatively it may be that individuals were referred into the study earlier from Area Two and therefore the ill person was relatively more well than those being cared for in Area One.

Table 6.5 Total Number of Interviews Conducted at Each Time Point

	Baseline	Time Two	Time Three	Time Four
Area One	8	5*	5	1
Area Two	8	6	4*	4
Combined Area scores	16	11	9	5

* Plus 1 suspended interview due to family caregiver commitments

Figure 6.1 indicates the reason for the attrition at each time point in the study. There was no attrition between time two and time three as the two people who were bereaved during this time agreed to be interviewed at time three. At time two 31.25% (n = 5), had withdrawn from the study. One family caregiver missed the time two interview

and recommenced the study at time three, and one family caregiver missed the time three interview and recommenced the study at time four. This was due to poor health of the family caregiver, and family circumstances respectively. By time four there was an overall attrition rate of 62.5% (n = 10).

Due to the high attrition rates throughout the study the following sections will review the findings of each questionnaire in relation to combined data from both areas and remaining participants at each stage of the study.

Figure 6.1 Sample Attrition Rates

```
┌─────────────────────┐                              ┌─────────────────────┐
│ 23 Family Caregivers│                              │ 5      Due       to │
│ approached to enter │                              │ deterioration    of │
│ study.              │                              │ patient             │
└─────────────────────┘        ┌─────────────────┐   │ 1 Due to time       │
        │                      │ 7 Declined    to│   │ pressures           │
        ├──────────────────────│ participate     │───│ 1 No      reason    │
        │                      └─────────────────┘   │ given               │
┌─────────────────────┐                              └─────────────────────┘
│ 16 Family Caregivers│
│ admitted to study   │
└─────────────────────┘                              ┌─────────────────────┐
        │                                            │ 2      Due       to │
        │                      ┌─────────────────┐   │ deterioration    of │
        ├──────────────────────│ 4  withdrew after│  │ patient             │
        │                      │ time 1 interview │──│ 2 Due to death of   │
        │                      └─────────────────┘   │ patient             │
┌─────────────────────┐                              └─────────────────────┘
│ 11 completed time 2 │
│ interview           │
│ (1 Suspended due to │
│ ill health of family│
│ caregiver)          │
└─────────────────────┘
        │
┌─────────────────────┐
│ 9 completed time 3  │
│ interview           │
│ (1 Suspended due to │                              ┌─────────────────────┐
│ other commitments)  │                              │ 3      Due       to │
│ (Plus 2 bereavement │   ┌─────────────────┐        │ deterioration    of │
│ interviews          │   │ 6  withdrew after│       │ patient             │
└─────────────────────┘   │ time 3 interview │───────│ 3 Due to death of   │
        ├──────────────────│                 │       │ patient             │
        │                  └─────────────────┘       └─────────────────────┘
┌─────────────────────┐   ┌─────────────────┐
│ 5 completed time 4  │   │ 1 death of patient│
│ interview           │───│ one week after last│
│ (Plus 1 bereavement │   │ interview         │
│ interview)          │   └─────────────────┘
└─────────────────────┘
```

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6.3 Caregiver Activity Questionnaire

It was anticipated that family caregivers would report changing levels of caregiving activities during the course of the study. The caregiving activity questionnaire was designed to identify four different types of caregiving activity: general household activities, personal assistance given to the ill person, emotional and supportive activities and nursing type activities (appendix 10). In order to assess the perception of change in level of activity undertaken for the ill person at baseline family caregivers were asked to identify both the current level of support given and the past level of support, either since entry into a palliative care phase or since the previous month, whichever was earlier.

6.3.1 Caregiver Activity Questionnaire Baseline Data

At baseline all respondents reported participating in some level of caregiving activity above that normally undertaken due to the family members illness. Table 6.6 demonstrates the mean, range and standard deviation in level of activity undertaken in the past and at baseline for Household Activities.

Table 6.6 Mean, Range and Standard Deviation of Household Activity Undertaken in the Past and at Baseline

	Household activities undertaken in the past	Household activities currently undertaken
Mean baseline score	19.31	23.25
Range	10-30	17-31
Standard deviation	5.17	4.12

Table 6.6. demonstrates that there appeared to be a slight increase in level of caregiving activities related to household chores for the family caregivers since entry to a palliative care phase.

Table 6.7 demonstrates the mean, range and standard deviation in level of activity undertaken in the past and at baseline for Emotional Activities.

Table 6.7 Mean, Range and Standard Deviation of Emotional Activity Undertaken in the Past and at Baseline

	Emotional Activities undertaken in the past	Emotional Activities currently undertaken
Mean baseline score	11.56	12.56
Range	8-13	7-18
Standard deviation	1.26	2.34

Table 6.7 reveals that there did not appear to be a perception of change in the level of emotional activities undertaken by the family caregivers following entry to a palliative care phase.

Table 6.8 demonstrates the mean, range and standard deviation in level of activity undertaken in the past and at baseline for Personal Care Activities.

Table 6.8 Mean, Range and Standard Deviation of Personal Care Activity Undertaken in the Past and at Baseline

	Personal Care Activities undertaken in the past	Personal Care Activities currently undertaken
Mean baseline score	6.88	11.38
Range	4-14	6-23
Standard deviation	3.44	5.24

Table 6.8 suggests that there appeared to be an increase in the perception of level of personal care activities undertaken for the ill person following entry to palliative care.

Table 6.9 demonstrates the mean, range and standard deviation in level of activity undertaken in the past and at baseline for Nursing Care Activities.

Table 6.9 Mean, Range and Standard Deviation of Nursing Care Activity Undertaken in the Past and at Baseline

	Nursing Care Activities undertaken in the past	Nursing Care Activities currently undertaken
Mean baseline score	8.81	11.06
Range	6-21	4-21
Standard deviation	4.51	3.60

Table 6.9 also suggests that family caregivers appeared to report a slight increase in the level of nursing type activities undertaken for the family caregiver following entry to a palliative care phase.

6.3.2 Changing Caregiving Activity over Time

The level of caregiver activity for each dimension over time can be seen in Table 6.10.

Table 6.10 Mean and Standard Deviation of Each Dimension of Caregiving Activity over Time

Mean score	Household Activities (Standard Deviation)	Emotional Activities (Standard Deviation)	Personal Care Activities (Standard Deviation)	Nursing Care Activities (Standard Deviation)
Baseline	23.25 (SD 4.12)	12.56 (SD 2.34)	11.38 (SD 5.24)	11.06 (SD 3.60)
Time Two	22.44 (SD 5.68)	12.40 (SD 2.55)	10.90 (SD 5.63)	10.78 (SD 3.38)
Time Three	21.67 (SD 5.45)	12.70 (SD 1.89)	10.20 (SD 2.97)	9.80 (SD 2.94)
Time Four	19.80 (SD 6.18)	11.20 (SD 3.27)	8.40 (SD 2.30)	7.75 (SD 3.77)

Table 6.10 reveals that all caregiving activities appeared to gradually decrease over time. This is especially notable in the case of household activities, nursing care activities and personal care activities. Emotional activities although decreasing slightly over time remained relatively stable.

6.3.3 Summary Caregiving Activity Data

At entry to the study family caregivers did appear to report a slight increase in household activities, personal care activities and nursing care activities in relation to a pre-palliative care phase. However, little change in levels of emotional activity in relation to the ill person were noted either at baseline or throughout the study. Over the course of the study caregiver activity levels did not appear to increase further, but rather to decrease to levels similar to a pre palliative care phase. This was contrary to expectation, although the high levels of attrition recorded during the study may have an impact on the findings, particularly at time three and four. It is possible that those

family caregivers who were providing the most direct caregiving activities had withdrawn from the study by time three and four, therefore leaving family caregivers whose situations had remained relatively stable during the course of the study.

6.4 State Trait Anxiety Questionnaire

6.4.1 State Trait Anxiety Baseline Data

The state trait anxiety questionnaire (appendix 13) was used to determine both the state and trait level of anxiety experienced by the family caregiver at initial assessment. Subsequent interviews recorded only the state anxiety measure. Use of this scale allowed both the transitory feelings of fear or worry (state) and the stable anxiety response of an individual to stressful situations (trait) (Bowling 1995), to be identified. Scores on both scales range from 20-80. The higher the score the greater the anxiety experienced. Mean and standard deviation levels of anxiety can be found in Table 6.11.

Table 6.11 Mean and Standard Deviation of Trait and State Anxiety Measures over Time

	Trait anxiety at baseline	State anxiety at baseline	State anxiety at time 2	State anxiety at time 3	State anxiety at time 4
Number of Participants	16	16	8	9	5
Mean	39.38	38.31	38.50	36.33	43.40
Standard Deviation	9.56	12.88	13.99	11.46	13.89

As can be seen in Table 6.11, the mean level of anxiety expressed over time varied little until time four when state anxiety appeared to increase. This could be due to an increase in anxiety of those family caregivers remaining in the study at time four, perhaps due to prolonged and uncertain period of caregiving. Alternatively this may be a result of the most anxious family caregivers remaining at time four. However, these results should be considered carefully owing to the small number of family caregivers remaining at time four.

6.5 State Anxiety over Time

A correlation was performed of the state and trait anxiety measures across time to determine if any significant association was found between the measures. Trait anxiety was significantly correlated with state anxiety at all time points except time four and can be seen in Table 6.12.

Table 6.12 Correlation of Trait and State Anxiety Measures over Time

	Trait at baseline	Anxiety at baseline	Anxiety at time 2	Anxiety at time 3	Anxiety at time 4
Trait at baseline	1.000				
Anxiety at baseline	.696**	1.000			
Anxiety at time 2	.806*	.954**	1.000		
Anxiety at time 3	.883**	.906**	.883*	1.000	
Anxiety at time 4	.664	.941*	1.000**	.873	1.000

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

Table 6.12 shows that there was a perfect correlation between anxiety at time 2 and anxiety at time 4. However, due to the small numbers involved in this study, particularly at time four these findings should be treated with caution, as the results may be confounded with the high degree of missing data to be found at time four due to the high attrition rates.

6.4.3 Summary State Trait Anxiety Data

Mean state and trait anxiety scores range between 20-80 (Speilberger et al 1983). Family caregivers therefore appeared to demonstrate a moderate level of anxiety at baseline. Over time anxiety remained similar rising slightly at time four. Trait and state anxiety levels were significantly correlated at baseline, time two and time three, but not time four. This may be a result of the small sample size at time four which occurred due to the high attrition rate in the study.

6.5 Caregiver Stress Questionnaire

6.5.1 Caregiver Stress Baseline Data

The caregiver stress questionnaire (appendix 11) was included to highlight perceived stress experienced by the family caregivers. This measure is subdivided into three categories; personal distress experienced, amount of life upset caused by caring, and negative feelings experienced due to caring.

Each response was scored on a 1-4 scale. Due to the high degree of missing data within the study summed scores for each aspect of the scale were used. The higher the score the more distress experienced by the family caregiver. The scale for each of the subscales at baseline can be seen in Table 6.13.

Table 6.13 Mean, Range and Standard Deviation Scores of Stress Experienced at Baseline

	Distress experienced due to caregiving	Degree life upset due to caregiving	Negative feelings due to caregiving
Mean	7.40	11.06	3.13
Range	2-16	4-19	1-11
Standard Deviation	3.96	4.82	2.39

At baseline Table 6.13 shows that there appears to be a moderate amount of distress and life upset caused by caregiving. However, family caregivers appeared to report relatively low levels of negative feelings relating to caregiving.

6.5.2 Caregiver Stress over Time

The mean, range and standard deviation of caregiver stress experienced over time was calculated and can be seen in Table 6.14.

Table 6.14 appears to show a variable range of caregiver stress over time. However, overall there appears to be a slight but gradual increase in all three scales relating to caregiver stress over time. Most variation in scores over time would appear to be found in the degree to which life is felt to be upset by the caregiving experience.

Table 6.14 Mean, Range and Standard Deviation Scores of Caregiver Stress Experienced over Time

	Distress experienced due to caregiving		Degree life upset by caregiving		Negative feelings due to caregiving	
	Range (Standard deviation)	Mean	Range (Standard deviation)	Mean	Range (Standard deviation)	Mean
Baseline	2-16 (SD 3.96)	7.40	4-19 (SD 4.82)	11.06	1-11 (SD 2.39)	3.13
Time Two	1-23 (SD 6.27)	10.11	5-18 (SD 3.92)	12.30	1-9 (SD 2.42)	3.89
Time Three	4-20 (SD 4.85)	9.35	3-16 (SD 4.58)	9.50	2-9 (SD 2.22)	4.50
Time Four	7-16 (SD 3.63)	9.80	3-13 (SD 3.81)	7.00	0-9 (SD 3.24)	4.00

6.5.3 Summary of Caregiver Stress

Over time family caregivers appeared to report a small but gradually increasing rise in their perception of stress resulting from the caregiving experience, in all three categories. There was a large variation in the mean levels of reported stress relating to the degree to which life was felt to be upset by the caregiving experience. The increasing caregiver stress could be due to the family caregivers perceived changes in the caregiving experience over time. Alternatively, those family caregivers who remained in the study at time four could be more distressed than the overall sample size at time one, possibly due to the length and continued uncertainty regarding the duration that the caregiving experience would continue. Understanding in more detail why some family caregivers perceive an increase in stress over time would be a useful avenue for further research. However, due to the small numbers included in the time three and four sample, findings should be considered with caution.

6.6 Social Support

6.6.1 Social Support Baseline Data

The Significant Other Scale (appendix 12) was included to take account of the possible changes to levels of social support over time. Also there was an interest in understanding who family caregivers identified as providing social and emotional support.

Family caregivers were asked to list up to four individuals who they felt were able to provide them with either emotional or practical support. A number of individuals were identified as possible providers of social support, including other close family, friends, neighbours and for some health professionals. For example close family members identified as important were Husband, Daughter, Son, Daughter-in-law, Sister, Brother, Mother and Niece. Examples of health professionals identified were Macmillan/home care nurse, District nurse and GP.

The significant others social support scale gives a score for perception of emotional and practical support available. Within each of these it can be calculated the ideal rating of support, the actual rating of support provided and the discrepancy between the two. The discrepancy between the two scales gives an indication of the likely satisfaction with the available support provided. The mean, range, and standard deviation for both emotional and practical support at baseline can be seen in Table 6.15.

Table 6.15 Mean, Range and Standard Deviation of both Emotional and Practical Support Perceived by Family Caregivers at Baseline

	Perceived Emotional Support			Perceived Practical Support		
	Ideal	Actual	Discrepancy	Ideal	Actual	Discrepancy
Mean	12.43	10.48	1.33	10.82	9.56	1.33
Range	8-14	2-14	0-6	7-14	4-14	0-5.25
Standard Deviation	2.03	4.11	1.85	2.52	3.30	1.70

Table 6.15 appears to show that family caregivers perceived a relatively small level of discrepancy between the ideal and actual support provided by the social network for either emotional or practical support.

6.6.2 Social Support over Time

The number of significant sources of support reported by the family caregivers varied throughout the study, and can be seen in Table 6.16.

Table 6.16 Percentage Number of Significant Others Reported at Each Time Point

	Percentage Number of Significant Sources of Support Reported				
	None	One	Two	Three	Four
Baseline	0	31.25% (n=5)	31.25% (n=5)	6.25% (n=1)	31.25% (n=5)
Time Two	9.09% (n=1)	9.09% (n=1)	27.27% (n=3)	45.45% (n=5)	9.09% (n=1)
Time Three	0	22.22% (n=2)	22.22% (n=2)	22.22% (n=2)	33.33% (n=3)
Time Four	0	40% (n=2)	40% (n=2)	20% (n=1)	0

Table 6.16 appears to indicate a variable level of sources of support over time. Only one person reported no sources of support at time two. By time four the family caregivers appeared to concentrate on just one or two sources of support. At time four only one individual nominated three sources of social support.

Discrepancy between the actual and ideal levels of emotional and practical support over time can be seen in Table 6.17

Table 6.17 Mean and Standard Deviation of Emotional and Practical Support over Time

Time Point	Data Statistic	Perceived Emotional Support			Perceived Practical Support		
		Ideal	Actual	Discrepancy	Ideal	Actual	Discrepancy
Baseline	Mean	12.42	10.48	1.33	10.82	9.56	1.33
	Standard Deviation	2.03	4.11	1.85	2.52	3.30	1.69
Time Two	Mean	12.04	10.73	1.31	11.08	9.98	1.60
	Standard Deviation	3.55	3.36	1.70	1.53	2.14	1.76
Time Three	Mean	11.46	12.17	0.60	10.61	9.44	1.17
	Standard Deviation	3.67	1.39	0.62	1.66	2.31	1.42
Time Four	Mean	12.20	11.77	0.43	8.10	7.00	1.10
	Standard Deviation	1.09	0.59	0.66	2.13	1.73	1.95

Table 6.17 appears to show a slight discrepancy between the perceived actual and ideal levels of support for the family caregivers. Over time there appears to be a reduction in the discrepancy between the actual and ideal levels of emotional support. The discrepancy for practical support appears to remain the same over time.

6.6.3 Summary of Social Support

Overall perceived social support reported by the family caregivers was variable, but tended to concentrate on two or three individuals. Some family caregivers nominated more individuals than others, although only one could not identify any source of support at time two only.

Discrepancies were noted between the actual and ideal perceived levels of support for both emotional and practical assistance. However, these discrepancies appear to be slight and therefore it could be inferred that generally family caregivers appeared to be satisfied with the amount of support provided by the social network.

6.7 Discussion

6.7.1 Caregiving Activity

It was anticipated that levels of caregiving activity would increase over time as the ill person become more dependent on the family caregiver. However, rather than increasing caregiving activity appeared to decrease. There are a number of possible explanations for this finding. One explanation is that those family caregivers remaining in the study were representative of the most well patients. Thus, levels of caregiving activity reported by these family caregivers could be relatively stable and represent a type of maintenance level of caregiving activity. Alternatively the individuals remaining at the end of the study could have been referred earlier in the disease trajectory, or when the ill person was in a period of remission. Understanding at which time point family caregivers are fulfilling more instrumental activities of caregiving as highlighted by this questionnaire could assist health professionals to tailor interventions and support more appropriately. Exploring this trend would be a useful avenue for future research.

One aim of the use of the caregiver activity questionnaire was to assess its usefulness as a means of gathering information about the activities of family caregivers in palliative care. The scale appeared to be easy to use and understand by the family caregivers, and was found to have face validity. However, it was a very long scale that appeared to be somewhat repetitive at times, and therefore further work is required to develop this measure for use in clinical settings in palliative care.

6.7.2 Family Caregiver Anxiety

Family caregivers appeared to demonstrate a moderate level of anxiety at baseline, rising slightly by time four, which may support the findings of Hinton (1994), who found that anxiety increased as death approached. However, six of the family caregivers had already experienced a bereavement by time four and it is not clear due to the small numbers in the final interview how strong this effect may be and should therefore be treated with caution. Investigating the exact items and reason for an increase in anxiety may be a useful area for future research. By understanding more precisely what increases anxiety for family caregivers it may be possible to develop interventions or provide appropriate support networks to help reduce such distress.

6.7.3 Family Caregiver Stress

Overall family caregivers reported a small increase in all three subscales of the caregiver stress scale; distress experienced as a result of caregiving, degree life upset as a result of caregiving and negative feelings towards the ill person due to caregiving. There was a relatively small score for the negative feelings sub-scale throughout the study. An explanation for this could be that this particular subscale asked the family caregiver to report feelings of frustration and anger with the cared for person. This could, and indeed often was, taken to be disloyal towards the ill person and therefore these questions were perhaps not answered as honestly as some other questions in the questionnaire. In addition one question relating to feelings of embarrassment about the cared for persons behaviour was omitted during this study as it was found to be distressing and inappropriate for this group of caregivers. Therefore the weighting of this aspect of the scale was different from the original scale.

The extent to which family caregivers reported distress experienced due to caregiving was relatively stable over time with a slight increase between baseline and time two. The perception of life upset caused by the caregiving was most significant at time four. However, this could be accounted for by the very high score of one participant who was somewhat distressed at the final visit by the length of time the caregiving experience had extended. Again this result must be interpreted cautiously as only five family caregivers completed the questionnaire at this time point.

6.7.4 Family Caregiver Social Support

A range of individuals was nominated as being an important source of support for the family caregivers. The largest group to provide this type of support to the family caregivers was other members of the family network, primarily close kin such as spouses or adult children. However, if close kin was not available then other family friends or even health professionals were mentioned as sources of support.

Over time there was a gradual decrease in the discrepancy between the perceived ideal and actual level of emotional support received by the family caregivers. Perceived satisfaction with practical support provided by the social support network for the family caregivers appeared to remain relatively stable, although there was a slight increase in this discrepancy at time four. The actual number of individuals mentioned over time as important also appeared to have focused on just one or two individuals. It is possible that by time four there were less people in the social support network available to support the family caregivers but that those that were available engaged in more support. However, this would require further investigation before any conclusions can be drawn as to the importance of the social support network for family caregivers in palliative care.

6.8 Summary

This chapter has focused on the findings of the questionnaire data completed by the family caregivers. Due to the high attrition rate throughout the study and the small sample size no firm conclusion can be drawn. However, some interesting trends have emerged from the data which would benefit from further investigation.

Chapter Seven

Family Caregivers Perceptions' Of Their Role in Palliative Care

7.1 Overview

In the following two chapters the perceptions' of the family caregivers regarding the nature of their role and relationships during the palliative care phase will be explored. In this chapter I will explore the perception of the family caregiver regarding their role in palliative care. In chapter eight I will then consider the family caregivers relationship with health professionals and other sources of support. Three themes emerged from the data relating to the way family caregivers talk about their experience of palliative care; The Role of Carer in Palliative Care, Telling The Patient's Story and The Family Caregiver's Story.

Prior to considering the themes that emerged from the interviews, I will first introduce the family caregivers who participated, and some of the similarities and differences in their perceptions. Secondly I will consider the family caregivers perceptions' of the role of carer in palliative care and the implicit assumptions and expectations that may be assumed by this term. The consequences of the use of the term carer will also be discussed in this section. Thirdly I will move on to consider the theme of the patient's story, which appears to be central to the family caregiver's perception of the situation. Finally I will consider how the family caregiver's story appears to be placed secondary to that of the patient, and the implications this may have for the family caregivers.

7.2 The Family Caregivers

It was clear from the interviews with these individuals that each had a different and particularly personal interpretation of the situation they found themselves in. This was in part due to the particular circumstances that resulted in the family caregiver being requested to participate in this research. However, a full understanding of the family caregiver's perspective would not be possible without taking into account the often complex and dynamic caregiving relationship that had developed between the family caregiver, the ill person and others involved in the situation. A brief description of

each family caregiver's background and their relationship with the ill person can be found in appendix 9. In order to protect the anonymity of each family caregiver, and yet at the same time retain an essence of the characteristics of the family caregivers' experience, all names have been altered throughout the research.

Despite the individual differences found in each family caregivers background history there were a number of similarities between the accounts. All the family caregivers shared the experience of caring for someone who was a close member of kin, either a spouse or a parent. All were caring for someone with a terminal diagnosis of cancer, and who was in contact with SPCS, although the degree to which the family caregivers themselves had contact with this group was sometimes variable. All the family caregivers were also either co-resident with the ill person or lived in close proximity to them. And perhaps most importantly of all, each family caregiver had a shared history of the ill person's life, both before diagnosis, throughout the treatment calendar (Costain-Schou & Hewison 1999), and into the palliative care phase of the illness.

Many differences between the family caregivers accounts also emerged during the interviews. There was clearly an age difference between some family caregivers, which resulted in specific changes and adaptations being made. For example the youngest family caregiver was just 37 years old and was caring for his wife, young family and maintaining a full time job. The oldest family caregiver was 77 years old, caring for her husband, and had been retired for a number of years. The different level of adaptation and disruption to the lifestyle of the family caregiver resulting from the caregiving experience were important issues that influenced the family caregivers perceptions' of the situation.

Another important difference between the family caregivers was the level of caring experience that they had. Some considered themselves to be very much a 'carer', and often had been giving care to their relative for some considerable time, whilst others had only limited experience of caring and saw their role relating much more to their relationship responsibilities.

7.3 The Role of Carer in Palliative Care

7.3.1 Identifying with the Term Carer

As discussed in chapter two there are a number of ambiguities surrounding the term 'carer'. It was not perhaps therefore surprising that defining who and what a 'carer' might be was often difficult for the family caregivers. Only six (one male and five female) family caregivers readily identified themselves as a 'carer' to their loved one. All of these individuals had been giving care for well over a year and in some cases for a number of years, especially if the person they were caring for had a chronic illness or disability prior to a cancer diagnosis. Both daughters in the study identified themselves as a carer, although only Mrs Nash was in receipt of the carers' allowance, having given up work at her mother's request to be available to care for her during the day. Mrs Page on the other hand had come to recognise herself as a carer only when she had been called a carer by a member of the social services day care centre that her mother attended weekly.

"And she said to me "You must be your Mothers carer." So I thought well I
suppose I am." Mrs Page

For Mrs Page, development of a carer identity was strongly influenced by her interactions with others, as prior to this experience Mrs Page had not considered herself to be a carer but a daughter. However, for other family caregivers there appeared to be a pattern of caring throughout their lives, which could be thought of as a 'caring career'. For these individuals large parts of their adult life, and sometimes childhood, had been spent caring for others, particularly close kin. Mrs Vaughan had been caring for her husband and her mother for a number of years (although it was due to the care she provided for her husband that she was invited to participate in the study). She identified strongly with the term "carer", and was an active member of the local carers support group. She had even written articles in the local paper about her life as a carer. Mrs Vaughan suggested her role as a carer began as a small child when she had been involved in caring for her grandmother's emotional well being.

"I didn't actually do the nursing, but I was there to give her security."
Mrs Vaughan.

This pattern had continued throughout her life, as she willingly, and apparently actively sought a caring role first for elderly neighbours, for whom she had an intercom fitted so that they could contact her at any time if they needed her, and then her own mother and husband.

"I've always done something for somebody." Mrs Vaughan.

Clearly Mrs Vaughan gained a lot of personal satisfaction and pleasure from the role of carer, and was very proud of her achievements. For Mrs Vaughan being a carer was not necessarily tied up with having received formal training, but was inherited. For this reason Mrs Vaughan believed that there were 'natural carers'.

"It stems from the family because we've got a lot of medical professional people in our family, so it's born in, it's in your genes. ... Some people are natural carers some people aren't." Mrs Vaughan.

A large part of Mrs. Vaughan's sense of identity was associated with the role of carer, and she described her biggest worry as knowing what she would do when her caring role ended.

"What do the carers do when the caring ends?" Mrs Vaughan.

Such a strong identity with a caregiving role could have serious implications for an individual following bereavement, where there would not only be a loss of the cared for person but also the role to which there was attached a clear sense of purpose and usefulness. Assisting family caregivers who identify with the term carer in this way to adjust to the multiple losses that will occur following bereavement may be a useful area for development of bereavement services within palliative care.

Similarly Mrs Gardner, who was a lady in her late 70s, also discussed the years that she had been a carer for her mother prior to becoming a carer for her disabled husband some years before his diagnosis of cancer. Unlike Mrs Vaughan though, Mrs Gardner appeared almost surprised and apologetic at recognising herself as a carer.

"I mean um, after Helen's gone (home care), I mean I am on my own, and I
feel that I'm really to be quite honest a full time carer aren't I?"
Mrs Gardner.

The sense of being ultimately responsible for the ill person was a theme that emerged for Mr Andrews, who was the only male family caregiver that identified with the term carer. Mr Andrew's was in his mid 50s and worked full time on nights.

"Well basically the buck stops with me doesn't it. I mean it means that
we've got to make sure um, that Win has the best quality of life that we can
give her, and that's not just a matter of the personal things, but fighting on
her behalf, the efficacy part as well." Mr Andrews.

For Mr Andrews, caring was a continuation of their normal daily lives, although there had been a gradual need for him to take on increasing amounts of activities around the house that his wife had previously been able to do.

"I mean its been a gradual process, its not been an overnight thing. I
suppose that's what's pushing a lot of it, its just an extension really."
Mr Andrews.

However, unlike the female family caregivers Mr Andrews considered himself to be very much a part of a family of carers. This was helped by the fact that one son still lived at home and was able to help with household chores and cooking, and in addition a second son and his wife lived next door.

"(I'm) one of a family of carers because all the family cares for her. Well,
especially as I say the boy, my son next door and his wife, and the son that
lives here. So basically it's a shared role." Mr Andrews.

Whilst many family caregivers did mention a number of extended family members as being an important resource on which to call for additional support and assistance as required, it was much more common to find that there was one primary family caregiver identified both within the family and by other agencies (Keating et al 1994).

Often this was related to the patterns of caregiving developed within the family. For the majority of the family caregivers rather than identifying with the term carer, they saw what they were doing as bound up in their kinship obligations and reciprocity.

7.3.2 Kinship, Obligation and Reciprocity

The majority of the family caregivers believed that what they were doing was more strongly related to their relationship with the ill person, than a particular role or job. Indeed much of what can be considered caring work is often bound up in the complex and enmeshed relationships between these individuals. Mr Sawyer emphasised that he saw what he was doing as being related, not only to his long marriage, but also primarily to the love and concern he felt for his wife. For him this was not 'caring as such', but a desire to share with his wife.

> *"It can apply to a husband or wife who've been married for 40 - 50 years and are still in love with each other as much. So the word caring would probably not apply there. Be just love and concern for the other person. That's what the motivations would be. So that's my feeling about it."*
>
> *Mr Sawyer*

In some families there was a precedent already in place for certain individuals to participate in such types of caregiving. This was true for both the daughters in the study. Mrs Nash was the only member of her mother's immediate family to be directly asked to look after her at home following her diagnosis.

> *"Well I used to work. Um, when Mum found out about her illness, um, she said would you be there at home with me in case I need you? And I said yes." Mrs Nash*

Neither of Mrs Nash's two brothers, who both lived locally, or her father had been asked to participate in caring for her mother. This did at times cause some resentment for Mrs Nash, particularly when she had to make fairly complicated arrangements for her own daughters to care for her mother when she went away for a few days. When

Mrs Nash questioned her father about spending more time with his wife, he replied that he would do so only when the situation deteriorated further.

> *"And I have suggested to him why don't you cut down (working) and do a couple of days a week, you know. And he said "If I feel that your mother is getting to the stage that she needs me to be there all the time I will."* Mrs Nash*

The frustration Mrs Nash experienced in relation to this conversation could be related to Keating et al's (1994) suggestion of those who 'should help', but do not. However, within this particular family there was also a very strong tradition of the daughters and women 'looking after' other family members. Mrs Nash's own mother had been involved in caring for her mother for 14 years until her death a few years previously, and it is possible that the implicit assumption within the family was that Mrs Nash, as the only daughter, would repeat the pattern her mother had set previously.

For the other daughter in the study, Mrs Page, there was a similar assumption of a traditional caring role being adopted, although for Mrs Page this was complicated by the fact that both her brothers lived a long distance away from her mother, whereas she lived in the next street. For Mrs Page the practical aspects of the caregiving role were shared towards the end of the study by the return home (to the same town) of one brother, which did relieve some of the burden of caring for their mother.

> *"I mean he has done quite well, and the other night when she called him in the night, well, half past eleven or whatever it was, um, she said to me on the Sunday "You didn't mind?" "No Mum" I said, "that's what we said, you know, let (brother) take a bit of the pressure off", I said. After all (brother) didn't have to get up for work in the morning which I did, you know."* Mrs Page*

A further reason for the family caregivers to participate in caregiving was a desire to return care given to them in the past by the ill person. Such caregiving reciprocity is one explanation for the provision of mutual aid and support within a relationship (Finch & Mason 1993), although it is not always clear how far such support should extend.

For example the normative level of reciprocity between more extended family members, or individuals whose relationships have been changed by divorce or remarriage is unclear (Finch & Mason 1993). For Mr Lloyd there was a definite sense of reciprocity in his caregiving for his wife, although he accepted that the consequences of his wife's condition were somewhat different to the patterns of care she had extended to him in the past.

> *" 'Cos when you're actually married to someone you're there through thick and thin any way aren't you? If I was ill she'd look after me, and if she was ill I'd look after her like, you know. Um, I remember when I was in hospital, I had too bad injuries playing rugby where I was put in hospital, and I had an operation. When I came out I couldn't, I was on crutches. Er, she always looked after me then. I mean it's just this is, I don't know, a bit longer that's all."* Mr Lloyd.

7.3.3 Activities of Caregiving – 'Its Nothing Special'

Much of what is considered caring work was bound up in the relationship context and activities of daily living for the family caregivers. However, for some family caregivers there was a clear distinction between this 'normal' type of caregiving and the additional knowledge and expertise in caring possessed by professional or paid carers. Whilst some family caregivers acknowledged that they had themselves learnt about particular aspects of their loved ones medical or nursing care, for example their medication or handling and moving someone who was very frail and weak, it did not necessarily follow that they therefore saw themselves as a carer.

Despite this lack of recognition of their own caregiving role, there was nevertheless a great sense of responsibility for the ill person's care, particularly in relation to monitoring the ill person's condition and supervising their medication. For many of the family caregivers, this was the most obvious aspect of the caring role that sometimes required a need for specialised knowledge and expertise, which they had often developed but appeared to be unconscious of.

"You look for things, um, I have to check for bed sores every morning and notice, yesterday was the first time we'd noticed that, yes, he's started to get the symptoms of one, the redness." Mrs White

Monitoring the ill person's medication and ensuring that the tablets had been taken was often mentioned by the family caregivers. However, there was a fine line between maintaining the ill person's independence in taking the tablets and being seen as overprotective.

"I say "have you taken your tablets?", "oh no". So that's why I've written them down so if she's on the phone I can say to her right you need, have you taken you MST's?" Mrs Nash

Mrs Nash was able to monitor her mother's medication by keeping a list and checking what tablets her mother was due at any one time. This enabled her mother to maintain control of her medication, and at the same time allowed Mrs Nash to be reassured that her mother was not accidentally overdosing on her analgesia.

Care given was often reported to be 'nothing special', although some family caregivers obviously spent a great deal of time and energy providing for the physical needs of the patient. In addition all the family caregivers were undertaking more household chores for the ill person than they had done previously. For some, particularly the men, this had been a steep learning curve, especially in terms of becoming responsible for the planning and preparation of meals.

"I do everything around the house. Do the cleaning, cooking, looking after the kids, the washing. Just got used to it now (laughs). ... When she was well I just used to come home like and have me dinner ready, made for me like. Big shock this." Mr Lloyd.

On the whole the household tasks were undertaken willingly and appeared to present few difficulties for the family caregivers, and more often than not were reported as 'normal' caring such as might happen when someone had a heavy cold or flu. This was the case even if the tasks were not always an agreeable choice. Mr Bradley was a

gentleman in his early sixties who had worked outside all his life. When his wife became bed ridden shortly after diagnosis he decided to look after her at home even though he was not used to this lifestyle and sometimes found being in doors all day somewhat restrictive.

"I've always worked outside, I've always been outside, but um, I've got to
alter at the moment for a while so I've got to put up with it." Mr Bradley.

Many of the family caregivers had developed new skills relating to the care given to the ill person. For example the district nurses had shown Mr Bradley how to care for his wife in bed, and he was most concerned that he was carrying out this task well.

"I don't say I'm very good at nursing, that extent, but trying, you know,
trying. Hope I get it right." Mr Bradley

For Mr Bradley, as with many of the family caregivers there was an underlying and implicit belief that caring in this situation was just something you got on with, and was therefore 'nothing special'.

Emotionally family caregivers spent a lot of time just being with the patient, supporting them by keeping their spirits up, providing emotional security and maintaining a sense of normality. This was seen as important to the well being of the ill person and helped to give a focus for everyone concerned.

"So you feel like you've got to be, jolly him along. I don't quite know what
the word is, reassure him perhaps." Mrs Foster

"You've got to provide them with security and love, and a normal life."
Mrs Vaughan.

"Well my part obviously is to support (husband) as much as I can, and um,
keep him in the same mood as what he's in." Mrs Davis

Maintaining normality and keeping the ill person in a positive frame of mind appeared to be one way that the family caregivers sought to limit the negative effects of the situation on all concerned.

7.3.4 Limitations to Caregiving

Some family caregivers were happy to take on any aspect of care for the patient, and felt rewarded and fulfilled by being able to do this. However, for others there were distinctions made between what they felt they could or would be happy undertaking.

Some limitations to the willingness or availability of the family caregivers to provide care for the ill person were related to particular medical or nursing type activities, others arose from changing circumstances when the person became too poorly to be managed by the individual alone or at home. For example Mrs Foster, was a lady in her mid fifties who worked full time, and was caring for her husband. She was happy to take on responsibility for his daily care needs with the exception of undertaking the injections required for his treatment. Mrs Foster reported that it had been quite difficult to refuse to take on this task as she had felt a certain degree of pressure from the health professionals to undertake this part of the care for her husband at the time.

"Well, I wouldn't give the injections when he had to have the hormone injections. ... I think they (health professionals) thought I should. ... But I don't think, I didn't feel I could do it, and I didn't feel I really wanted the responsibility." Mrs Foster.

For Mrs Vaughan, although there was a certain degree of disappointment that she was unable to care for her husband until he died at home, the extent of his medical needs resulted in him being admitted to the hospice just prior to his death. This admission was precipitated by a sudden deterioration in her husband's condition, which resulted in Mrs Vaughan being unable to manage to move her husband without assistance. However, Mrs Vaughan was satisfied that she had done all she could to support him, and had no regrets about her contribution to his care.

"I don't have any regrets at all, I did all that I could." Mrs Vaughan.

A further limitation to caregiving was found when the situation extended beyond that originally anticipated. The caregiving role then sometimes began to have an adverse effect on the family caregivers' relationships with other family members. When this perceived time limited caring continued beyond expectations family caregivers began to question their ability to provide continued care. This was particularly noticeable for the younger carers in the study who were often juggling other roles such as partner, parent and worker.

> *"You sort of run out of momentum sometimes. ... Because you begin to wonder yourself sometimes, which is only, you know, understandable is there going to be an end." Mrs Foster*

In order to ensure the best care for the ill person, their comfort and needs were almost invariably prioritised over and above the family caregiver, or any other family member. This could cause conflict for the family caregiver. For example Mrs Page commented that she spent more time looking after her mother than she sometimes felt she should, given that her husband had retired early due to ill health.

> *"You can't split yourself in two, you know. You can't be over the road there and over here as well. ... If you please one, you upset the other, and I know lately I have got very, more often than not upset my husband rather than upset my mother." Mrs Page*

Clearly there are limitations, both physical and emotional to the ability of family caregivers to provide all the care required by the ill person. Recognising these limitations and accepting that it is not always possible for one person to provide all the care required by the ill person is perhaps an area that health professionals could usefully develop with this group of individuals in palliative care.

7.4 Setting the Scene - Telling the Patient's Story

When describing their experiences all the family caregivers prioritised the patient's story above their own. This is perhaps not surprising, as caregiving is not a solitary activity. For someone to be considered a 'carer', another person must require care.

Despite an emphasis on the family caregivers views being explored, the patient's story proved to be a predominant feature of the first interview. Telling the patient's story provided the background for the context in which caring occurred, and the actions and responses of the family caregiver. As such it was important that newcomers to the situation, such as the researcher, were introduced to the circumstances that had occurred thus far. Often long and detailed descriptions of the diagnosis, treatment and subsequent circumstances were provided by the family caregiver.

"Well going back, er, since last, oh it must be over a year I've noticed there was a difference in me mum. ... And she kept going to the doctors, going to the doctors, he kept saying its a chest infection, sent her up the hospital for x-rays, that keep coming, kept coming back clear, nothing wrong. ... So I went to the doctor with her and I said I think we need to see somebody, so then she was referred to a throat specialist. ... And then she was referred to (surgeon) and that's when she was told she had a tumour in the bronchial tube. "

Mrs Nash

By initiating the newcomer into the history of the patient's story the family caregiver was reinforcing the legitimacy of the ill person's story. Furthermore, it could be that repeating the patient's story in this way helped the family caregiver to combine their own account of the shared experience with that of the ill person's, thus reinforcing their position within the situation.

A number of different aspects of the patient's story appeared in the reports provided by the family caregivers. Significant time points and circumstances, such as the time of diagnosis were commonly reported. Changes in the physical health experienced by the patient and the treatment of these symptoms were also noted.

There was a general sense of a medical history being given within this narrative as individual family caregivers attempted to report the 'facts' about the illness and its consequent symptoms. It is possible that this particular relaying of information was due to the prolonged contact many family caregivers had had with the medical profession prior to interview. During this time they may well have learnt to report

information about the nature and condition of the patient that was assumed to be pertinent to health professionals.

7.4.1 Significant Time Points - Diagnosis and the Treatment Trajectory

A large portion of the initial discussion focussed on the diagnosis and treatment received by the patient prior to palliative care commencing. Diagnosis was one of the most significant time points in the patient's story. It acted as a point of reference from which all other events were chronicled.

For many family caregivers the significance of the date of diagnosis was also related to the way individuals had been informed of the news. A number of the family caregivers had difficulty with accepting the way information had been passed to them from health professionals.

> *"But the doctor at the hospital originally sort of. Well we didn't. You're so gobsmacked at the time you don't think to ask. And he sort of said, oh well take her home, that's all right, you know and. But we'd only just been told it and within an hour we were all back home again. ... And for a long time it took a while to settle down to the fact that it's just going to go on, you know." Mrs Page*

Mrs Page was shocked at the bluntness of the diagnosis given to her mother at the hospital, particularly as the original poor prognosis had proved to be unfounded. Similarly Mrs Gardner who was a slightly anxious lady in her late 70's was shocked at the blunt way the consultant had informed both her and her husband of his poor prognosis. This had an effect on her subsequent ability to attend consultations with her husband, even though this experience was later tempered with good experiences from consultations with medical personnel whom she already knew.

> *"So um, it upset us a bit the way he told up, I mean he was very abrupt when he told us, it did upset us a bit. Um, I think these some of these surgeons could really go at it a little bit easier. You know, could have put it over a bit*

*better, but to blurt it straight out at us. And you've got six to nine months to
live, and that's how it was blurted to us." Mrs Gardner*

Mrs Gardner was never able to overcome her initial anxiety of attending consultations
with her husband for anything connected with his cancer.

*"And er we had to go and see the chemotherapy man and that, my daughter-
in-law came with us again. I went, we went, I pushed him to that door and I
froze. I couldn't move. I couldn't go in that room with that doctor."*

Mrs Gardner

Clearly, the effect of communication between the ill person, the family caregiver and
the health professional at the commencement of an illness consultation can have a
profound impact on their ability to negotiate further interactions with other health
professionals at a later date.

Other significant time points were the start of radiotherapy or chemotherapy. For the
family caregiver such dates often represented times of attending hospital with the cared
for person on a daily or weekly basks. For some this involved a fairly complicated
journey to a regional centre for radiotherapy, which was made even more difficult if
there was a dependence on public transport. It was during this time that friends and
neighbours were often called on to provide assistance previously offered.

*"So we went off by train, you know, every day. My friends and that took me
at night. I was quite all right. But it was difficult for anybody that hasn't got
any help whatsoever And the first day I got a taxi, but the second day
someone told me there was a bus quite handy which takes you up to the
(hospital). So I found that out, so I didn't take long you know. ... But I
thought then if anybody was on their own, they didn't have much help, you
know, and anybody around them that's very difficult getting all out to that
hospital. But I suppose that's the way it's got to be isn't it?" Mrs Davis*

7.4.2 Current Symptoms and Treatment

Additional information was provided by the family caregiver with regard to the current situation and changes in symptoms and treatment of the patient during the course of the study. Family caregivers would attempt to recall and recount circumstances, particularly treatment or tests, by using the medical terminology associated with them. For most participants this particular discourse appeared to have been 'picked up' during the process of the ill person's diagnosis and treatment. This was demonstrated in the way family caregivers were able to report typical patterns of treatment cycles and commonly abbreviated medical words such as chemo for chemotherapy.

"But we've been finding the longer she's been going on with this chemo

now, I mean it used to be like three or four days she was really sick for, and

then she starts perking up. Now its like 10 or 12 days that she's ill for."

Mr Lloyd.

Often such information would be provided as though a report was being given on the patient's condition to a health professional. Reporting the condition of the ill person therefore tended to focus on the physical symptoms and aspects of care rather than emotional or spiritual effects. Why family caregivers had developed this particular way of prioritising the physical symptoms and treatments of the ill person is not clear, although it is possible that the constant interaction with health professionals who generally concentrated on symptom control and management may have had an influence. Family caregivers may have been producing public accounts of the ill person's condition, which prioritises the medical discourse, and failing to acknowledge private accounts which focus on emotional or psychological well being. Alternatively it may be that the experience of some of the diagnostic tests and examinations had been so traumatic or difficult for both the patient and the family caregiver that they are vividly alive in their memories and recalled at every possible opportunity.

In addition to learning to report salient factors of the ill persons condition to appropriate health professionals, many of the family caregivers became familiar with a number of treatment procedures experienced by the patient. These treatments ranged from identifying particular pain control tablets, liquids or patches to more complicated

radiotherapy and chemotherapy regimes. Mr Reynolds was in his early forties and looking after his wife. He had taken on the responsibility for ensuring his wife received her medication at appropriate times.

"I'm like saying to her it's your tablet time due. ... I see her get the bag out and she's getting all her tablets out and I'm like says to her, you haven't forgot nothing have you? And sometimes I just pours it out for her. She'll have a measure and I'll say right, 10 ml, and its in the bedroom and she might be in the kitchen and I'll just go in there and get it, pour it out and give it to her like." Mr Reynolds

Many of the family caregivers felt responsible for the ill person's medication regime being maintained. This was particularly important if the ill person became easily confused and unable to remember which tablets had to be taken themselves.

7.5 The Family Caregiver's Story - Seeing Things My Way

The family caregiver's story was very embedded in the patient's story, particularly during the first interview. However, it began to emerge in subsequent interviews, although the patient's story still dominated much of the family caregivers' conversation. The family caregivers' story focused on their own needs, concerns, coping strategies and the impact the cared for person's illness had on changing expectations and roles, although it was extremely difficult for many family caregivers to identify their own needs and concerns without first referring to the patient's. In some cases where a couple had been married for many years the enmeshed nature of their relationship made it even more difficult to distinguish between one spouse story and the other. It is possible that in such relationships there was an implicit understanding and acceptance of each other's needs that was reflected in their joint story. However, it may also be that the accounts individual family caregivers gave of the situation may be reflecting socially acceptable stories that privilege the ill person, particularly as this illness was known to be terminal. Furthermore, family caregivers may have felt that to concentrate on their own stories would be selfish, when the ill person clearly had a great need of understanding and care. Therefore, the family caregivers own story and needs were often hidden and needed to be drawn out from the

many implicit assumptions and expectations that were made about the caregiving situation.

7.5.1 Changing Life Roles and Expectations

The progression of the cared for persons illness often resulted in changes to the roles and expectations about the future held, either individually or jointly, by the family caregiver and the ill person. For the patient one of the most significant life changes, for those under the age of retirement, was connected with work. The necessity of leaving employment or becoming long term sick or taking early retirement or redundancy had financial as well as psychological consequences for the patient and also the family caregiver as they sought to support them during this time. Mrs Foster reported that her husband had found it quite difficult being at home all day when she was still at work full time.

"He's had to take early retirement. .... Um, in fact he's talking about me not going to work full time any more because he'd like me to be around at home." Mrs Foster

Whilst Mrs Foster wanted to support her husband and comply with his desire for her to be at home, she also enjoyed her work and felt that it gave her some "time off" from thinking about the situation. This was the only from of escape she was able to control, and she was therefore reluctant to give this up.

For the family caregivers who were in employment there were various degrees of support provided by their work which enabled them to undertake the caregiving role. Some employers were extremely sympathetic to the family caregivers need for time off work, for example Mr Lloyd was given a different job which allowed him to work reduced hours so that he could be available to look after his wife and children.

"They've (work) been really good to me since we found out. Um, I've had
(a change of job) so I can get the time off to look after her. So job wise
they've been really good to me." Mr Lloyd.

However, others were unsympathetic towards the family caregivers need for time off work, which was very upsetting at a time when anxiety and concern were already high. Mr Bradley's employers insisted that he take all his annual leave before his doctor signed him off sick to look after his wife.

"I had to have me holidays, I took some of me holidays. But um, I thought
there might have been some, you know, perhaps a little bit of compassion. I
didn't expect to have months off, but the word profit the word profit was
mentioned." Mr Bradley

Mr Bradley had worked for his company for 38 years with very little sick leave and was hurt by the lack of compassion towards his circumstances and the particularly clumsy way that his case had been handled, for which his line manager later apologised. Not only did this increase his distress during his wife's final weeks, but had the potential to make things difficult for him on his return to work following his wife's death.

Plans and dreams about activities that would be undertaken during retirement, which were clearly no longer going to be possible, were expressed by some of the younger family caregivers. Mrs White, a 49 year old special needs teacher reported missing, and being angry, about the things that she would no longer be able to do with her husband.

"Cheated. ... Because of all the things that we were going to do. And we
can't do. For (husband) more than myself I think. All the places that we
looked round and. Cheated on all the things that we can't do, or (husband)
can't do, both of us really. Er, just go for a walk in the woods." Mrs White

Mrs White was more concerned about her husband's loss of dreams and identity, which have been described as biographical disruption by Bury (1982), than her own. However, for the family caregivers who clearly shared a very enmeshed relationship with the ill person, such a threat to the shared dreams and expectations caused by the terminal diagnosis of cancer is likely to threaten their own sense of identity as well. By constantly placing the patient's needs over their own there was a tendency for the family caregiver to ignore or hide a recognition of their own forthcoming loss. This may well have enabled them to continue in the family caregiving role, but one consequence of this may be that they were less prepared for the death of their relative than would be anticipated in a palliative care setting which stresses the importance of an open acknowledgement of the death of the ill person.

As a result of this openness regarding the prognosis of the ill person there was often a desire to accommodate the patients desires and wishes as much as possible, for example a desire to be cared for at home. Mrs Taylor and Mrs Gardner had both been looking after their husbands for a long time prior to the diagnosis of cancer, and despite anticipated difficulties in nursing them at home due to their own age and health status, they both accepted that they would look after their husbands for as long as possible.

"And er, and I've made him a promise that he will die at home, he won't die up there (hospice)." Mrs Taylor

The desire to fulfil the ill person's wishes was complied with even if the family caregiver did not believe this was necessarily in the cared for person's best interests. Mr Bradley described how he would have preferred his wife to make more effort to get out while she still had the opportunity. His wife had been offered a place at the local hospice day centre, but only went approximately three times when she felt she wanted to, despite Mr Bradley feeling that is would be a good thing for her to do.

"No I think I used to try to get her to go out somewhere, you know, like for a ride in the car and that but, or they have been trying recently tried to make sure she went to the hospice because it does give me that um, sort of four or

five hours break. ... But um, if she don't go well it's just one of those things,
just carry on." Mr Bradley

Although Mr Bradley believed that his wife would have had more pleasure on taking some trips out he was content to allow her to choose how she spent her final few weeks, even though this resulted in him not being able to get a break from the caregiving role.

7.5.2 The Health of the Family Caregiver

In order to provide the level of care that was desired, family caregivers needed to be relatively well themselves. However, a few, in particular the older family caregivers, were not well themselves. This had consequences for their capacity to take cope with the patient's needs and wishes.

"The doctor told me about a month or more ago that I could have it if I
didn't watch it, and watch where I walked and how much I walked, could
affect my legs and I could have gangrene set in." Mr Evans

Mr Evans was in his late 70s and had himself been diagnosed with cancer, although he was hopeful of being given the 'all clear' by his doctors on his next appointment. For this reason he was careful not to overdo things as much as possible.

Despite the need for good health themselves, family caregivers often reported 'not having time to be ill', or ignoring symptoms that at other times they would have sought advice about from their doctor. Some family caregivers complained of feeling tired, and this was sometimes linked to sleeplessness due to anxiety, the patient waking them, or the increased number of activities they were having to undertake.

"Sometimes I'm like an old women when I get out of bed, and that. ... I
don't seem to have enough hours in the day." Mrs Taylor.

Due to the lack of care taken with their own health some family caregivers may have been in danger of negative consequences as a result of the caregiving experience. Furthermore, some family caregivers complained of experiencing negative mood states such as despondency, guilt, regrets and generally feeling upset which was related to the uncertainty of the situation.

"As I said because I was so down (at the beginning), you know, over it all and everything I just couldn't believe it was happening again. Mrs Davis.

For Mrs Davis the confirmation of her husband's cancer came just a few months after the death of her niece, with whom she had been particularly close, also from cancer. This added to her anxiety about the situation and uncertainty surrounding her husband's condition. For Mrs Davis the vicarious experiences of watching another person she loved die was particularly distressing, which could be similar to Hinton's (1994b) finding that family caregivers' anxiety increases shortly before the death of the ill person.

Although for some family caregivers there were negative consequences to the caring role, there were also a number of positive aspects. For example Mrs White talked about being grateful for the extended period of time that her husband was well enough for them to enjoy each others company following his original gloomy prognosis.

"The registrar told us that (husband's) condition was inoperable, and they gave him a maximum of six months. That was a year ago. ... But now we've decided that we don't want to know. Because we wake up and we're both here in the morning, that's a bonus." Mrs White.

7.5.3 Coping Strategies of the Family Caregiver

Family caregivers reported a number of strategies that they used to deal with the situation. Past experience of caring for other members of the family, with or without cancer, was a common feature in some of the stories. For some people their experience of cancer care was from a long time ago and they recognised that things would almost certainly be different now.

"Breast cancer it was you know. And um, I went through all they, well the one Aunt was very close to me she was my Godmother. ...She'd seen what had happened to her sisters you see, and she took her own course. Because things were different then weren't they? We're talking about 40 years ago you know." Mr Sawyer

Many of the participants appeared to have a strong sense of identification with the patient, as observed in the way they talked about the patient and themselves in the same context, often using language such as 'we' and 'us' rather than 'I' and 'me'. For this reason it was sometimes hard to differentiate between the patient's perspective and the family caregivers. Some couples who had been married for a long time were often able to anticipate each other's sentences, and it may be that they did think about the situation in the same way as their identities had become so entwined over the years.

Learning to put a brave face on things so that the patient would not be upset was also common to many of the family caregivers. Mr. Lloyd used laughter to help him deal with things, and reported finding the ribbing he received from his work mates as helpful in taking him out of himself for a period of time.

"I mean the lads in work, I mean they all take the Mick like, you know, but that's part of being in the job. ...That probably does me good that does, going in. And even though I'm not there long like, just having the Mick taken out of me, and banter like that, perks me up when I'm feeling down." Mr Lloyd.

Obtaining information about the situation, treatment, or prognosis was also a useful strategy for dealing with the situation, and was seen as important for both the patient and the family caregiver. When issues arose for the family caregivers that required professional information or expertise addressing these issues, either with health professionals involved in the situation or those who were not, enabled the family caregivers to deal more effectively with the situation. For example Mrs Nash was particularly concerned about her mothers cancer and the implications this might have for her own health. As it proved difficult to talk to the visiting home care nurse without

upsetting her mother she decided to visit her own GP for information about the situation.

> "I went and saw my own GP, when we, when they told us that Mum had this um, er, tumour on the ovary. I thought to myself well should I see my doctor and explain? ... And I said is there some sort of test that I should go through? And she said no, she said because it's very hard to detect and you can't always tell that its there until its too late, you know." Mrs Nash.

For Mrs Nash there was a lack of information surrounding her mother's cancer that had implications for her own health. By approaching her own GP, Mrs Nash was able to explore these issues with a health professional who was not attached to the situation and who could give her the information she required for her own health needs independently of her mother's care.

7.6 Summary

Within this chapter I have discussed the perceptions of the family caregivers regarding the role of 'carer', and explored why this term may have more meaning for some than others. In addition I have considered the importance for the family caregiver in reporting the ill person's story, over and above their own. Finally I considered some of the issues that arose for the family caregiver themselves as a result of their participation in a family caregiving capacity within palliative care. The following chapter will continue to explore the family caregivers' perceptions of the extent and effectiveness of the support that is available to them in maintaining this role.

Chapter 8

Family Caregivers Perception of their Relationship with Health Professionals and Other Sources of Social Support

8.1 Introduction

The purpose of this chapter is to explore the relationship between family caregivers, health professionals, and other sources of social support that may be available to the family caregivers. Therefore the chapter will be divided into two sections. The first will consider the family caregivers relationship with the health professionals. The second will consider the relationship of family caregivers with others sources of social support such as family, friends and neighbours.

8.2 Family Caregivers Liaison with Health Professionals

8.2.1 Knowing who to Contact

The family caregivers had a diversity of experience and familiarity with visiting health and social care professionals. Understanding the different roles of these health professionals was important for the family caregiver's ability to understand who and how to access different service providers. However, how the family caregiver's knowledge of these different roles developed is not clear. It is possible that their knowledge was built up over a period of time with increasing contact with the health professionals. Thus, if a situation arose where professional input were required the family caregiver would be able to identify the most appropriate person to contact. As most family caregivers visited during this study had been caring for some time, they appeared to have established to their own satisfaction who they would contact in different circumstances. Generally, there appeared to be a lack of any written literature available to the family caregivers that differentiated between the roles of various health professionals. The knowledge of who was responsible for what aspects of the ill persons well being therefore appeared to be learnt rather vicariously by many of the family caregivers. One family caregiver did comment that she would have liked to have access to written information, particularly at the beginning of her husband's illness.

"At the very onset you are in such a whirl when you are told this is what is happening that you do need that information. ... Go away and read this, you know, you're not going to feel like reading it but this is going to give you the help that you do need." Mrs White

When health professionals were only seen periodically, for example the Occupational Therapist (OT), there was less clear identification of role boundaries or accessibility to a service. During one visit Mrs Gardner talked about contacting someone for advice regarding an extra handrail in the bathroom to assist her husband. Although, they had clearly been in contact with the OT service in the past, Mrs Gardner was very unclear about how or who to deal with this query.

"But I'm going to try and get in touch with the council to see it they will give him a hand rail to hold onto. Anyway I should think they do. ... I'm wondering whether the council will come and fit one of them on, so I'm going to ask them." Mrs Gardner

Mrs Vaughan on the other hand, with her long experience and involvement with the health care system, had no difficulty in identifying the professional boundaries between groups of health professionals.

"A district nurse actually just assesses people. 'Well I think you ought to have a doctor.' .... Macmillan nurse is more of a counsellor. A Macmillan nurse is not allowed to sit with a patient on her own, a Marie Curie Nurse does that. ... They (Macmillan nurse) can't touch a person, they can look but they can't administer the drug. ... (Hospice Doctor) he's a pain control doctor. ...Well the Occupational Therapist is the person that assesses the patient to the equipment he requires in the home to lead what you call a good quality life." Mrs Vaughan

Obviously there are a number of issues surrounding the boundaries between health professionals in this example. For example the issue of what a Macmillan nurse is allowed to do and not do. Mrs Vaughan had a very clear idea that the Macmillan nurse did not fulfil the same role as the Marie Curie nurse.

Generally family caregivers appeared more likely to seek information and advice from those health professionals with whom they had most contact. For example Mr Bradley relied much more on the district nurses who were assisting him with the nursing care of his wife than the hospice nurse whom he only contacted if he required advice about some aspect of her treatment, particularly the drug regime.

> *"I mean (district nurses), they've all you know, what they've said I've gone*
> *along with. They are the people who are dealing with this sort of thing all*
> *the time aren't they? And you know you've got to take their advice."*
> Mr Bradley

Mrs Vaughan on the other hand was much more likely to contact the hospice nurse or the hospice itself if she had a query about her husbands condition, as she had much less contact with the district nurses.

> *"Because she's (hospice nurse) what you call my tie line between the hospice*
> *and home."* Mrs Vaughan.

GP's and hospice doctors were generally only contacted after consultation with the visiting nurse, whether from the hospice or community, unless there was an emergency. This is not perhaps surprising, even though some of the patient's GP's made an effort to keep in close contact, and in some situations would visit routinely, as many of the family caregivers reported more contact with the nursing staff on a routine basis. As more than one caregiver said *"I don't want to waste their time, I know they're busy"*. There is an implicit assumption that doctors are always busy and should therefore only be contacted or approached in an emergency. Some family caregivers used the hospice care nurses and district nurses as a means of accessing the doctors and legitimising their need for a visit.

> *"The district nurse is actually looking after the patient, she can actually*
> *assess the patient if he required any medical, she can refer that back to the*
> *doctor."* Mrs Vaughan

"Well, the district nurse actually phoned her (doctor), because (wife) mentions everything to the district nurse." Mr Reynolds

Not all family caregivers had experience of a particular service. In fact only a few mentioned having had contact with services outside of the hospice, community or hospital teams. Those that had had previous contact with other services did feel able to contact them again if there was a need if there had been extensive use of a service. For example Mrs Vaughan had contacted the OT when she felt her husband required more equipment in the home following his admission to the hospice for breathing difficulties.

For most family caregivers a number of health professionals were involved in the situation. This could sometimes be an added stress for the family caregivers. Whilst they were often grateful for the knowledge and expertise available, having a constant stream of visitors requiring much the same information about the ill person's condition was exhausting, and also reinforced the fact that something was seriously wrong.

"And we both in the end we both sat down and broke down, you know. ... So we did speak to (hospice nurse) about it and we spoke to the doctor about it. Well we told sister (district nurse) too. And they all decided then that they would ease it out and come, one would come one week another on another like that. Ease it like that." Mrs Gardner.

When Mrs Gardner highlighted the distress caused by the constant flow of visitors, the visiting health professionals organised their visits so that they complimented each other rather than overlapped. This resulted in regular visits that did not overwhelm Mr and Mrs Gardner, but at the same time left them feeling supported.

Initially it was envisaged that the involvement of health professionals would consist of community and SPCS doctors and nurses. However, during the course of the interviews it became increasingly clear that some individual family caregivers were referred to social care staff, such as that provided by social services. In particular, home care and social workers were involved with several of the family caregivers. Social care was provided for five of the sixteen family caregivers. Two younger

(under 60 years of age) family caregivers and three older family caregivers were in receipt of social care, which consisted of assistance with personal care such as bathing for the ill person and some household chores and preparation of meals. For the older family caregivers the provision of social care had been initiated prior to the diagnosis of cancer. For the younger family caregivers provision of social care was requested when it became clear that the ill person's condition had deteriorated and the family caregiver could no longer manage to provide all the care required alone. For example the visiting hospice nurse suggested Mrs White might benefit from additional help when her husband's condition deteriorated. Mrs White requested that someone might help with the household chores in order for her to be able to concentrate on giving more personal care to her husband.

"That was organised because when (husband) was very bad, just before then it was suggested that we needed some form of home help. ... They do the hoovering, er they hoover through and she washes the kitchen floor and bathroom floor, and the downstairs loo." Mrs White

However, for Mr Reynolds social care was provided as he had a long standing health problem of his own which prevented him from assisting his wife with personal care. It would appear that referral into the social care system was taken when the family caregiver was no longer able to manage to support the ill person unaided. This does not mean that the remaining caregivers were not in need of more practical help, but that they had not been referred into the social care system at the time of the study. It is unclear what effect the changing patterns of social care in the community will have on the future support of this group of family caregivers.

8.2.2 Availability and Approachability of Health Professionals

How available health professionals were perceived to be to the family caregivers as a source of support was often important to the situation. Some family caregivers appeared to only want to know that health professionals were available to talk to if necessary and would rarely if ever contact them. These family caregivers would often be prepared to wait until the health professional contacted them, either by regular appointment or telephone contact, although they could always ask her to call earlier if necessary.

"Um, she (hospice nurse) makes an appointment say once a fortnight, once a month something like that, not unless we want to see her for whatever reason." Mr Reynolds

However, for Mrs Nash, access to the visiting health professional was blocked by her mother. This appeared to be primarily because she was concerned that issues would be discussed about her illness and treatment that were being kept from her.

"You see if I try to speak to (hospice nurse) then my Mum feels that I'm talking behind her back. I mean I've only got to see (hospice nurse) out the door and if I'm not straight back she'll say what are you talking about? Are you talking about me?" Mrs Nash

In fact Mrs Nash was particularly concerned about the implications for her own health following her mothers' diagnosis, and eventually sought reassurance and information from her own GP.

Generally most communication with the health professionals was concerned with the welfare and care of the patient, and there was little or no opportunity to discuss the family caregivers own reactions to the situation or concerns for their own well being. This may well be the result of the family caregivers focus on putting the patient first (often because of a perceived limited time span) or perhaps due to a misconception of the role of the health professional in relation to their own well being.

Enquiries about the family caregivers concerns or feelings appeared to focus on general polite questions regarding how they were coping with the situation, often at the end of a visit.

"And she (hospice nurse) always says to me and how are you?"
Mrs Gardner

Few of the family caregivers talked about the health professionals as a means of emotional support in the situation, although they clearly found their presence and the expertise that they brought to the situation helpful. Health professionals were

generally only referred to for information and advice about the medication and treatment of the patient and possible side effects experienced, rather than supportive emotional care. Perhaps it is just this informational advice that is indeed the most helpful thing health professionals can contribute to the situation. That is, they can almost certainly provide guidelines for the family caregiver about expectations of treatment regimes and symptom control. This reassurance may be all that the family caregiver and the patient expect from health professionals. If this is the case it is interesting to ask why this might be. Is it perhaps due to the pervasive notion of the ideal of family caregiving (Keating et al 1994, Clark 1995) and the responsibility and obligation of family members to provide care for their relatives (Finch & Mason 1993, Finch 1995). Or could this be due to the implicit assumption that family caregivers are acting from a desire to return care given in the past, or presumed to be available in the future, which results in an altruistic attitude focusing on the individual requiring care. If the reasons for giving care are reciprocity and altruistic behaviour, there would be little expectation by the family caregivers of receiving emotional support from health professionals. Rather they would require specific and focused information and advice about how to carry out their caregiving role. Emotional support would therefore be expected to come from another source.

8.2.3 The Emergence of the Family Caregiver Role

Many of the family caregivers acted, often unconsciously, as a legitimate source of information about the ill person's status for the health professionals. In this respect family caregivers could be thought of as a co-ordinator between the visiting health and social care professionals both at home and from the hospital or hospice settings. For example as the family caregiver was almost always involved in consultations between the ill person and health professionals throughout the illness trajectory, they held a great deal of information about the progress, suggested treatments and changes in the ill person's care. Furthermore, some of the cared for people requested that the family caregiver be present whenever there was a consultation with medical personnel as they were not always able to understand or take on board the implications and changes proposed in treatments. Thus, some family caregivers had more accurate information about the situation than the ill person themselves.

"Well (wife) don't take a lot of it in while she's in there anyway see. And this is one of the reasons why she says to me you have to come along because its not sinking in my head." Mr Lloyd.

By taking on responsibility and acting as an advocate for the ill person during medical and nursing consultations the family caregiver often became very proficient at communicating with other health professionals who may need to know and understand the latest suggestions for treatment. For example the most common topic of conversation with the health professional was reported to be concerning the patient and their current symptoms and status.

"I tend to speak for him (husband), but its because I feel as if he's not putting his case over enough, you know." Mrs Taylor

Within this co-ordinating role, the family caregiver also developed certain expertise about dealing with the situation. This involved not only understanding the treatment regime itself, which could be quite involved;

"They decided that they would do this stem cell replacement treatment. ... (He) went in for a week's intensive chemo, and came home and had hormone injections which boosts apparently the cells out of the bone marrow and into the blood and that was harvested. ... Then they did the stem cell replacement which the weeks chemo knocked out all your immune system completely, and the stem cell was obviously supposed to boost it back up. He was quite ill several times, but we got through that and we came home. ... They did a scan and said well it had gone, its shrunk from about the size of a grapefruit to about the size of a walnut, but its not gone." Mrs Foster

But also the implications of various medications;

"So I have to keep reminding her about things like that (taking medication,) you know. So I might say to her well you know that's going to take twenty minutes to start working so have a bit more you know. And um, I've learnt

little tips from (hospice nurse). Like if you are to be sick, then have all your

tablets again, just in case you have been sick and you've lost them."

Mr Reynolds

And general nursing care of the ill person;

"I mean they tell me about her medication and what, you know, what to do,

how to go about things and that," Mr Bradley

For one family caregiver, Mrs Taylor, there developed a very definite sense of a co-worker type role.

"I tend to take over the nurses role, you know. ... When the nurse comes in

(to the home), she becomes the doctor, I become the nurse. I'm the one

that's got all the drugs there. I'm the one that can tell you what is there, and

that it's already laid out ready for them. ... Because if I didn't keep the

drugs up and run up and down that health centre, they'd be running out

here." Mrs Taylor

For Mrs Taylor, although she did not actually undertake the wound dressings required by her husband, she had developed an understanding of the requirements of the district nurses for maintaining a number of drugs and equipment in the home. Mrs Taylor, clearly saw maintaining this level of equipment in the home as her responsibility.

For the family caregiver prioritising issues surrounding the ill person's care with the health professional could result in a decreased opportunity to discuss more personal and emotional issues relating to the situation.

8.3 Family Caregivers' Perceptions of Extended Family Support

Family caregivers were asked to discuss their relationship with other people involved in the situation. From this information two groups emerged as important to the family caregivers: other family members, and close friends and neighbours. Most commonly other family members, in particular adult children, were mentioned. However, for one

or two of the family caregivers there were few or no family members that were perceived to be available to them, either because of geographical distance to their nearest relative or because of small family size. For these individuals the availability of friends and neighbours became much more significant. Whilst both groups were seen to provide emotional and practical assistance, differences emerged in the type and extent of their involvement.

For family caregivers it was especially important that help was perceived to be available from the extended family network. Underpinning issues of family support is the nature of the relationship with the extended family members and the family caregiver and patient prior to the illness. Occasionally this was acknowledged as being difficult due to a family rift or argument.

> *"We haven't seen him (son) for a good few years now. Why I don't know,*
> *just something that goes on in families I presume." Mr Evans*

In such circumstances it was difficult if not impossible for there to be a sense of reconciliation or a willingness to seek assistance from those involved. Generally however, there was perceived to be a willingness for the extended family members to be involved in the situation and to share the care of the ill person with the family caregiver.

8.3.1 Sharing Care with the Extended Family Network

Despite changing demographic and work related patterns (Clark 1995) the notion that the extended family would be available to support the primary family caregivers was particularly strong within this setting. Half the family caregivers reported having at least one member of the extended family available to assist with both practical and emotional support. This could be reflecting the particular circumstances surrounding palliative care, or this may be a result of societal norms regarding family caregiving.

Although some family caregivers could identify a number of significant others who may be able to provide support, differences were noted in the level of involvement that extended family members took in caregiving. This was particularly found in the case of the daughters who were providing care for their mothers. Sharing care with the

extended family members was often intended to give the primary family caregiver a break from the caring situation. However, sharing the responsibility for the patient's care was often difficult for the family caregiver, particularly if they strongly identified with the role of carer. During a short break away, Mrs Page's brother was asked to take on the role of 'keeping an eye' on their mother. Although he did visit every day, there was some confusion about the tablets that Mrs Page had put out ready for their mother. As a result their mother apparently took more medication than needed, whilst this was not life threatening, it did result in her becoming quite confused for a few days. Mrs Page blamed herself for not having explained to her brother that he would have to check on their mother's tablets, as she herself normally did automatically:

"I felt afterwards perhaps I didn't emphasise quite enough about. Well she seemed quite happy with her tablets, and I mean I'd organised them so I didn't say have a, have a look." Mrs Page

Mrs Nash also found herself to be monitoring her father's administration of her mothers medication when she was not around:

"I'll say to me Dad what tablets did you leave out for her, you know."
Mrs Nash

Thus, for the daughters in the study even when others agreed to participate in the caring role, they retained a sense of responsibility for monitoring and co-ordinating the situation. This sense of responsibility for caring made it difficult for the daughters to accept other extended family member involvement in giving direct care to the ill person.

For Mrs Page sharing the responsibility of caring for her mother with a brother who was returning to England after three years working abroad was a mixed blessing. On the one hand she wanted to forgo some of the caring responsibilities, particularly as she was becoming tired of the caring role.

"But hopefully in a months time when my brother comes home from Hong Kong then there will be somebody else to sort of share it with. ... It's still,

silly really but, you know, I mean at the end of the day if he wants to, if he
wants to help her do it well then he'll have to get on and do it because I think
I'm rapidly running out of steam really, you know out of enthusiasm and
that." Mrs Page

Whilst at the same time she resented his interference and the added complications of having to liase with someone else when making arrangements concerning her mother's care:

"It's going to be funny in a way because it means that I can't just go ahead
and, or, you know, I have to sort of check up on what they're (brother and
sister in law) doing as well." Mrs Page

The conflict for Mrs Page was between sharing the responsibility for her mother's care with her brother and remaining in control of the situation. Whilst she recognised that she was increasingly stressed and exhausted by maintaining a caring role for her mother she was not entirely sure how much responsibility her brother and his wife would actually adopt. This created an uncertainty for Mrs Page, for whom there was a sense that it would almost be easier just to carry on with the status quo than adapt to the changes sharing care with her brother would bring.

"It'll take a while before she (mother) remembers that (brother) is
there, you know. ... And I mean obviously they've got things to sort out.
...You can't expect, I can't expect them to suddenly just down tools and
just take over completely. I don't really want that anyway" Mrs Page

During the final visit to Mrs Page, it had become clear to the whole family that their mother was no longer able to remain at home, and indeed she had decided herself that she wished to move into a residential care home. This was duly organised, however, there was a problem with finance and so Mrs Page and her brothers had a family meeting to decided who was willing to pay the extra money required for their mother to stay at her preferred residential choice:

"We sat, my other brother, three of us sat together the other weekend and worked out what we were going to do, and decided between us that we were quite happy to go in together to pay the extra that would be needed you know." Mrs Page

For Mrs Page the decision to share the financial responsibility for their mothers care was somewhat easier to accept and agree to than the uncertainty of the level of involvement of her bother in the physical and emotional aspects of their mother's care. It is possible that when caring has been extended for a prolonged time, as in the case of Mrs Page, sharing the emotional commitment for caring with other family members may be problematical. Recognising the family caregivers who may find difficulty in sharing care, if it is available, could alert health professionals to the possibility that the family caregiver might be in danger of taking on too much and later feeling unsupported.

For Mrs Nash also there were times when a need arose to share responsibility for her mother, when Mrs Nash needed to be away from her mother for a short time during the day the extended family members were called on to help.

"I've got, tomorrow I've got to stay in and wait for a washing machine man to come. And my mum's brother's wife said if anytime you can't get round just give me a ring. So I've arranged it that if the washing machine man doesn't' come before the normal time I leave, if she'd pop round you know, so Mums' not on the own, because Mum has good days and bad days." Mrs Nash

However, the willingness to share responsibility for her mother's care was only for limited activities and with certain people such as her mother's brother and his wife, or her daughters. When Mrs Nash had the opportunity to go away for a few days, she preferred to arrange for her daughter to care for her mother rather than allowing her brothers take over, as she did not consider them to be capable of domestic caregiving.

"My daughter er Katy, she's going to be here, so she'll come down every day. ... My brothers, because I know, I mean all right I suppose if I, if it was

really desperate most probably one of them would do something, but they're

not, they're not domesticated I don't think, you know." Mrs Nash

Whilst she was away Mrs Nash had to phone home every day to reassure herself that her mother was all right and her daughters, whom she had left in charge of her mother's care, were managing the situation satisfactorily. Therefore, even when there were people that she trusted left in her place she was unable to release the feeling of responsibility towards her mother and allow them to carry out the job in the same way that she would:

"I just need that um, that just to make sure she was ok." Mrs Nash

One of the reasons for Mrs Nash's inability to release the sense of responsibility she felt towards her mother could be due to the enmeshed nature of their relationship (Frude 1990). Such a relationship could result in an over dependence on the ill person which might result in difficulties for the family caregiver following bereavement.

For the family caregivers who were the partner of the ill person, sharing care with extended family support was less clear. For some there were times when they had been able to share care, and perhaps more importantly the responsibility of care with others. Mr Bradley found it a relief to have his sister in law staying because it meant that a second person was around in the house all day.

"Um, I've had her sister down for a week, she went back Saturday yes to

Scotland, but um, not that, that's helped because as I say it's been a bit of

relief because you know a second person about." Mr Bradley

This also meant that he could go out to collect other relatives who wished to visit knowing that his sister in law was available to sit with his wife whilst he was out, which gave him more time to do things than he normally allowed himself.

Similarly Mr Lloyd was grateful that his parents had been able to look after the children for a week so that he and his wife could get some time away together on their own.

> *"And the good thing that has happened, we've had some um, good trips away like. I mean last, two weeks ago I think it was, the girls went up my mothers house, and I took (wife) down to Torquay." Mr Lloyd.*

A short break away was considered helpful to a number of the family caregivers, however, without the support of their son and daughter in law Mr and Mrs Gardner would not have been able to get away. Mrs Gardner was reassured by the fact that someone would be able to assist them if necessary and that her son and daughter-in-law would be only a phone call away in the hotel.

> *"This time I'm, we're downstairs and he's up, but there's a phone there and I've only got to dial the room number and she'll be down, or they'll be down straight away." Mrs Gardner*

This made the prospect of a time away much more pleasant and enjoyable for both her and her husband. In addition her son would be available to help her husband in and out of the shower if necessary:

> *"I get my son at night to come down, before he goes to bed and ask him to give him a shower." Mrs Gardner*

This situation contrasted with the time they had stayed with their other son when they were unable to get upstairs to use the bathroom at all. This, while not diminishing their enjoyment of spending time with their son, did cause Mrs Gardner some concern about her husband's personal care:

> *"I mean I bothered about it when we was up my other son because it was a fortnight and he didn't have a proper wash down at all." Mrs Gardner*

Although sharing care was helpful for some family caregivers this was not the case for everyone. Mrs White explained that she did not feel able to devolve responsibility to her husband's brother when he visited as she had not invited them to 'baby-sit' her husband so she could have time off.

> *"Even like when my brother and sister in law come down, I don't feel I could say right you're here I can now go and do X, Y, or Z, because I feel I haven't invited them down as baby-sitters so as to speak. They're down as part of the family." Mrs White*

Thus, whilst she appreciated their visits she reported finding them hard work as she felt obliged to entertain them. Mrs Foster had similar difficulties when her son and his young children visited for weekends, which even though both her and her husband enjoyed was found to be quite exhausting.

> *"And also because they've got two small children, its when they come down to see us coming from (away) they don't come for a couple of hours to tea, they come for a whole weekend. So that's quite tiring." Mrs Foster*

For both Mrs White and Mrs Foster the increase in visits from the extended family members, whilst appreciated in some ways, did not represent a chance to take a break from the caring responsibility. Rather, it created an increase in tension, therefore support from the extended family members could be both helpful and a problem.

8.3.2 Practical Support Provided by the Extended Family Network

In addition to being able to share care with the extended family network, most family caregivers reported increased availability of practical support. This was seen most frequently in increased visits to the ill person, providing transport for hospital appointments and shopping trips, and helping to maintain routine household jobs.

Visiting the patient more frequently than usual was one way that an extended family network could be seen to be helping, as this not only gave the patient something to look forward to, but also provided time off for the family caregiver. Mrs Gardner

reported looking forward to a visit by her sister in law, when they would be able to do some shopping together.

> *"We're going out Saturday morning, hopefully. And we're gonna see, I*
> *want to buy a new anorak, and she's coming with me and we're gonna*
> *have a little bit of lunch out, and then we'll get back home here about*
> *four." Mrs Gardner*

When transport was a difficulty for the family caregiver, for example if the family caregiver had no access to a car, other family members could generally be relied on to assist, particularly if it was for a hospital appointment.

> *"Transport from the family that's the main thing." Mr Sawyer.*

Providing transport, not only gave the extended family members an opportunity to be involved in caring for the ill person and supporting the primary family caregiver, but also in some cases enabled them to have direct contact with the health professionals. For example for Mrs Gardner the fact that her daughter-in-law could accompany them to a hospital or outpatient appointment was particularly helpful as she felt unable to enter the consultation following a very bad experience on receiving the news of her husband's illness.

> *"And so, 'cos I couldn't take him in. I got to the door and I freeze. So my*
> *daughter in law, she's very good like that you know, so she took him in and*
> *she's taken him since … My daughter in law takes him in and I wait outside"*
> *Mrs Gardner*

In this respect the daughter-in-law acted almost as the patient and caregivers advocate in asking questions and seeking information about the situation from the health professionals that they both felt unable to do by themselves:

> *"Well daughter in law's going to write it all the questions down and we're*
> *going to ask him about this kidney infections he keeps getting" Mrs Gardner*

Other support provided by the extended family members at this time included helping to sort out the ill person's belongings. Mrs White talked about one of her son's helping to sort out his father's extensive tools and equipment.

> *"(Son) has started trying to tidy out (husbands) tools. (Husband) has asked him to turn out all his tools. And, you know, we've got rid of the big power tools and stuff like that some time ago. But like all his hand tools that I would never ever use. So he's sorting them out the ones that I will be able to use and the ones that I won't need to use." Mrs White*

She further acknowledged that this represented an implicit expectation of support from her son, despite this having been prompted by his offer to help her sort out her husband's equipment which was stored in the garage:

> *"And that's not a very pleasant job, you know, and really I suppose we've just expected them to do it without thinking about it." Mrs White*

Many implicit expectations about the type and degree of support were found between family members, which could potentially be quite difficult for the extended family member to deal with. For the sons helping to sort out the equipment that belonged to their father may be seen as pre-empting his death. This could appear to be disloyal to their father even though he had requested this task be undertaken. It also highlights the certainty of the father's death, which may not have been accepted by the sons at that time. Pre-empting the death is a particular problem in palliative care where the family member wishes, or is expected to acknowledge the fact of the ill person's death, while at the same time carrying on as normal an existence as possible. Such a discrepancy is likely to make the situation more difficult for the individual caring of the ill person.

Some members of the extended family network had professional knowledge and expertise that was found helpful in enabling the family caregiver and ill person to manage the situation. For example Mrs Vaughan's son, who was a paramedic, had informed her that small oxygen tanks were available on prescription. The availability of these smaller and more manageable tanks enabled her to take her husband out and

about much more easily, which gave them both more freedom. She was also quite pleased to have been able to inform the doctor that such things existed. In a way this gave her the chance to reciprocate some of the information he had given her in the past:

"I've also got, um, an oxygen tank which my doctor didn't know about, through (son) being a paramedic. He actually informed me there was a small oxygen tank, which is down there, which I carry in the car. That's if I want to take (husband) out he's not restricted to one room, I can take him out with that oxygen tank in he car." Mrs Vaughan

The availability of a small oxygen cylinder was an important factor in the improvement in the quality of life of Mrs Vaughan and her husband, because prior to this they had both effectively been confined to the house due to her husband's breathing problems.

8.3.3 Emotional Support Provided by the Extended Family Network

The extended family network was also able to provide emotional support for the family caregiver. For those family caregivers whose extended family lived a long way away, the telephone became an important means of communicating and maintaining contact with this emotional support. Mr Lloyd found great support from telephone contact with his mother:

"I haven't been really close to me mother at all. And this has probably brought me and her closer than I've ever been to her. And she's been great. Anything I have problems with I phone her up and she's like, you know, a pillar of strength, she's great. She's really got a sound head on her shoulders and talks sense to me." Mr Lloyd

This had developed since his wife had become ill, and primarily because they lived a long distance away from each other. Despite this they were still able to visit on a fairly regular basis, especially for specific family occasions:

"They still pop, they're coming down this weekend I think, because the girls, my two daughters are supposed to be doing a thing up in our local club, er, raising money for the ward." Mr Lloyd

For others too phone contact with extended family members was also an important way of managing the situation.

"I've got some step sisters and that which they one or the other rings, you know, once a week. They sort of organise it amongst themselves they all often ring in. They keep in touch to see how (wife) is, yes." Mr Bradley

By maintaining contact with the extended family members in this way the family caregivers were able to share their concerns and worries about the ill person's status, and also gain comfort from knowing that the extended family member was in touch with the situation and aware of any changes.

8.3.4 Maintaining Normality

Despite some difficult circumstances for some family caregivers, many were able to engage in their normal social and family activities such as birthday treats and attending family gatherings. Mrs Gardner was particularly pleased with a birthday meal out that all the family had been able to go to including her youngest grandson who was approximately six years old.

"As I say on the Saturday they were here for my birthday so we, we all went out for a meal. .... And er, we had a lovely meal and it was very nice, you know, it was nice to have the little family together. So um, the little boy was very good he sat and had his meal" Mrs Gardner

Occasionally the family caregiver was able to attend family gatherings, even if the ill person was unable to attend due to treatment regimes.

"I mean we all had um, like a family bar-b-que on Saturday. You know, um, because (husband) didn't come obviously because that was his crucial stage. Um, I mean they all understood why he didn't go." Mrs Davis

It was important for all the family caregivers to be involved in maintaining the sense of normality for themselves and the person they were caring for, as this helped them to cope with the situation.

8.3.5 Reasons for Non-Participation in Family Caregiving

For some family caregivers there was a perceived availability of family members to help if necessary, although they would not always be called on to provide such assistance. This was especially found if other family circumstances were considered important by the family caregiver. Mrs Gardner commented that her daughter-in-law's parents had offered to take her shopping if necessary, but were currently unlikely to be asked to assist in this way due to the illness of their other daughter:

"Well I've got help. I mean if I want help, um, my daughter in laws parents, they're only down the road, they'll come up in the car and they'll take me shopping and then they'll come and help me carry it in. Um, at the moment they're bound up 'cos they're other daughter fell down the stairs and she's lying in (hospital), she's badly injured her back ... so I haven't bothered them." Mrs Gardner

For others the problem of geographical distance hampered or was recognised and legitimised as reasons for non-involvement in practical day to day care.

"Our Son is now in Japan, because he's teaching. Touch wood he'll be home this Christmas." Mr Cook

In the case of adult children providing practical support there was sometimes a reluctance to depend on them due to an awareness of the business of their lives. For others there was an implicit sense of not wanting to use up too many favours too soon, and a desire to keep the offer of help as a backup for emergencies, or deterioration in the situation.

"And usually people have volunteered, and to start with we didn't take it up because we didn't think it was going to be, but after two years you've got to take help from somebody." Mrs Foster

Another legitimate reason for an inability of the extended family network to provide support was found in extenuating family circumstances. Mrs Davis found that although family support was available if she had asked for it she felt unable to do this and consequently felt very alone in the situation.

"I think I was beginning to feel sorry for myself because I thought well no one wants to know, you know. And of course they want to know. But trudging around my shopping, loads and loads of these bags of shopping, and I thought there's all these people got cars and no wants to take me shopping (laughs). But of course they did, I only had to ask, instead of being independent like I was." Mrs Davis

Mrs Davis situation was complicated by there having been a number of recent deaths in the family, one of which was associated with cancer, and for the family as a whole her husband's illness was particularly difficult to cope with emotionally. Therefore the circumstances within the family had lead to a reduced ability to support one another both emotionally and practically than might otherwise have been expected. This lack of perceived support obviously had an impact on Mrs Davis

8.3.6 Perceptions of the Responsibilities of Non-Family Support

For family caregivers who did not have a close family network to provide practical support, friends and neighbours became more significant. The anticipation that neighbours and friends would be available was lower and more limited than expectations made of family members.

"We've got to the stage now where I think its been going on so long that we just ask. Well people, lots of people have said is there anything we can do, and then you ask them. And they can always say no can't they?"
Mrs Foster

Furthermore, Mrs Foster felt that friends and neighbours were more likely to be happy doing practical things to help.

"And I feel that people, they like to be doing something practical really then you know, they feel they're helping then don't they?" Mrs Foster

Of the family caregivers who did not have immediate close kin available, most reported having at least one friend or neighbour on whom they could rely for practical or emotional support. One family caregiver reported having very little contact with any family members or neighbours and relied much more heavily on the district nursing team and home care teams, referring to them as friends.

"I mean those nurses have come in now, well there's four of them, five regular ones, all the time they've been coming in we treat them now as friends, and they treat us as friends." Mr Evans.

8.3.7 Satisfaction with Family Caregiving

On the whole family caregivers reported being reasonably satisfied with the support provided by extended family members. Some were particularly appreciative of the practical and emotional care, and acknowledged that the close relationship was a continuation of previous patterns of relationship within the family.

"They're 100% with us. ...We all have a lot of common interests, which helps a lot you know. ... We're very close, very, very close." Mr Sawyer

Likewise Mr Andrews was very grateful for the support of his family who lived next door and the son who still lived at home. They were constantly asking if they could do things for them, and the son who lived at home did all the gardening, and some cooking:

"I mean he does my gardens anyway for me and that and er, he does he cooks. He can cook the one that lives at home can cook as well can't he? Quite a good cook" Mr Andrews

Sharing of such tasks allowed Mr and Mrs Andrews to enjoy each other's company without having to worry about household jobs.

Although most family caregivers reported contact with a number of extended family members it was notable that a few were much less well supported by this group. It is perhaps with these family caregivers that health professionals could have most influence in providing additional emotional and practical assistance.

8.4 Summary

This chapter has focussed on the relationship of family caregivers with health professionals and other sources of support, particularly extended family and friends. It was found that family caregivers have had a range of experience and contact with a number of different health and social care professionals. Few of the family caregivers saw health professionals as a source of emotional support, however, they did appreciate and rely on this group for information and advice regarding aspects of the patients care. Through their contact with health professionals, family caregivers often appeared to act as a co-ordinator between service providers. In addition they reported acting as an advocate for the ill person and developing expertise in caring for this persons needs. Family caregivers support from the extended family and close friends was occasionally seen as a way of sharing responsibility for the ill person, particularly in the case of the daughters who were family caregivers. The extended family network provided both practical and emotional support to the family caregiver, which enabled them to share their concerns about the ill person and maintain a sense of normality. Thus, family caregivers appeared to receive support from both health professionals and extended family and social networks. The extent and type of support provided by each of these groups varied.

Chapter 9

Discussion

9.1 Overview

In this chapter I will discuss the implications both theoretical and practical resulting from the two studies. I will begin this section by reflecting on the research process and the evaluation of the findings. I will then move on to consider the main issues arising from the work and the theoretical implications of the study. I shall then consider some of the limitations of the research. Following this I shall discuss the practical and policy implications suggested by the research. Finally I shall suggest further avenues of research resulting from the thesis.

9.2 Introduction

The research adopted an individual perspective approach in order to explore the perceptions of family caregivers in palliative care. It was expected that this would result in a better understanding of the role, needs, types of support and interactions between family caregivers and health professionals. The previous chapters have explored issues arising from both a health professional and family caregiver perspective. This chapter will therefore concentrate on a discussion of the wider issues for family caregivers providing palliative care, which may reveal new approaches to clinical practice, and further areas of research relating to family caregivers in this setting.

9.3 Reflecting on the Research Process

One important aspect of qualitative research is the ability to be reflexive about the process and conclusions drawn. Furthermore, in accordance with Yardley's (2000) criteria for judging qualitative research it is important to acknowledge the way in which sensitivity to context may be useful in considering the purpose and usefulness of a piece of research. In this section I shall therefore consider some of the ways in which the research may have been conducted differently, and the way in which this research may be judged to have achieved its aims.

Reflecting on the research process is a useful way of identifying how and why things may be done differently if the research were to be repeated in the future. Although this research was conducted as two separate studies, they were related by their concentration on the perception of the role of the family caregiver from both a health professional and family caregiver perspective. The study was originally designed in this way to gain access to the perception of two distinct groups about one role. However, the findings revealed that the perspective of both groups regarding the role reflected on the interaction that was possible between the two groups. Therefore, if the study were to be repeated it would be useful to identify and co-ordinate a study which could explore the interaction of a particular health professional or set of health professionals with a particular family caregiver.

Within this research it is clear that an implicit burden model was used to guide the process of data collecting, particularly in relation to the questionnaires used during the family caregiver study, which was not always supported by the qualitative data. On reflection of this effect it was important to note the reason that such questionnaires had been included in the original design. The study sought to build on previous work in the area and to assess whether family caregivers in a palliative care setting had additional or different needs and perceptions to those that had been identified in other settings. As pervious research has, until recently, concentrated on the negative and burdensome nature of family caregiving, the measures guiding this research reflect this perspective. In order to achieve parity with previous research it was therefore decided to use measures that reflected this perspective to identify any similarities or changes within this particular group of family caregivers. Whilst the questionnaire measures did reveal some interesting data, this was not always supported by the qualitative interview data. Furthermore, the small number of family caregivers who remained in the study for all four interviews made any statistical analysis of the data questionable. Thus, if the study were to be repeated, and questionnaire measures chosen, I would recommend that a larger sample of participants be recruited initially to address the issue of high attrition experienced in this type of research.

The activity questionnaire was intended to give a brief account of the type of activity a family caregiver was undertaking for the ill person. Pervious research and advice from other health professionals and researchers working in the field guided the design and

content of the questionnaire. This resulted in a measure that was long and fairly cumbersome and repetitive to complete. In addition it was clear from the qualitative data on carers' roles that these family caregivers placed a great emphasis on maintaining a sense of normality and acting as an advocate for the ill person. It is possible that such supportive roles may be more important to family caregivers in this situation, particularly if the ill person remains relatively well and physically able. Understanding the significance and extent of the supportive caring role provided by family caregivers would be a useful avenue for further research

In judging qualitative research Yardley (2000) suggests that it is important to consider the sensitivity to context, and the socio-cultural impact that a study may have. This research has sought to build on previous research within family caregiving, which has concentrated on one particular disease setting. As little was known previously about the nature of family caregiving in a palliative care setting this research has contributed to the body of knowledge within this field and as such has been sensitive to the context of the research.

A further means of judging qualitative research is the impact it has on the socio-cultural setting. This study has practical implications for the way in which health professionals view and interact with family caregivers in a palliative care setting and therefore has the potential to change practice and increase awareness of the family caregivers' perspective. In order for this to be achieved the findings need to be disseminated in a variety of ways, through academic publications, conference presentations, reports to funding bodies and those who participated in the research, and at an individual level with clinicians. In this way it is possible that the findings of the research may have an impact on the way that family caregivers are supported within a palliative care setting.

9.4 Issues Arising from the Research

One of the striking findings of the research was the number of similarities, and also differences, in the perspectives of the family caregivers and the health professionals. Understanding these differences can help to give some insight into the areas where problems may occur in the nature of the relationship between family caregivers and

health professionals in this setting. Within the next section I aim to highlight some of the similarities and differences resulting from the main findings of the research.

Generally health professionals and family caregivers expressed similar perceptions regarding the nature of the relationship between the family caregiver and cared for person. Both groups expected these caregivers to be close kin, participating in caregiving for familial reasons such as obligation, kinship and reciprocity. However, family caregivers were much less likely to define themselves as a caregiver than health professionals, unless they had been participating in caregiving for a prolonged period of time. Health professionals may be more likely to perceive family caregivers as part of the service provision for the patient, particularly if they view the family caregiver as a resource or co-worker (Twigg 1989). Alternatively family caregivers are more likely to view what they are doing as being related to their family relationship (Finch 1989), and will have little or no concept of a service definition.

Although both family caregivers and health professionals generally agreed that the ill person's wishes and desires should be accommodated as much as possible, there was a tension between the desire and ability of family caregivers and health professionals to provide this level of care. For health professionals enabling the family caregiver to support the ill person at home sometimes created an ethical dilemma revolving around the desire to provide care and support to the family caregiver without undermining the care and confidentiality given to the ill person. Furthermore, health professionals also expressed concern that such privileging of the patient's wishes could have a negative effect on the family caregiver. For example, competing demands on a family caregiver's time from both the cared for person and a work role, may prove difficult to sustain, especially for a prolonged period of time. It is debatable if privileging the patient's wishes in this way is either ethically or morally sound. This is particularly pertinent in palliative care, which has as an underlying philosophy of supporting both the patient and their family. This philosophy suggests an equal distribution of care should be provided to both groups, and yet there is clearly a conflict in the practical application of this process.

For the family caregiver there was also a tension between a desire to fulfil the cared for person's wishes and a recognition of their own needs and ability to sustain such care.

Often there was a feeling of failure or guilt if they were unable to respond to earlier requests from the ill person to be cared for at home. This was especially notable in younger family caregivers who had other work and family commitments and responsibilities in addition to the caregiving role.

9.4.1 Ambiguity of the Family Caregivers Status in Palliative Care.

The combined studies clearly revealed the ambiguity surrounding the term family caregiver, for both groups. The concept appeared to be underpinned by a number of implicit assumptions and expectations, which resulted in a lack of clear understanding about the status of family caregivers. This produced tensions for many of the family caregivers and health professionals as they attempted to define and negotiate the role of carer within palliative care.

However, some family caregivers strongly identified with the term carer and appeared to have incorporated this role into their identity, which legitimised their status in the situation. These family caregivers had all been giving care to the ill person for a number of months or even years and as a result had often built up a degree of expertise and knowledge relating to the ill person's medical history and treatment. In addition these family caregivers became expert at monitoring the ill person's condition and co-ordinating the involvement of additional support from health professionals. Family caregivers who identify with this role have been termed 'expert carers', and health professionals may need to negotiate with this group in a different way to other less experienced family caregivers (Allen 2000). For example less experienced family caregivers who do not identify with the role of carer, may experience difficulties in articulating their concerns or feeling they have a legitimate right to indicate those concerns to health professionals.

For health professionals the ambiguity surrounding the term carer resulted in tensions between the type and level of involvement that could be anticipated from a particular family caregiver. Whilst there was an acknowledgement that there should be no coercion or pressure for a relative to undertake such a role, there was also an implicit acceptance that adoption of such a position did often take place within palliative care. Consequently it was recognised that a family caregiver may become involved in the

situation by undertaking a caring role, and yet have no personal recognition or acceptance of that role. Health professionals appeared to find it much easier to respond to the activities that the family caregiver was undertaking, particularly if they were instrumental caregiving tasks, than any anticipatory or non-instrumental activities that many family caregivers in this situation adopted. This in turn limited the ability and opportunity for family caregivers to seek support, either emotionally or practically, for their individual needs from the health professionals.

9.4.2 The Relationship between Family Caregivers and Health Professionals.

Due perhaps to the ambiguity surrounding the term carer, the relationship between family caregivers and health professionals was sometimes perceived as problematical by both groups. Often there was a tension between a recognition of the family caregiver as a member of kin and family caregiver as co-worker (Twigg 1989). By adopting a co-worker role family caregivers present the health professional with a conflict of interests. On the one hand they wish to support the family caregiver in their own right, but on the other they recognise the limitations of service provision and the need for the family caregiver to be involved in the care and support of the ill person.

Furthermore, within palliative care there is an explicit philosophy of caring for the family both during and following the death of their relative. For the family the assumption implied by this philosophy is that the increased support will result in less emotional trauma. That is increased support will not only enable the patient to experience a 'good death' (Smith 2000), but this process will also help to prevent the family from damaging long term psychological consequences. That is, there is an assumption that assisting individuals to engage in grief work prior to the death will help mitigate abnormal grief reactions following bereavement. This is often referred to as 'anticipatory grief', which is similar to post-death grief, but is commenced prior to the death of the ill person. However, Evans (1994) argues that the equivocal findings in the research regarding the effectiveness of anticipatory grief and post bereavement outcome may be due to the narrow view of the death itself as the only loss incurred during the terminal phase. Rather, Evans suggests that individuals suffer multiple losses during the terminal phase of an illness and that current theories of loss fail to recognise the impact of these multiple losses on an individual. For example, within the

research a number of family caregivers reported the way their lives had been limited by the cared for persons' illness by reducing social contacts with friends and families, isolation from work, and a loss of a shared future together. Alternatively, some family caregivers reported that they had achieved a number of gains from becoming a carer, notably a particular role and status, from which they gained both pleasure and reward.

However, for health professionals there remains a difficulty in determining how joint care with family caregivers may be organised so that equity of support can be delivered to both the ill person and their associated family members. Thus, if health professionals are unclear about the extent of their responsibility towards the family there is likely to be a privileging of the patient's needs and wishes over the family caregiver, despite the rhetoric of their concern for the whole family. Privileging the patients needs and concerns this way fails to take account of the rights of the family caregiver, even though some decisions may have a direct consequence on their health and well being.

9.4.3 Supporting Family Caregivers in a Palliative Care Setting.

Understanding the most appropriate way to support the family caregiver was an aim of the research. It is clear from the family caregiver study that a number of individuals may be involved in this process, particularly in relation to emotional support and practical assistance with caring for the ill person. Family caregivers were reliant on a number of other, often related, individuals in order to sustain the level of care given to the ill person, and as a means of maintaining their own emotional support. Thus, other family members such as adult children and their spouses, or the spouses of the daughters were a significant resource on which the primary family caregiver relied, although the degree to which this was perceived as helpful was variable.

The expressed availability of extended family support by some family caregivers, was not always sought for a number of reasons. Keating et al (1994) argue that this difference relates to actual and potential elements of sources of support. Whilst there may be a large potential for extended family care, for example in the number of family members who could potentially provide assistance, the actual degree to which others support the primary family caregiver may be small. If family support is perceived to be

unavailable non-kin family and friends may be drawn into the network as sources of support.

For the primary caregiver a tension arose if there was a perceived difference between the actual provision of assistance from those who 'would help' and those who it is perceived 'should help' (Keating et al 1994). If individuals are perceived to be available to help (would help) they might not be called on to provide such assistance, especially if there are perceived to be other legitimate calls on their time such as family or work commitments (Finch & Mason 1993). However, if an individual within the family network who it is thought 'should help' does not, this can lead to frustration and resentment for the family caregiver. Thus, the size of the family caregivers support network does not necessarily provide an accurate reflection of the degree of support perceived to be available to the family caregiver. This is important in palliative care when the number of individuals mentioned in connection with social support was often small. It is possible that in a palliative care setting family members draw closer in order to support the ill person and the primary family caregiver. Alternatively the family group may not be able to support each other during this time due to difficulties in coping with the situation and therefore the primary family caregiver is left to seek support from other sources such as friends, neighbours and health professionals. Understanding the social support perceived to be available to the family caregiver would increase awareness of situations when additional support may be beneficial.

9.5 Theoretical Implications of the Research

The studies presented in this research have a number of theoretical implications for both service provision and palliative care. In the following section I shall attempt to draw on these frameworks to explore the nature of family caregiving in palliative care.

9.5.1 Romanticising the Role of Family Caregiver in Palliative Care

For both the family caregiver and the health professional there appeared to be an underlying belief in the desirability of family caregiving. This resulted in a romanticised vision of family caregiving which emphasised the importance of everyone being together and supportive of the ill persons needs, despite the cost this may have

for the family during the time before death and on bereavement. Such romanticism surrounding the desirability of giving up all for the cared for person is also found in the romanticised notion of bereavement popularised during the Victorian age (Walter 1999). The society and cultural expectations of middle and upper class women particularly at that time was to retire from all social activities and concentrate wholly on their grief. Similarly for family caregivers there is an expectation that all their own commitments to any other individual or organisation will be put aside for the duration of the cared for person's illness. However, within palliative care this is both unrealistic and possibly harmful for the family caregiver. The uncertainty of the disease trajectory, particularly in cancer care, with multiple periods of recurrence and remission can make the expected time frame, and therefore need for caregiving, very unpredictable. The family caregiver is therefore constantly deliberating whether or not a particular crisis or exacerbation in symptomatology in the ill person is the final stage of the illness, and whether or not it is therefore time to make preparations for the death of the cared for person.

Over a prolonged period of time such an investment in the situation may not be viable for several reasons. Firstly, the emotional roller coaster that this type of uncertainty produces may be one reason that family caregivers exhibit increased anxiety and negative psychological consequences (Hinton 1994b). Secondly, if the family caregiver is able and willing to give up, or reduce, other social contacts there is a possibility that the very mechanisms that may support them during the caregiving experience and following the death of the cared for person will be unavailable when they are most needed. This is particularly important if the caregiving experience is conducted over a prolonged period of time. For example, both of the daughters in the research commented on the negative effect the period of caregiving had on their own interactions with their spouses and children. Similarly those family caregivers who were still in employment had experienced a range of consequences from their employers regarding the need to take time off work to care for the ill person. This ranged from full and active support of the family caregiver in undertaking this role, to open hostility and sanctions regarding the necessity of this course of action. If the supportive social relationships with extended family members or active employment roles are damaged during the caregiving experience, this may result in difficulties for

the family caregiver following bereavement when there is an expectation that people will reintegrate into society.

9.5.2 Family Caregivers and Service Provision

In chapter two it was seen that a number of attempts had been made to define the term carer. Within a service orientation Twigg (1989) has suggested that carers could be viewed in a number of ways, as resources, co-workers, co-clients and superseded carers. The pervasive and implicit acceptance of the term carer within this model would appear to indicate that the term and the role of carer are commonly found in practice. This contrasts sharply with the family caregiver perspective, which is dominated by a relationship boundary with the cared for person rather than a service provision model.

Despite a dominance of service definitions of family caregiving for the health professionals, there was a desire to engage in individual interactions with family caregivers. Nolan et al (1996) have suggested that family caregivers may be seen as experts in caring, and indeed many family caregivers do acquire a range of skills and expertise related to the cared for person's needs. A service definition however, fails to acknowledge the context and complexity within which family caregiving is undertaken. That is, health professionals relate to individuals in the context of their social roles such as patient, carer, husband, wife. However, everyone occupies multiple roles for example mother, partner, and worker at the same time. The complexities of these multiple roles will have an impact on the level at which one individual is able to interact with another. I would suggest the lack of understanding and agreement about the status and role of family caregivers may cause a tension between what is expected and what is actually possible.

In palliative care, whilst family caregivers are considered integral to the care of the ill person they do not generally receive the same priority from health professionals as patients. And yet, if all has been done to make the patient as comfortable as possible and give them the best quality of life and no further action is to be taken, then it is the family caregiver who may require as much if not more support. This raises the question of how much health professionals should prioritise the patient's wishes above

those of the family when those wishes may have a direct impact on them. For example, if the patient wishes to die at home and the family caregiver feels unable to provided this level of care, is it appropriate to effectively force the situation on them by providing additional services in order for the patients wishes to be met? If the time before death was fraught with anxiety and worry about how the situation can be managed the family caregiver may feel let down and will remember the cared for person's death in a more negative light which may have implications for their well being.

9.5.3 Family Caregiving in Palliative Care

Family caregiving research has traditionally been conducted within elderly care, and in particular, Alzheimer's disease. This study has shown that many of the activities and difficulties experienced by relatives within a cancer palliative care setting mirror those found in other types of caregiving situations. However, despite the rhetoric of palliative care philosophy to support the family as well as the ill person, help for the family caregiver was often only directed towards enabling them to continue to care for the ill person at home as long as possible. Rather than helping the person to come to terms with the situation the use of the term carer generally defined their involvement in the situation in terms of instrumental activities. This limited the type of help they may receive from others such as health professionals and social care agencies. Thus, health professionals and social care agencies may unconsciously include the family caregiver as a member of their team and act as a specialist resource to them providing them with information and help to accomplish the desire to maintain the ill person at home. Rather than providing support for the family caregiver this relationship could be said to deny them access to their own emotional and physical support and increase the ambiguity within their role.

Within palliative care there is a certainty about the impending death of the person being cared for that is generally openly acknowledged and perceived to be of a discrete time frame. For some of the family caregivers this knowledge had become overwhelmed by the length of time that the caring experience had continued. Rather than being a discrete event that occurs over a number of weeks or months, for a few, the experience had extended over many months and even years. What had been presented at the time

of diagnosis or recurrence as a defined time period had in fact turned out to be much longer than expected. As a result the resources that had been called upon to manage a short term situation were beginning to be exhausted and the result of this was a tiredness and a wondering how this would be managed for the foreseeable future.

Whilst the family caregivers wanted to prolong the life of the cared for person, and enjoy their company and shared experiences for as long as possible, at the same time they did not wish them to suffer or become distressed by their symptoms. Therefore the family caregiver may wish the person to live and die all at the same time. This tension can be difficult to live with for the family caregiver, and may feel like disloyalty towards the ill person. The conflict for the family caregivers therefore becomes one of attempting to prolong the life and quality of time spent with the ill person whilst at the same time being constantly prepared for their death and mourning the loss of shared experiences and expectations that they may have held. The disruption to the shared experiences and expectations, and the threat to the social identity of patients caused by chronic illness have been termed biographical disruption by Bury (1982). As the family caregivers in this study were all closely related to the ill person, and often demonstrated very enmeshed relationships with the ill person, it is possible that there may be similar threats and disruption to their shared biography. Some family caregivers appear to be able to make sense of the limited time together, and continue with their normal activities. However, others have great difficulty adjusting to the changes. It is a challenge for health professionals to acknowledge and assist family caregivers and patients who are struggling to come to terms with this loss.

By using a case study approach it was possible to see that the traditional and pervasive accounts of "burden" were not unduly noted by this group, despite the extent of their loved one's disability or dependence. Difficulties arose only when the needs of the ill person exceeded the resources of the carer. For example one carer had to reluctantly allow her husband be admitted to the hospice owing to the fact that she was no longer able to manage to move him on her own. Those family caregivers that did report a sense of burden and stress associated with the caring role were more likely to have been caring for their relative for a considerable time, generally over one year. It is possible that the level of burden and stress experienced within this group is related to carer

fatigue or burn out due to the unexpected length of caring commitment rather than a genuine sense of burden with the role.

9.6 Practical and Policy Implications

The Carers Act (HMSO 1995) and the Carers National Strategy (1998) have sought to raise the profile of family caregivers and their support needs in recent years. However, there continues to be an emphasis on the physical burden of caring (Nolan et al 1996b) and the implicit assumptions underpinning the role. Furthermore the carers national strategy assumes that individuals identified as a 'carer' acknowledge and identify with this term. It is important to recognise that there may be different perceptions between the health professional and the individual family caregiver regarding the use of the term. This may result in confusion as to the role and activities the individual is able or willing to undertake. If health professionals develop a clearer definition of the role of carer within palliative care, there may be less likelihood of family members being unexpectedly placed in the position of accepting a role or level of responsibility that they may feel uncomfortable with. However, such definitions could also have the potential to limit an individual approach towards each family caregiver and therefore reduce the extent of the role some family caregivers may wish to undertake.

In addition, explicit recognition of the role of family caregiver by health professionals would result in the family member's position being openly acknowledged. This in turn would have the benefit of highlighting the rights and needs of this group, which would also help health professionals to identify clear areas of responsibility towards the family caregiver. Furthermore, family caregiving is a complex and dynamic process. Whilst the family caregiver is protective of the ill person, likewise the ill person often feels a sense of responsibility towards the family caregiver. Assisting the family caregiver to recognise and deal with their own needs in a systematic way may help to reduce the anxiety of the ill person regarding the family caregiver. For example an ongoing assessment of the family caregivers perceived level of responsibility towards the ill person may help to highlight the need for additional information, educational or counselling needs which could then be addressed. This in turn can assist the situation to be experienced as less stressful for everyone.

Whilst the Carers Act (HMSO 1995) and the Carers National Strategy (1998) recognise the increasing reliance on family caregivers to provide support and assistance to the sick and disabled, support has been targeted at those providing direct physical care and has failed to acknowledge those providing supportive care. Without adequate support for this group there continues to be a danger that this situation will be unsustainable. With an increasingly mobile population the availability of close kin who are able to provide care can not be relied on. Also changing family dynamics with increased numbers of divorces and multiple marriages challenge the view that families are a stereotypical cohesive unit (Clark 1995). For example will members of a reconstituted family be so willing or accepting of their obligation and duty to provide care for non-blood kin? In addition as family caregivers are most likely to be co-resident with the ill person it remains unclear what effect the increasing number of single people will have on the ability and willingness of the family or informal network to support ill people at home.

9.7 Limitations of the Study

There are a number of weaknesses with this study. One is the large attrition rate from the study, which was an expected and anticipated consequence of the research, as this is a common problem within palliative care research (Jordhøy et al 1999). This results in those who are most sick, or caring for those who are most sick, failing to be represented in the literature. For family caregivers whose anxiety levels are known to increase during the last few weeks before death (Hinton 1994b) this could reflect a serious problem, as those who may be most in need of support are underrepresented in the literature. Thus, members of this group are in danger of receiving inappropriate or deficient support.

A further issue that arose during the course of the family caregivers study was the gate-keeping activities of the nurses who provided access to the individual family caregiver. Not all family caregivers that were known to the Macmillan/home care nurses were referred to the study, or given any information about the study being undertaken. There were a number of reasons given for this type of professional gate keeping, chiefly that the nurses perceived the situation to be particularly complex and problematical. Frequently the complexities were revealed to be unconnected to the patient's symptom

control issues, but rather focussed on the patient caregiver relationship or complex family dynamics. Whilst acknowledging that there needs to be some control over the degree to which individuals are considered for entry into research, particularly in a sensitive area, I feel that this can leave the door open for a degree of paternalism to creep in. In turn this could limit the opportunity for family caregivers or others to share their experiences and hence benefit others in similar situations. I found that far from being traumatised by participating in the research, individuals often found this give a reason and a positive slant to an otherwise negative situation.

This research was conducted with family caregivers who were in receipt of SPCS services, and had a terminal diagnosis of cancer. For many of these individuals there is a clear acknowledgement that they have reached the end of curative treatment and that a palliative phase of care has commenced, which made the provision of services from SPCS appropriate. For many other individuals suffering from chronic, but equally terminal conditions the transition between curative treatment and palliative care is much less clear, and they are often therefore prevented from benefiting from the additional services and expertise provided by SPCS. As the recruitment for this study occurred via the visiting Macmillan/home care nurse it was not possible to access family caregivers who were not in receipt of the additional service support such as that provided by SPCS. It is possible that the increased level of support provided via SPCS may be of benefit to the family caregiver following the death of the cared for person. If this is the case it could be speculated that the lack of such services to family caregivers who are caring for someone with a non-malignant yet terminal condition, may be at increased risk of problems following the death of the cared for person. Alternatively the increased number of health professionals introduced into a situation as a result of SPCS may be overwhelming, thus, reducing the effectiveness of the additional support. Indeed several of the family caregivers in the study found the number of visiting health professionals confusing, and therefore tended to relate to one individual who they came to know and trust. Understanding the perspective of family caregivers providing palliative care without the support of SPCS would provide a valuable addition to the awareness of the potential benefits and deficits of additional support for family caregivers and the cared for person.

9.8 Further Research

This research has highlighted the complexity of the relationship between health professionals and family caregivers in palliative care. It is possible that initial contact and development of interaction between health professional and family caregiver will set the pattern for future interactions. This may be positive or negative and a study exploring the development of these relationships may help to develop the body of knowledge relating to family caregivers in palliative care. By developing a clear understanding of the nature of the relationship and its development it might be possible to be more explicit about the type of support that can be provided by health professionals in this situation. Understanding the nature of these relationships would also help to clarify the position of the family caregiver.

For those family caregivers who do identify with the role, the psychological loss following the death of the loved one may have a detrimental effect, not only in terms of their bereavement but also of the role they had adopted. Further explorations of the effect of SPCS on a future bereavement would be a useful addition to knowledge of family caregiving.

This thesis in line with many other caregiving studies concentrated on a primary family caregiver. The importance that some family caregivers placed on support from the extended family network clearly raises the issues of the extent that palliative care is able to identify and support this family circle. It is unknown the effect that the progressive death of a family member will have on the extended family network who are perceived to be providing emotional and practical support to the primary family caregiver. How their life is affected by providing support, and whether SPCS are able to offer support to the extended network are all questions that deserve further investigation.

9.9 Summary

The thesis explored the perception of the status and role of family caregivers within palliative care from both a health professional and family caregiver perspective. Ambiguity around the definition and use of the term carer was found for all

participants, and a number of implicit assumptions about the person and place of family caregivers was made.

The development of SPCS, particularly for cancer care, has enabled improved symptom control and increased life expectancy for many whose disease is no longer responding to curative treatment. However, this has placed increasing pressure on family members and in particular close kin to provide extended and yet at the same time uncertain length of care to their loved one.

Whilst SPCS may attempt to improve the position of family caregivers by additional support, this is usually aimed at maintaining the position of the family caregiver in supporting the patient's desires and wishes, and fails to acknowledge the individual perspective of the family caregiver. Understanding this perspective and acknowledging the implicit expectation relating to this role can be useful in adapting practice to improve the support offered to family caregivers.

Appendix 1

Introductory Letter to Health Professionals

Health Research Unit Address
Direct Line: Tel. No.

Date

Dear

My name is Paula Smith, and I am undertaking a research study for a PhD at the University of Southampton, funded by the NHS Executive, Research and Development Directorate, South and West. I am also a District Enrolled Nurse, and have recently completed a MSc in Health Psychology, where I undertook a preliminary investigation into the needs of informal carers in palliative care.

In the first phase of my PhD study I plan to investigate health professionals perceptions of informal carers in palliative care. I propose to use this information in the second phase of the investigation, which will involve interviewing carers themselves. All information provided will be completely confidential.

I would therefore be grateful if you would agree to a short interview, lasting approximately half an hour to discuss your views on this issue. The interview would take place at a time and location convenient to you.

I shall be contacting you by telephone within the next week to arrange a time to meet if you are agreeable to participating in this project. If you would prefer me not to contact you please telephone me on Tel. 01703 595422.

Thank you for your attention to this matter, and I look forward to speaking with you soon.

Yours sincerely

Miss Paula C Smith MSc, BSc, DEN.
Postgraduate Student

Appendix 2

Health Professional Interview Schedule

Thank you for taking part in my study, as I explained earlier I am trying to obtain different views and perceptions from various health professionals about informal carers in palliative care. I am not trying to judge professional practice, and there are no right or wrong answers. Some of the questions may appear very simple, they are not trick questions, but I hope they will help me to understand some taken for granted assumptions. You have the right to withdraw from the study or ask for the tape to be stopped at any time. Is that all right?

1. There have been various attempts in the literature to describe who or what an informal carer/caregiver is but I would like to know what does the term informal carer or caregiver mean to you.

2. In your experience who do you think informal carers are most likely to be?
    Prompt: Is it likely to be anyone other than family members?

3. What do you think are the main reason for caregiving?

4. In your experience how do you decide who the caregiver is, in a palliative care setting?
    Prompt: For example is it explicitly stated 'I'm the carer' or do you, assume it's the person they're married to?
    Is it something that is ever asked about?

5. What sort of things would you expect an informal caregiver to do?
    Prompt: What do you mean by support?

6. Are there any things you would not expect informal caregivers to do?
    Prompt: What if the carer does not have the appropriate skills to undertake certain tasks?

7. When you are assessing the needs of the patient how do you consult the carer?
    Prompt: What do you do if the carer is unwilling to undertake a particular task?

8. Do you ever spend time with the carer alone discussing their needs?

9. Do you ever spend time alone with the carer discussing their ability to care?
    Prompt: do you see a difference between their own personal needs and their ability to care?

10. What percentage of time, relative to that spent with the patient, would you say you spent with the carer e.g. 50:50, 90:10, how much less?
    Prompt: Do you consider time spent with the patient and the carer as part of the time spent with the carer?

Appendix 2 (continued)

11. Is time spent with the patient and carer primarily for the patient's needs, carer's needs or joint needs?

12. What responsibility, if any, do you think you have towards the carer?

13. Does it make a difference for you if the carer is also one of your patients?
    Prompt: Is it more difficult if the carer is registered with another doctor or practice.

14. When would you suggest the intervention of SPCS, at what sort of stage?
    Prompt: Is the carers ability to cope part of this assessment.

Would you mind if I finished by asking a few questions about your experience?

15. How many terminally ill patient's with cancer would you expect to see in a year?

16. What qualifications do you hold?

17. How long have you been qualified?

18. How long have you been in your present post.

19. Do you have any further questions or thoughts about informal carers in palliative care?

Thank you very much for your time.

Appendix 3

Demographic Questionnaire: Health Professional Study

I would be grateful if you could complete the following questionnaire:

Please state the professional qualifications that you hold

How long have you been qualified?

Specialist training

How long have you been in your current post?

How long have you been working in this professional field?

Approximately how many terminally ill patients would you normally visit in a year?

Please circle the appropriate age group to indicate your age last birthday.

20-30 years   31-40 years   41-50 years   51-60 years

Appendix 4

Master Code List from Health Professional Study

Perceptions of an Informal Carer

Credentials for caring role
Pay
Training
Professional/informal/lay

Readiness of individuals to participate in caring
Availability/unavailability
Decisions to care or not care
Geographical closeness/distance
Close kin/friends and neighbours

Motivation for family caring
Obligation/duty/reciprocity
Satisfaction/dissatisfaction with role

Activities of family caregiving
Personal care
Household care

Responsibility and Conflict for Health Professionals
Responsibility felt by Health Professionals
Putting the patient first
Professional role
For treatment regimens
For carer or carers
To support both patient and carer

Conflict for Health Professionals
Between patient and carer needs
Carer demand/refusal of help offered
Limitation of services provision
Mediating between patient and carer

Resolution of conflict for Health Professionals
Checking out perceptions of patient and carer
Explaining need for extra help to both patient and carer
Liaison between patient and carer
Advising carer on own needs

Appendix 5

Interview Schedule Family Caregivers Perceptions

First of all I would like to thank you for taking the time to talk to me. As you know I am interested in your experiences of looking after someone who is ill, so there are no right or wrong answers. I have a list of questions that other people have mentioned as significant to them, which we can use if we need to, but most important are your experiences.

I am going to record the interview so that I can listen to what you have said at a later date. However, if you want to stop the interview or the tape recorder at any time you can. All the information you provide will be strictly confidential, your name will not be mentioned in any reports arising from this study. Are you happy to sign the consent form?

Your Role as a Carer:
1. Can you give me a brief history of how you came to be involved in looking after your ......?
>   Prompt: was it a conscious decision, were you expected to do it, did it evolve
>   slowly or happen quickly.

2. Do you feel you have a part to play in looking after ....?

3. How would you describe that part?

4. Has looking after ..... changed the way people talk to you?
>   Prompt: family members, friends, neighbours, health professionals. Topic of
>   conversation, ... illness rather than your health.

5. Has looking after ..... altered your normal routine?
>   Prompt: social life, work, household tasks, free time, money

6. What does the term 'Carer' mean to you?
>   Prompt: paid/non-paid, family/non-family, 'doing for', words/images that
>   come to mind

7. Would you describe yourself as a 'Carer'.

8. If yes why. If no why not.

9. What things have you found most rewarding about looking after ....?

10. What things do you find most difficult about looking after ......?

Appendix 5 (continued)

Your Support:

11. Do you see yourself as someone who normally copes with things well?
    Prompt: general daily activities, illness, disasters, small hassles

12. Who has helped you most while you have been looking after ....?
    Prompt: family member, friend, neighbour, Health professionals

13. What is it that they do that is so helpful?
    Prompt: provide transport, sit with patient, do shopping, listen to my worries.

Appendix 6

Letter to General Practitioners of Participants in Family Caregiver Study

Address of Health Research Unit
Direct Line Tel. No.

Dr.

Date

Dear Doctor

My name is Paula Smith and I am a postgraduate student at the University of Southampton, where I have been funded by the South and West NHS R&D to undertake a study exploring the role, needs and sources of support of informal carers in palliative care.

In accordance with the Local Research Ethics Committee recommendations, I am writing to inform you that a family carer of your patient ...., has agreed to participate in this research study.

The aim of the study is to understand the perceptions of family caregivers in a palliative care setting in relation to their role, needs and sources of support. The study will involve four interviews, conducted over a period of three months. In addition a number of questionnaires will be used to measure the carers level of activity, social support and anxiety. No information about the patient or her condition is being sought, except a diagnosis of cancer with an estimated prognosis of six months or less. Any information provided by the carer that may relate to the patient or any visiting health professional will be strictly confidential. In any future reporting of the study, all names will be altered to protect individuals identity.

Should you have any further queries about this study I would be happy to answer them, and can be contacted at the above address.

Yours sincerely

Miss Paula C Smith
Postgraduate Research Student.

Appendix 7

PARTICIPANT CONSENT FORM

I   ....(Full Name)

of   ....(Address)

hereby fully and freely consent to participate in the study entitled:

Family Caregivers:
Understanding their role, needs and sources of help.

I understand and acknowledge that the investigation is designed to promote medical knowledge. I further acknowledge that participation in the study will not influence the medical treatment received by either the person I care for or myself.

I understand and acknowledge that I may withdraw my consent at any stage in the investigation. I acknowledge the purpose of the investigation and any risks involved. The nature and purpose of the procedure has been detailed to me in an information sheet, and has been explained to me by: Miss Paula Smith, and I have discussed these matters with her

Signed ....

Date ....

DECLARATION BY THE INVESTIGATOR

I confirm that I have provided an information sheet and explained the nature and effect of the procedures to the volunteer and that his/her consent has been given freely and voluntarily.

Signed ....

Status ....

Appendix 8
Participant Information Sheet

Family Caregiver Study

My name is Paula Smith and I am a postgraduate researcher at the University of Southampton, where I have been funded to carry out a three year project into the needs and perceptions of family caregivers of someone who is ill.

The purpose of this study is to understand the way family caregivers think about their role and the type of help that is useful to them. I hope that this information will lead to improved services and assistance to other family caregivers in this situation.

I would like to come and listen to your experiences of caring, and to learn how you deal with changes over time. The study will involve three interviews, which I would like to tape record, as well as a few short questionnaires. The interviews will be carried out over a six week period, and each interview will last approximately 45 minutes to one hour. I will come to your house at a time convenient to you to carry out the interviews.

Any information you provide will be confidential, and you will not be named or identified in any future reporting of the study. The audio tapes will be kept in a locked cupboard, and will be deleted on successful completion of the project, of which this study is a part.

If you would be willing to take part I will contact you in the next few days to arrange a time and place convenient to you. You are free to decide that you do not want to take part or talk to me without explaining why, and also to change your mind about taking part at any time. This will not affect your treatment rights, or those of the person for whom you care, in any way. Your identity will be concealed in records of any information you give to me.

Approval to carry out this study has been given by the local Research Ethics Committee.

If you would like more information or have any questions, please contact Paula Smith, School of OT and PT, University of Southampton, Highfield, Southampton, SO17 1BJ Tel. (01703) 595260 (work switchboard) or (01703) 595421 (DIRECT LINE)
Thank you for your time and help!

Appendix 9

Demographic and Background Details of Family Caregivers

The demographic and background details of the family caregivers who participated in the family caregiver study are presented in this section. These notes were compiled after each interview with the family caregiver and represent the researchers interpretation of the background details, some of which proved to be of significance, of the individual family caregivers interpretation of the situation and the circumstances they found themselves in. They are presented here to give the reader a sense of the contextual circumstances surrounding each family caregiver's involvement in the caring situation.

To ensure anonymity details that may be used to identify the family caregivers have been changed or omitted.

Appendix 9 (continued)

Family Caregiver: Mrs. Vaughan

Caring For: Husband of 31 years, who had a very disfiguring facial carcinoma, which was originally diagnosed 4 years previously.

Age: 52 years.

Extended Family: One son living on the other side of town who is married but has no children. Little contact generally as son works shifts. Mother who Mrs Vaughan visits every day to prepares meals and attends to her financial affairs.

Friends and Neighbours: Mrs Vaughan has a very supportive neighbour living next door.

Own Health: Mrs Vaughan is not in good health herself, she has arthritis of the spine and COAD, which she feels have been exacerbated by caring for husband.

Past Caring History: Reported being a carer from the age of 12, when she looked after her neighbours who had no children. Then looked after her grandmother who died of cancer. Also looked after her neighbour who had a stroke. Has been looking after her mother for some time prior to her husband becoming ill.

Background Details:
Mr and Mrs Vaughan lived together in their own home, a 3 bed semi-detached house. They are both fully aware of her husband's diagnosis and know as much as is possible to know about what might happen, given that the doctors are unsure of the exact disease trajectory.

Mrs Vaughan appears to have taken charge as soon as her husband was diagnosed. She gave up work as a receptionist when her husband became jealous at the way she presented herself for work. When the cancer returned two years ago, she persuaded the staff at the hospital to operate on the facial tumour to give her husband 'more time'. Mrs Vaughan very strongly identifies with the term 'carer', and ignores her own needs and issues, and resolutely refuses to talk about them to anyone else. She will only cry if she is on her own. Mrs Vaughan feels it is her job to 'jolly along' her husband and help him to continue with as much normality as possible, particularly when he was finding it difficult to accept the changes in his appearance.

Mrs Vaughan does not see her son very often, which may be due to a history of bad feeling between her and her son's wife's family. There appears to be few people that she is comfortable asking for help from, although the neighbour (who is a nurse), has been helpful and will sit with her husband once a week so that she can go to bingo.

The only thing Mrs Vaughan reported being worried about was what she will do if 'something' happens to both her mother and husband at the same time.

Appendix 9 (continued)

Family Caregiver: Mr Andrews

Caring For: Wife of approximately 36/37 years, who he married after they ran away together and eloped at the age of 16/17. Mr and Mrs Andrews live together in their own home with their youngest son. Also another son and his wife and children live next door.

Age: 54

Extended Family: Apart from the two son's living near, they also have another son who lives on the other side of town.

Friends and Neighbours: Mr Andrews relies primarily on the extended family for support with the caring role, and did not appear to have much contact with friends and neighbours.

Own Health: Mr Andrews appears to be in good health, although he has had a colostomy for 12 years following surgery to remove a cancerous tumour.

Past Caring History: Has been involved in looking after wife for some years since she had a bad fall that exacerbated her arthritis. Mrs Andrews cancer was diagnosed some time (years) ago, but condition had recently deteriorated.

Background Details: Mr Andrews works full time on nights in a local factory, which has resulted in him being ineligible for financial assistance to make adaptations around the house for his wife. Mr Andrews reported having little faith in various social and health services due to disappointments and unmet expectations in previous encounters with such services. Mr Andrews was heavily involved in a local support group, for whom he co-ordinated a local newsletter and magazine.

It appeared difficult for Mr Andrews to differentiate the extra care his wife has needed since the recurrence of her cancer began to cause difficulties, although he did feel that there she was less able to do small jobs around the house that she used to manage. He did appreciate the close support and assistance provided by his two son's and his daughter in law in caring for his wife, particularly when he was at work.

Appendix 9 (continued)

Family Caregiver: Mrs Davis

Caring For: Husband. This is a second marriage for both Mr and Mrs Davis. They live together in a three bedroom council house.

Age: 60

Extended Family: Mrs Davis has a son living approximately 20 miles away, who she sees occasionally, but has regular telephone contact. Mrs Davis also has a sister (now alone since the death of her husband) and niece who both live approximately 5 miles away, and a sister and brother in law living across the road.

Friends and Neighbours: Mrs Davis mentioned a number of friends and neighbours who would, and apparently did help, especially at the beginning when her husband needed transport to and from the hospital. All lived close by.

Own Health: Mrs Davis suffers from high blood pressure, which has been exacerbated by husband's condition, although this is now under control. Mrs Davis was recalled for a mammogram at the time of her husband's diagnosis. Normally she said she would not have worried about this but because of the circumstances she was extremely anxious although it turned out to be benign and was reported as being caused by a problem with the equipment.

Past Caring History: During the previous year has been heavily involved in caring for niece who died of breast cancer at 40 years, seven months after diagnosis. Within last 14 months Mrs Davis has also lost a brother in law and another family member through illness (not cancer).

Background Details: Both Mr Mrs Davis are very optimistic about the prognosis, and are under the impression that 'he will always have to live with this', but it may not come back for a year, two years or five years. Mrs Davis gave up work as a shop manager for the local hospice organisation to look after Mr Davis when he first became ill, which has caused them some financial difficulties.

This has also been a particularly difficult year for Mrs Davis because she is still grieving over the loss of her niece who she was particularly close to. Mrs Davis reported having a feeling of history repeating itself as she has been accompanying her husband to all the places that she took her niece. Consequently she was somewhat depressed especially at the beginning of her husband's illness, and to make matters worse a clerical error meant that Mr Davis was not seen by a specialist until some 10 weeks after he first went to the doctor. They were also distressed by the way they were informed of Mr Davis diagnosis.

Primarily she sees her role at present as 'being there for him' and 'monitoring' his condition and reminding him to take his tablets. She does not see herself as a carer but rather the things she does are because she loves him and he is her husband.

Appendix 9 (continued)

Family Caregiver: Mrs. Foster

Caring For: Husband. They live together in their own three bed roomed detached house.

Age: Mid 50s

Extended Family: Two sons both living over 60 miles away. One son has wife and two small children.

Friends and Neighbours: Mr and Mrs Foster appeared to have a number of friends and neighbours who had volunteered help in the past. One neighbour regularly cut the grass for Mrs Foster, others provided transport to take Mr Foster to hospital when necessary.

Own Health: No personal health problems mentioned by Mrs Foster.

Past Caring History: Husband had an 'attack' of cancer some five years or so ago, and thought he was clear. Mrs Foster did not consider herself to be a carer, but to be caring as a result of their relationship.

Background Details: Mrs Foster worked full time in a responsible position within an accountant's office. As their immediate family lived away she came to rely heavily on friends and neighbours to assist with caring for husband. Mr and Mrs Foster did not want to rely on others for help initially, but have been forced to by the length of time the illness has continued.

As time progressed and Mr Foster continued to deteriorate, Mrs Foster arranged to work reduced hours in order to be at home with her husband. Although her employers were sympathetic to her situation she was unsure if this arrangement could be maintained as her role was particularly important within the office, and it was not possible for her to work from home.

Appendix 9 (continued)

Family Caregiver: Mrs. Taylor

Caring For: Husband. They lived together in a 3 bed roomed council house, and regularly had members of the extended family visiting.

Age: 51

Extended Family: 3 Son's and 2 Daughters who all live fairly close, although none of them help with the care of their father. Mrs Taylor regularly looks after the grand children by picking them up from school. In addition the youngest baby sleeps with them every Saturday night in order to give the parents a night off.

Friends and Neighbours: Mrs Taylor mentioned few friends who would be able to assist her in caring for her husband, either with practical or emotional support. Mrs Taylor had, however, been of assistance to some of her neighbours in the past and was therefore disappointed and hurt that this had not been returned when requests for help had been made.

Own Health: Mrs Taylor has chronic asthma which made doing heavy household chores difficult. Caring for her husband has sometimes been difficult due to her own poor health.

Past Caring History: Mrs Taylor had been caring for her husband for a number of years prior to the current illness (approximately one year ago) as he had heart problems and diabetes and was retired early on grounds of ill health. She considered herself to be very much her husband's carer and advocate particularly during encounters with both medical and social care professionals.

Background Details: For Mrs Taylor, her main source of support was her extended family, although this was sometimes variable and she often appeared to be disappointed at the lack of reciprocal care received particularly from her son.

Furthermore, Mrs Taylor had experienced great difficulty in obtaining the equipment and adaptations to their house that she felt were necessary. For example, because of her husband's heart condition going up and down stairs was difficult. Social services had agreed to make an out building into a bathroom and toilet for her husband, but when this work was completed there were various problems which made it unusable. The arguments that ensued in relation to this project appeared to have resulted in Mrs Taylor become very disillusioned with social services.

However, she has found that following her husband being diagnosed with cancer, people have been more obliging about getting equipment in the house. Despite this she is still waiting for a stair lift to be organised for her husband as it takes a long time to get upstairs at night because her husband is only able to go up two steps and then needs to take a rest.

Appendix 9 (continued)

Family Caregiver: Mr. Sawyer

Caring For: Wife, to whom he had been married for over 40 years. They lived together in a 3 bed roomed council house.

Age: 72

Extended Family: Three sons all living some distance away. One daughter with three grandchildren living on the other side of town.

Friends and Neighbours: Although Mr Sawyer reported being on friendly terms with their neighbours, they would not feel able to ask them for assistance as several were elderly and with health problems of their own.

Own Health: Mr Sawyer reported being in reasonably good health, and did not complain of any health problems.

Past Caring History: Mr Sawyer had witnessed two aunts and his mother die from cancer in the past, but was not directly involved in their day to day care.

Background Details: Mr Sawyer relied most heavily on his children and their partners for both emotional and practical support. On a daily basis this was most frequently undertaken by their daughter who took them shopping on a weekly basis. One son, who was currently living abroad, had taken a month of leave to be with them recently.

Both Mr and Mrs Sawyer try as much as possible to maintain a normal lifestyle and appear to be quite philosophical about the situation.. Mr Sawyer thinks there are two types of people, those who think 'why me' and those that just get on with things.

Appendix 9 (continued)

Family Caregiver: Mr. Bradley

Caring For: Wife. They lived together in a two bed roomed terraced house.

Age: 61

Extended Family: Mr and Mrs Bradley have no children of their own. However, Mr Bradley had two sisters who live some 30 miles away. In addition Mrs Bradley had one sister who lived in Scotland but visited regularly, and one sister with whom they no longer had contact due to a family disagreement some years previously.

Friends and Neighbours: Mr Bradley had a close neighbour and friend who often came to visit his wife and sit with her so that he could go shopping. This neighbour had offered more help, but he did not want to make a habit of calling on her for assistance as she had her own family problems to deal with.

Own Health: Mr Bradley appeared to be in good health.

Past Caring History: Mrs Bradley has had a long history of mental illness and anxiety over the years, which the Mr Bradley has lived with, although he did not consider himself to be a carer. Also about four years previously his wife had a very mild heart attack, from which she was reluctant to take on strenuous physical activities, although she did resume the household chores.

Background Details:
Mr Bradley had worked for the same firm for nearly 30 years and was very hurt by their unsympathetic response to his situation. Currently they receive daily visits from the district nurse, who assist his wife with washing and dealing with her medication.

Appendix 9 (continued)

Family Caregiver: Mr. Mathews

Caring For: Wife. They loved together in their own 3 bed roomed semi detached house.

Age: 65

Extended Family: One daughter and her children living across town. Also has a son living in Japan.

Friends and Neighbours: Mr and Mrs Mathews had a number of friends and acquaintances, but they did not feel they would be able to ask them for their assistance, although they did appreciate their visits.

Own Health: Mr Mathews was medically retired from work after suffering back problems, which have been exacerbated by the caring roll. He is also quite deaf, (from work related industrial injury) and was frustrated with his hearing aid which increased the noise level rather than making sound more audible. Furthermore, Mr Mathews has problems with the sensation and dexterity in his fingertips (also due to work) which sometimes makes things like turning the pages of a newspaper, and preparing meals difficult.

Past Caring History: Mrs Mathews was first diagnosed with cancer seven years ago, after which she has been quite well until the last few months, when she has become progressively more incapacitated.

Background Details: The rapid deterioration in his wife's condition made the situation somewhat confusing for Mr Mathew's. Mr Mathews did not consider himself to be a carer for his wife, but saw what he was doing as being connected to his relationship obligations. His main source of support in this was his daughter, who they saw regularly, and who helped with many of the household activities.

Family Caregiver: Mrs. White

Caring For: Husband. Mr and Mrs White were about to celebrate 29 years of marriage. They lived in their own three bed roomed detached house with their two sons and one girlfriend.

Age: 49 years

Extended Family: Two son's both currently living at home, (one with his girlfriend) whilst they are looking for their own accommodation. Mr White's brother and his wife also visit regularly but live some distance away and can therefore only help at weekends.

Friends and Neighbours: Mrs White still maintained regular contact with her work colleges, despite having been off sick long term herself in order to care for her husband. Whilst they were on friendly terms, she would not wish to ask for their assistance.

Own Health: Mrs White suffers from Migraines very badly and is receiving preventative treatment for this. This is a concern for her as she worries about how she will manage to care for her husband if she has a bad attack. Otherwise Mrs White reported not having time to worry about her own health.

Past Caring History: Mrs White was a care assistant in an old people's home when the children were young for a short time. She gave this up because her husband did not like her coming home smelling of 'death'. Mrs White does consider herself to be a carer.

Background Details: Mrs White and her husband were going out to celebrate her success in gaining a degree when they received the news of her husband's prognosis. Since then she has given up her job, which she had been in post for less than a year to look after her husband full time. He is registered as 95% disabled and requires help with all aspects of daily living except using the toilet. However, he has had problems with constipation recently due to the high doses of analgesia that he is receiving, and the district nurses have asked if Mrs White would be willing to give him an enema if necessary, which she is happy to do.

Both son's are currently living at home and this appears to be causing a great deal of stress for Mrs White because they do not get on that well and also they do not voluntarily offer help to either Mr or Mrs White. In addition she is reluctant to ask for help from them because if they are not willing to help without being asked she is not going to ask them.

Mrs White reported being content with the caring role but would really appreciate some time to herself to get her hair done or do the shopping whilst her husband is being looked after or treated to some reflexology.

Appendix 9 (continued)

Family Caregiver: Mr Reynolds

Caring For: Wife. They lived together in a two bed room high rise council flat.

Age: 40

Extended Family: Mrs Reynolds had a teenage daughter who they have some contact with. Her son died about two years ago quite suddenly which was a shock to the whole family. Mrs Reynolds mother and family were the main point of emotional support and were in daily telephone contact with the couple. Mr Reynolds had less contact with his family, although they also live in the same town.

Friends and Neighbours: Mr Reynolds mentioned a few friends who sometimes called to visit both himself and his wife. However, most social contact appeared to be with his wife's family.

Own Health: Mr Reynolds has been long term sick prior to his wife's illness, due to lung problems. These have not completely resolved and so he remains unable to take outside employment.

Past Caring History: Mr Reynolds had not been involved in giving care prior to his wife's illness and did not consider himself to be a carer.

Background Details: For Mr and Mrs Reynolds the extended family was the main source of emotional and practical support. There was some involvement from social services who provided home care for Mrs Reynolds. Due to Mr Reynolds own health problems there were a number of financial difficulties that caused anxiety for both Mr and Mrs Reynolds. In addition, the loss of Mrs Reynolds son and their own baby the previous year added to the emotional distress the couple experienced.

Appendix 9 (continued)

Family Caregiver: Mrs. Page

Caring For: Mother, who lived in two bed roomed terraced house in next street.

Age: 58 years

Extended Family: Two daughters and one son. The daughters both live in the same town, but the son lives over 100 miles away. All three children are married and between them they have four grandchildren. In addition Mrs Page has two brothers who are involved in the caregiving situation for their mother. Both live away. One over 100 miles, and the other in Hong Kong, although he was due to return to this country during the course of the study. Mrs Page is the oldest child, and has always taken responsibility for looking after their parents, partly because she lives so near and the others do not, but also partly because she is the only girl in the family. Most important for Mrs Page is the support, both practical and emotional, that is provided by her husband.

Friends and Neighbours: Mrs Page's circle of friends and neighbours was small, due to her commitment to caring for her mother and family.

Own Health: Mrs Page generally reported few health problems of her own but was recently somewhat run down, perhaps because of the extended caring given to her mother. She therefore went to a herbalist who prescribed her something to help her feel more relaxed.

Past Caring History: Appears to have been caring for, or at lest keeping an eye on her mother for some time, especially after father died four years ago. Mrs Page did identify with the caring role after she had been called her mothers carer by a member of the residential home her mother attended on a weekly basis.

Background Details: Mrs Page reported a number of family difficulties relating to the care of her mother. Principally the perceived lack of support provided by her brother who was living in Hong Kong. During the last year Mrs Page and her family had suffered a number of setbacks. Her husband had had to take early retirement following a heart problem, and was then diagnosed as having prostate cancer, which is now in remission. They then lost their grandson (of 5 months) when he died following a heart operation for valve problems, which had distressed the whole family. Following this her mother was diagnosed as having cancer of the lung, and initially they thought this was a poor prognosis. However, Mrs Page's mother has since rallied round, and whilst they have been pleased that she has been so well, the length of the caring has begun to take a toll on Mrs Page, who sometimes feels torn between caring for her mother and her husband and children.

For Mrs Page, remaining in work has been a conscious decision so that she does not become overwhelmed by the caring role for her mother.

Appendix 9 (continued)

Family Caregiver: Mrs Nash

Caring For: Mother who lived in the next street.

Age: Mid 40's

Extended Family:
Mrs Nash lived with husband and teenage son. Two daughters, one of whom was married also lived in the town and were seen regularly. Her father lives with her mother, but works during the day and they have not got on for some time. Mrs Nash had two brothers who lived in the town and visited their parents in the evening. Also there were a number of more extended family members who regularly visited her mother, although they did not keep in touch much prior to her developing the illness.

Friends and Neighbours:
Mrs Nash reported having several friends who she met socially on regular occasions. However, she would not be likely to ask this group for practical support, neither would she ask her neighbours who she had only a passing acquaintance with.

Own Health:
Mrs Nash did not report any physical health problems, but she did say she was somewhat anxious and was on medication from her own GP for this. No other reported health problems at this time.

Past Caring History:
There is a strong family history of female members giving care. Mrs Nash's own mother cared for her grandmother for 14 years prior to her dying about a year before she herself became ill. Mrs Nash did identify with the term carer.

Background Details:
Since the initial diagnosis her mother had asked Mrs Nash to stay with her which she agreed to do. She gave up her job as a cashier in a local supermarket and now receives the £38 per week carers allowance. She spends every day at her mothers home helping out with whatever her mother will let her do, from about 9.30 am till 3.30 p.m., and trying to encourage her to go out and do things whilst she can.

Mrs Nash gained most emotional and practical support from her own family, especially her husband and daughters. There was a great deal of tension between Mrs Nash and her mother possibly resulting from their very enmeshed relationship.

Appendix 9 (continued)

Family Caregiver: Mrs. Gardner

Caring For: Husband in a ground floor one bedroom council flat.

Age: 77

Extended Family: Two son's and their partners. The oldest son lives in the same town, the youngest lives over 300 miles away. Grandchildren ranging from 28 years to 6 years old.

Friends and Neighbours: Mr and Mrs Gardner had a neighbour who was always prepared to help and often sat with Mr Gardner when his wife went out shopping. This was much appreciated although at times they felt he overstayed his welcome, especially when Mr Gardner was very tired. They also had a number of other friends who would take them out in the car for trips, until Mr Gardner had a fall in his wheel chair which made him anxious about going out.

Own Health: Mrs Gardner appears to have suffered with anxiety for many years, for which she is receiving medication. Also she has recently been told that she has osteoporosis of the spine and is less able to lift things now, such as the wheelchair into the car, which does cause problems for her role as a carer.

Past Caring History: Mrs Gardner looked after her mother for may years until she had to go into a residential home when she was 94 years old. Mr Gardner has been disabled for as long as she has known him. First with a war wound that led to him having hip problems, and more recently in the last three or four years since he had a heart attack and subsequent heart problems. These have resulted in him becoming more or less wheelchair bound, although he can still drive if she is around to put the chair in the car for either end of the journey. Because of her long history of caring Mrs Gardner does identify with the term carer.

Background Details: Because Mr Gardner has been disabled for a long time they have adapted the flat and their routine to fit in with her husband's disability. They have a home care lady Monday to Friday to help him shower and dress. Mr Gardner is not happy to have anyone else in the evening or weekends because they have got used to this particular home carer and others appear rough or do not always want to do things their way. Until recently Mrs Gardner has always taken over if the carer goes away on holiday, but this year she does not feel that she can do that and so the carer has arranged for someone else to come who they do know quite well.

Mr and Mrs Gardner did not see much of their children prior to the diagnosis of cancer, but since then the son and daughter in law living in the same town have been very good. This is demonstrated by phoning or calling in most days, and assisting with hospital visits, which Mrs Gardner found difficult following a particularly bad experience at diagnosis. Mr and Mrs Gardner had a very enmeshed relationship probably due to their long marriage, and it was difficult to disentangle one story from another.

Appendix 9 (continued)

Family Caregiver: Mr Lloyd

Caring For: Wife. They had been married for 13 years and lived with their two daughters and his Mrs Lloyds son from a previous marriage.

Age: 37 years

Extended Family: Mrs Lloyd had an elder daughter who was not living in the family home, but who had some psychiatric problems, which was a source of tension between Mr and Mrs Lloyd. Mr Lloyd's parents lived a long distance away, but often visited and maintained contact by the telephone. Mrs Lloyd's brother and father also called in more frequently since her diagnosis.

Friends and Neighbours: A good friend of Mrs Lloyd who lived near by often helped out by collecting the children from school and babysitting when Mr and Mrs Lloyd were at hospital appointments. This friend was the main source of practical support for Mr Lloyd.

Own Health: Mr Lloyd reported being fit and well, with no health problems of his own.

Past Caring History: Mr Lloyd did not appear to have been involved in any other caring situation prior to wife's illness.

Background Details: This was a fairly complicated family situation due to the involvement of the oldest daughter and the younger children. Mr and Mrs Lloyd did have a number of relationship difficulties at the onset of Mrs Lloyd's illness although these were subsequently resolved, and Mr Lloyd felt that they were now closer than they have been for years.

Mr Lloyd had been particularly supported by his employers in undertaking the caring role, by arranging for him to work reduced hours so that he could care for his two young daughters. In addition whenever Mrs Lloyd had to go for chemotherapy he was given time off to care for her until she recovered.

Appendix 9 (continued)

Family Caregiver: Mr Cook

Caring For: Wife. They lived in their own 3 bed room detached home.

Age: 62

Other Family:
Mr Cook has one son who is currently teaching in Japan, and is expected home for Christmas due to mothers deteriorating condition.

Friends and Neighbours:
As Mr and Mrs Cook have always travelled, they have no close relatives living nearby, and their friends have been particularly supportive by calling and offering assistance as required. Mr Cook feels that he can manage as long as his wife is able to be up and about.

Own Health:
Fit and well. Plays golf several times a week usually.

Past Caring History:
Mr Cook has never had to care for wife before. Currently he does most of the housework and cooking since his wife's original treatment began 2 years ago. Now has some private help with housework twice a week.

Background Details:
Mr Cook took early retirement a number of years ago and since then has enjoyed a number of leisure pursuits, both on his own (eg golf) and with his wife. They both enjoy travel and have driven several times to the continent for holidays. However, his wife has taken a sudden turn for the worse over the last few days. They had been given some bad news about his wife's prognosis and recurrence of cancer on the week of the first visit of the study, which was a big shock as they were expecting to hear good news. Mr Cook is not quite sure how he will cope, or what services may be available to him in the future if his wife needs more intensive nursing care.

Appendix 9 (continued)

Family Caregiver: Mr Evans

Caring For: Wife. They have been married for over 40 years, and live together in a ground floor council flat.

Age: Mid 70s

Extended Family:
Mr and Mrs Evans have two son's. One they have not seen for a number of years due to a family rift. The other they see from time to time with their grandchildren.

Friends and Neighbours: Mr and Mrs Evans appear to have a very small circle of friends and neighbours, most of whom are too elderly to be called on to give assistance.

Own Health:
Mr Evans has recently been diagnosed with prostate cancer himself, and is waiting to hear the latest test result but is hopeful that this will be good news. He also has some problems with his legs which make walking long distances very difficult.

Past Caring History:
Mr and Mrs Evans have always shared the work around the house since his retirement. He is increasingly taking responsibility for preparing meals when his wife has bad days since the diagnosis of her cancer.

Background Details:
Mr and Mrs Evans appear to have a very limited circle of friends and neighbours, possibly due to their age and health status, which has been deteriorating over the years. They therefore appear to rely mostly on statutory services (district nursing and home care) for daily assistance with both their care needs, but particularly the wife's care needs. Mr Evans does not care for his wife's personal needs as home care comes in to do that. Mr Evans primary role if to help with household and cooking chores.

Appendix 10
Carer Activity

For each of the activities mentioned below, please indicate the extent to which you carry out these activities **NOW**.

Also please indicate how often you did these activities prior to your relative becoming ill, that is in the **PAST**.

CODE:
Never =   I never do/did this activity
Sometimes =   I do/did this activity once or twice a week
Frequently =   I do/did this activity several times a week
All the time =   I do/did this activity at least once every day

1. Cleaning	**NOW:** Never	Sometimes	Frequently	All the time
	PAST: Never	Sometimes	Frequently	All the time
2. Washing	**NOW:** Never	Sometimes	Frequently	All the time
	PAST: Never	Sometimes	Frequently	All the time
3. Shopping	**NOW:** Never	Sometimes	Frequently	All the time
	PAST: Never	Sometimes	Frequently	All the time
4. Cooking	**NOW:** Never	Sometimes	Frequently	All the time
	PAST: Never	Sometimes	Frequently	All the time
5. Dealing with finance	**NOW:** Never	Sometimes	Frequently	All the time
	PAST: Never	Sometimes	Frequently	All the time
6. Gardening	**NOW:** Never	Sometimes	Frequently	All the time
	PAST: Never	Sometimes	Frequently	All the time

Appendix 10 (continued)

| 7. Household maintenance | **NOW:** Never Sometimes | Frequently | All the time |
| | **PAST:** Never Sometimes | Frequently | All the time |

| 8. Sitting with the person who is now ill | **NOW:** Never Sometimes | Frequently | All the time |
| | **PAST:** Never Sometimes | Frequently | All the time |

| 9. Listening to the person who is now ill | **NOW:** Never Sometimes | Frequently | All the time |
| | **PAST:** Never Sometimes | Frequently | All the time |

| 10. Providing transport | **NOW:** Never Sometimes | Frequently | All the time |
| | **PAST:** Never Sometimes | Frequently | All the time |

| 11. Organising social visits | **NOW:** Never Sometimes | Frequently | All the time |
| | **PAST:** Never Sometimes | Frequently | All the time |

| 12. Liasing with other family members and friends | **NOW:** Never Sometimes | Frequently | All the time |
| | **PAST:** Never Sometimes | Frequently | All the time |

| 13. Washing/bathing the person who is now ill | **NOW:** Never Sometimes | Frequently | All the time |
| | **PAST:** Never Sometimes | Frequently | All the time |

| 14. Mouth care for the person who is now ill | **NOW:** Never Sometimes | Frequently | All the time |
| | **PAST:** Never Sometimes | Frequently | All the time |

| 15. Dressing the person who is now ill | **NOW:** Never Sometimes | Frequently | All the time |
| | **PAST:** Never Sometimes | Frequently | All the time |

Appendix 10 (continued)

16. Feeding the **NOW:** Never Sometimes Frequently All the time
person who is now ill

                          PAST: Never Sometimes Frequently All the time

17. Assisting the **NOW:** Never Sometimes Frequently All the time
person who is now
ill to get around **PAST:** Never Sometimes Frequently All the time
the house

18. Helping the **NOW:** Never Sometimes Frequently All the time
person who is now
ill to the toilet **PAST:** Never Sometimes Frequently All the time

19. Supervising the ill **NOW:** Never Sometimes Frequently All the time
person's medication

                          PAST: Never Sometimes Frequently All the time

20. Monitoring the **NOW:** Never Sometimes Frequently All the time
ill person's condition

                          PAST: Never Sometimes Frequently All the time

21. Reporting the ill **NOW:** Never Sometimes Frequently All the time
person's condition to
health **PAST:** Never Sometimes Frequently All the time
professionals

22. Carrying out **NOW:** Never Sometimes Frequently All the time
simple dressings
for the ill person **PAST:** Never Sometimes Frequently All the time

Finally please indicate any other activities you do for the person who is ill that are not mentioned here:

Activity: **NOW:** Never Sometimes Frequently All the time

                          PAST: Never Sometimes Frequently All the time

Activity: **NOW:** Never Sometimes Frequently All the time

                          PAST: Never Sometimes Frequently All the time

Appendix 11

Relative Stress Questionnaire:

1. Do you ever feel you can no longer cope with the situation?　　Never Rarely Sometimes Frequently Always

2. Do you ever feel that you need a break?　　Never Rarely Sometimes Frequently Always

3. Do you ever get depressed by the situation?　　Never Rarely Sometimes Frequently Always

4. Has your own health suffered at all?　　Not at all A little Moderately Quite a lot Considerably

5. Do you worry about accidents happening to ......?　　Not at all A little Moderately Quite a lot Considerably

6. Do you ever feel that there will be no end to the problem?　　Never Rarely Sometimes Frequently Always

7. Do you find it difficult to get away on holiday?　　Not at all A little Moderately Quite a lot Considerably

8. How much has your social life been affected?　　Not at all A little Moderately Quite a lot Considerably

9. How much has the household routine been upset?　　Not at all A little Moderately Quite a lot Considerably

10. Is your sleep interrupted by .....?　　Never Rarely Sometimes Frequently Always

11. Has your standard of living been reduced?　　Not at all A little Moderately Quite a lot Considerably

12. Are you at all prevented from having visitors?　　Not at all A little Moderately Quite a lot Considerably

13. Do you ever get cross and angry with ....?　　Never Rarely Sometimes Frequently Always

14. Do you ever feel frustrated at times with ....?　　Not at all A little Moderately Quite a lot Considerably

Appendix 12

Significant Other Questionnaire

Please list below up to four people who are important to you. For each person please circle a number from 1 to 7 to show how well he or she provides the type of help that is listed. The second part of each question asks you to rate how you would like things to be in an ideal world. As before please put a circle around one number between 1 and 7 to show what the rating is.

Person 1..............................*Never*   *Sometimes*   *Always*

1 a) Can you trust, talk to frankly and share
your feelings with this person?   1   2   3   4   5   6   7

b) What rating would your ideal be?   1   2   3   4   5   6   7

2 a) Can you lean on and turn to this
person in times of difficulty?   1   2   3   4   5   6   7

b) What rating would your ideal be?   1   2   3   4   5   6   7

3 a) Does he/she give you practical
help?   1   2   3   4   5   6   7

b) What rating would your ideal be?   1   2   3   4   5   6   7

4 a) Can you spend time with him/her
socially?   1   2   3   4   5   6   7

b) What rating would your ideal be?   1   2   3   4   5   6   7

Person 2.......................... *Never*   *Sometimes*   *Always*

1 a) Can you trust, talk to frankly and
share your feelings with this person?   1   2   3   4   5   6   7

b) What rating would your ideal be?   1   2   3   4   5   6   7

2 a) Can you lean on and turn to this
person in times of difficulty?   1   2   3   4   5   6   7

b) What rating would your ideal be?   1   2   3   4   5   6   7

3 a) Does he/she give you practical
help?   1   2   3   4   5   6   7

b) What rating would your ideal be?   1   2   3   4   5   6   7

4 a) Can you spend time with him/her
socially?   1   2   3   4   5   6   7

b) What rating would your ideal be?   1   2   3   4   5   6   7

Appendix 12 (continued)

Person 3............................ 1 a) Can you trust, talk to frankly and share your feelings with this person?	*Never*		*Sometimes*			*Always*	
	1	2	3	4	5	6	7
b) What rating would your ideal be?	1	2	3	4	5	6	7
2 a) Can you lean on and turn to this person in times of difficulty?	1	2	3	4	5	6	7
b) What rating would your ideal be?	1	2	3	4	5	6	7
3 a) Does he/she give you practical help?	1	2	3	4	5	6	7
b) What rating would your ideal be?	1	2	3	4	5	6	7
4 a) Can you spend time with him/her socially?	1	2	3	4	5	6	7
b) What rating would your ideal be?	1	2	3	4	5	6	7

Person 4............................ 1 a) Can you trust, talk to frankly and share your feelings with this person?	*Never*		*Sometimes*			*Always*	
	1	2	3	4	5	6	7
b) What rating would your ideal be?	1	2	3	4	5	6	7
2 a) Can you lean on and turn to this person in times of difficulty?	1	2	3	4	5	6	7
b) What rating would your ideal be?	1	2	3	4	5	6	7
3 a) Does he/she give you practical help?	1	2	3	4	5	6	7
b) What rating would your ideal be?	1	2	3	4	5	6	7
4 a) Can you spend time with him/her socially?	1	2	3	4	5	6	7
b) What rating would your ideal be?	1	2	3	4	5	6	7

PLEASE CIRCLE ONE NUMBER ONLY FOR EACH QUESTION

Appendix 13

State Trait Inventory Questionnaire

A number of statements which people have used to describe themselves are given below. Read each statement and then circle the appropriate number to indicate how you feel *right now*, that is, *at this moment.* There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

	Not at all	Somewhat	Moderately	Very Much
1. I feel calm	1	2	3	4
2. I feel secure	1	2	3	4
3. I am tense	1	2	3	4
4. I feel strained	1	2	3	4
5. I feel at ease	1	2	3	4
6. I feel upset	1	2	3	4
7. I am presently worrying over possible misfortunes	1	2	3	4
8. I feel satisfied	1	2	3	4
9. I feel frightened	1	2	3	4
10. I feel comfortable	1	2	3	4
11. I feel self-confident	1	2	3	4
12. I feel nervous	1	2	3	4
13. I am jittery	1	2	3	4
14. I feel indecisive	1	2	3	4
15. I am relaxed	1	2	3	4
16. I feel content	1	2	3	4
17. I am worried	1	2	3	4
18. I feel confused	1	2	3	4
19. I feel steady	1	2	3	4

Appendix 13 (continued)

	Not at all	Somewhat	Moderately	Very Much
20. I feel pleasant	1	2	3	4

Appendix 13 (continued)

A number of statements which people have used to describe themselves are given below. Read each statement and then circle the appropriate number to indicate how you *generally* feel. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe how you generally feel.

	Almost never	Sometimes	Often	Almost Always
21. I feel pleasant	1	2	3	4
22. I feel nervous and restless	1	2	3	4
23. I feel satisfied with myself	1	2	3	4
24. I wish I could be as happy as others seem to be	1	2	3	4
25. I feel like a failure	1	2	3	4
26. I feel rested	1	2	3	4
27. I am "cool calm and collected"	1	2	3	4
28. I feel that difficulties are piling up so that I can not overcome them	1	2	3	4
29. I worry too much over something that really doesn't matter	1	2	3	4
30. I am happy	1	2	3	4
31. I have disturbing thoughts	1	2	3	4
32. I lack self-confidence	1	2	3	4
33. I feel secure	1	2	3	4
34. I make decisions easily	1	2	3	4
35. I feel inadequate	1	2	3	4
36. I am content	1	2	3	4
37. Some unimportant thought runs through my mind and bothers me	1	2	3	4

Appendix 13 (continued)

	Almost never	Sometimes	Often	Almost Always
38. I take disappointments so keenly that I can't put them out of my mind	1	2	3	4
39. I am a steady person	1	2	3	4
40. I get in a state of tension or turmoil as I think over my recent concerns and interests	1	2	3	4

Appendix 14
Health Professional Information Sheet
Family Caregivers: Understanding Their Role, Needs and Sources of Help.

My name is Paula Smith and I am a District Enrolled Nurse undertaking postgraduate research at the University of Southampton, where I have been funded to carry out a three year project into the needs and perceptions of family caregivers in palliative care. Whilst changes within the NHS and palliative care settings have placed the emphasis of care on the family caregiver, little is understood about the way these carers perceive their role, needs or the type of support available to them. The purpose of this study is therefore to attempt to elicit the perception of family caregivers in a palliative care setting.

Method
I would like to interview 10 family/friend caregivers of the terminally ill, who are caring for someone with advanced cancer. The participants will be asked to take part in a series of four interviews over a period of three months. Each interview will be audio recorded and will discuss the experiences of the carer in relation to the caring role they are involved in. Furthermore, the participants will be asked to answer a few short questionnaires. In all the interview and questionnaire should take about 45 minutes to one hour to complete.

Any information provided will be confidential, and the individual will not be named or identified in any future reporting of the study. Participants will be free to withdraw from the study at any time without explanation. The audio tapes will be kept in a locked cupboard, and will be deleted on successful completion of the project, of which this study is a part

Your Help
I am seeking your help to identify the family/friend carers of people with advanced cancer. Once these people have been identified I would be grateful if you could explain a little about what I am proposing to do, give them a copy of the information sheet and ask them if they would be willing to participate. I will then contact you at an agreed time and date to collect the names and addresses of any carers who agree to take part. I will then arrange to meet the carers at a convenient time and place.

Identification of potential carers for the study
1. Carers should be a family member or friend who has been identified as the main informal carer of someone with advanced cancer.
2. The ill person should have a predicted life expectancy of six months or less.
3. They should be willing to take part in the study
4. They should be able to use and understand English.

If you would like more information or have any questions, I would be happy to answer them and can be contacted direct on Tel. 01703 595421, or at the Health Research Unit, School of Occupational Therapy and Physiotherapy, University of Southampton, SO17 1BJ, Tel. 01703 594791.

Thank you for your help with this research

Appendix 15
Macmillan/Home care participant detail referral sheet

Name of Family Caregiver	Address and Telephone number of Caregiver	Name and address of Patient	Relationship of Patient and Carer	Patient's Diagnosis	Name and address of Patient's GP.

Appendix 16
Thank You Letter to Family Caregivers

Name
Address

30th November 1998

Dear

I am writing to thank you for your participation in the study exploring the views of family members who are looking after someone who is unwell. I was extremely grateful for the way you shared your experiences of caring, as this has helped me to understand the family's position in this situation in more detail.

As you know I hope that eventually the information you and other family members provide can be used to ensure that palliative care services in the future are as relevant for both the patient and the person who is looking after them as possible. Should you have any queries about the study I shall be happy to answer them, and can be contacted at the above address.

Once again, many thanks for your assistance with this study, and my best wishes to you both.

Yours sincerely

Miss Paula Smith
Postgraduate Researcher

Appendix 17

Example of Coding Theme the Patient's Story

The Patients Story

Superordinate	Subordinate	Subtype	Code
Diagnosis	Time	Diagnosis, Prior to,	Time
		Treatment	
		Recurrence	
		Prognosis	
		Medical history	
	Emotional Reaction		Reaction
	Tests		Tests
Symptoms	Symptoms	Pain, Diarrhoea	Symptoms
		Infections, Sickness	
		Sleepiness	
		Anorexia	
	States	Poorly, Sleepiness	States
		Weakness	
	Changes	Progress	Changes
		Deterioration	
	Reactions		Reactions
Treatment	Medical	Tablets, Patches	Medical
		Stem Cell, MST	
		Chemotherapy	
		Radiotherapy 2	
		Oral diamorphine	
	Strategies	Going out	Strategies
		Pampering	
		Acceptance	
		Counselling	
		Waiting, Denial 1	
	Pragmatic	Wheelchair	Pragmatic
		Hospice	
	Discourse	Technical Terms	Discourse
		Explanation	
Life Changes	Job	Time Off 1	Job
		Finance	
	Family	Children	Family
	Issues	Money	Money
	Wishes	Patient's wishes	Wishes

Appendix 18
Master Code List from Family Caregiver Study

Perception of Role

Superordinate	Subordinate	Subtype	Code
Action Taken	Physical care of patient	Medication, Shop	Physical Care
		Cook, Food, Drink	
		Toileting,	
		Housework	
	Emotional care of patient	Emotion	Emotional Care
		Jolly Along	
	Care for Self		Self Care
	Putting Patient first		Patient First
Relationship to Patient	Kinship		Kinship
	Friendship		Friendship
	Obligation/Duty		Duty
Definition of 'carer'	Label	Professional/ Lay	Definition
		Identity/Non	
	Responsibility	Responsibility	Responsibility
		Advocacy	
		Supervisory	
		Monitoring	
	Emotional Maintenance	Time Spent	Maintenance
		Being With	
		Caring	
		Normality	
	Doing For	Help Out	Doing For
		Doing For	
		Household Cooking	
Roles	Relationship to Others	Back up other's	Relationships
		Outside Work 1	
		Family relationships	
	Boundaries to role	Change	Boundaries
		Things won't/can't do	
		Nursing/medical	

Appendix 18 (continued)
Master Code List from Family Caregiver Study

The Patients Story

Superordinate	Subordinate	Subtype	Code
Diagnosis	Time	Diagnosis, Prior to, Treatment	Time
		Recurrence	
		Prognosis	
		Medical history	
	Emotional Reaction		Reaction
	Tests		Tests
Symptoms	Symptoms	Pain, Diarrhoea	Symptoms
		Infections, Sickness	
		Sleepiness	
		Anorexia	
	States	Poorly, Sleepiness	States
		Weakness	
	Changes	Progress	Changes
		Deterioration	
	Reactions		Reactions
Treatment	Medical	Tablets, Patches	Medical
		Stem Cell, MST	
		Chemotherapy	
		Radiotherapy 2	
		Oral diamorphine	
	Strategies	Going out	Strategies
		Pampering	
		Acceptance	
		Counselling	
		Waiting, Denial 1	
	Pragmatic	Wheelchair	Pragmatic
		Hospice	
	Discourse	Technical Terms	Discourse
		Explanation	
Life Changes	Job	Time Off 1	Job
		Finance	
	Family	Children	Family
	Issues	Money	Money
	Wishes	Patient's wishes	Wishes

Appendix 18 (continued)
Master Code List from Family Caregiver Study

Family Caregiver Story

Superordinate	Subordinate	Subtype	Code
Own Health	Physical	OK, Medical, Tired	Physical
	Mood	Resignation, Despondent	Mood
		Denial, How End, Hope	
		Brave Face, Upset, Guilt	
		Disruption, Difficulty	
		Expectation, Regrets	
Coping	Practical Tasks	Baby Alarm, See GP	Practical Tasks
Strategies	Doing Other Things	Distraction, Talking, Pub	Coping Methods
		Out, Distancing, Gardening	
		Pottering about, DIY	
Identification with Patient	Changes Over Time	No change, Worse, Better	Changes Over Time
		Outings, Visiting 2,	
		Unable to get out, Routine	
		Satisfaction, Unhappy	
		Content, Dogs	
	Information	Being Informed	Information
	Identification with Patient	Identity Patient	Identification
	Preserving Self	Meet HPs, Own Identity	Preserving Self
Role Changes	Work 2	Salary	Work
		Change Hours	
		Enjoy	
		Time Off 2	
	Social	Travel	Social
	Household	House, Garden, Travel	Household
	Needs	Debt Counselling	Needs
		More Help	
	Future	Job, Holiday	

Appendix 18 (continued)
Master Code List from Family Caregiver Study

Relationship to Health Professionals

Superordinate	Subordinate	Subtype	Code
Health Professional Involved	**Terms used**	They, Health Professional	**Terms**
	Hospice	Mac Nurse, Marie Curie	**Hospice**
		Hospice Dr, Day Care	
		Psychiatric Nurse	
	Community	District Nurse, GP	**Community**
		Pharmacist, Home Care	
		In Patient Care, Hospice	
		Social Worker	
		Citizen Advice	
	Hospital	General, Oncology	**Hospital**
		Radiotherapy 1	
Advice	**Informational**	Information, Teaching	**Informational**
		Advice	
	Useful	Teaching, Practical,	**Useful**
		Break (day), Benefits	
		Respite (overnight)	
		Liaison with others	
		Nursing care, Transport 2	
	Treatment	Treatment	**Treatment**
Support	**Emotional**	Reassurance, Talking	**Emotional**
		Keeping an eye, Future	
	Availability	When to contact Dr	**Availability**
		Access more help	
		Not Available, Joint	
		Frequency, Delay Access	
		Availability, Phoning	
	Relationship With Health Professional	Liaison	**Relationship**
		Re. Carer, Re. Patient	
		Team, Trust, Character	
		Praise, Avoiding, Joint	

Appendix 18 (continued)
Master Code List from Family Caregiver Study
Other Sources of Support

Superordinate	Subordinate	Subtype	Code
Other Support	**Neighbour**		**Neighbour**
	Relations		**Relations**
	Friends		**Friend**
Type of Support Offered	**Practical**	Shopping, Trips, Visiting	**Practical**
		Transport, Gardening	
		Practical 2, Break	
		Sitting with patient	
	Psychological	Emotional, Avoid	**Psychological**
		Past Experience	
	Communication	Talk about things	**Communication**
		Past Experience, Situation	
		Self Help Groups Enquiring, Day to Day	
Help Requested	**Available**	Volunteered, Not available	**Available**
	Requests	Unwilling to ask, Help Accepted	**Requests**
	Feelings about	Satisfaction	**Feelings about**
		Thanks for help	

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