Sheffield Hallam University

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Family caregivers' experiences in the palliative care context:

A longitudinal, qualitative study

Joan-Anne Dunsmore-Dawson BA (Hons) MScRes MBPS

A Doctoral Project Report submitted in partial fulfilment of the requirements of Sheffield Hallam University for the degree of Doctor of Philosophy

November 2020

CANDIDATE DECLARATION

I hereby declare that:

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2. None of the material contained in the thesis has been used in any other submission for an academic award.
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Name	Joan-Anne Dunsmore-Dawson
Award	Doctor of Philosophy
Date of Submission	10th November 2020
Faculty	Health and Wellbeing Research Institute-Postgrad Research Centre
Director(s) of Studies	Dr Julie Skilbeck

Abstract

Caregivers who provide care patients for a family member with terminal illness towards the end of their lives play a key role in the UK health and social care system. This research project aimed to explore the longitudinal experiences of nine family caregivers who were providing care for a family member diagnosed with a terminal illness.

A longitudinal qualitative cross-sectional research design drawing on the principles of phenomenology was adopted to explore how and in what ways the family caregivers' experiences are similar or different to the patients during the time they provide care for the patient. This also considered how the caregivers' interactions with palliative care services impacted of their experience.

Nine family caregivers were recruited from three separate areas of a twelve bedded hospice in Yorkshire. Six participants were interviewed three times and three participants were interviewed twice over a period of one year. Interviews were conducted at different points in each family caregivers' journey which were identified by them as points which had marked a shift in their perceptions and gave shape to their experience of the phenomena.

In total, 24 interviews were conducted which produced a large amount of data. All first second and third interviews were iteratively analysed as a series of stand-alone studies using thematic analysis. Themes within the accounts of individual family caregivers revealed patterns of change and stability shedding light on their unfolding longitudinal experiences.

The study offers a number or contributions which add to the body of knowledge relating to family caregivers' experiences. These pertained to how the practical and emotional support offered to family caregivers across time plays a key role in helping them to adapt to the fluctuating needs of the patient throughout their illness. The crucial role played by palliative care services was seen to be important in their being able to cope with the demands of providing care by helping them to adapt their caring styles according to the fluctuating needs of the patient throughout their illness. An essential element of this support was identified as having consistent and reliable access to support from professionals in palliative care services over the course of the caregiving journey.

Inequality in terms of access to financial resources by individual caregivers presented a barrier to the family caregivers which increased the amount of caregiver burden they experienced. Those who are affected by a lack of access to appropriate funding are at greater risk of deterioration in their physical and psychological wellbeing. Support for family caregivers could be strengthened by being delivered according to the needs of the family caregiver over the time they provide care. Tools which assess the family caregivers' needs should take into account the unique demands of the psychosocial context in which caregiving occurs.

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Chapter 1 Introduction

1.1 My experience and motivation for the study topic

My early career as an ODP was spent in clinical practice where I encountered patients undergoing a range of diagnostic and surgical procedures. Ordinarily my contact with patient's ended when their procedure was over. This meant I this meant, I gained a snapshot of the patient's illness experience and often thought about them long after they had been discharged from the hospital. On reflection, I see this was the beginning of my desire to know more about the lived world of people living with ill health.

My interest in the experiences of understanding more about the experiences of people who provide care for patients with ill health came later. This happened when an acquaintance asked me for a lift to the hospital when he had an appointment. I was aware Daniel had been having tests for a long-standing medical condition. However, I had no knowledge of the stage of his illness nor of how ill he had been. As we neared the hospital, he seemed agitated as asked me to accompany hm to his consultation so I could 'translate' the results of his recent tests. I agreed, and in the consultation, Daniel was told that he had incurable oesophageal cancer. He was offered no cure for his illness but instead, was told he would be eligible for palliative rather than curative treatment. He was asked to name someone in his medical notes as his next of kin and having been estranged from his family for over twenty years, looked to me with a question on his face. In that moment, I agreed and thus became his official and documented primary caregiver until his death four months later. I have since reflected on that consultation and the heedless way this important decision was made.

Through being Daniel's documented caregiver, I encountered palliative care services. Later, I volunteered to work as receptionist, in a local hospice. Here, I welcomed the patients' friends and family members as they arrived to visit the inpatient unit. It became apparent to me that there were distinct differences in how various individuals reacted to the patients' admission to palliative care services and I would often chat to them as we walked while trying to gauge their feelings about palliative care.

 I noted in my personal journal at the time

The patient's friends and families appear to respond to the news of the patient's admission differently. It seems their responses vary according to their individual views of what palliative care is and what their hopes and expectations of the patient's illness are from this point.

I later became a bereavement support worker for individuals coming to terms with the impact of their relatives' illness. I recall being baffled at how bereavement support was offered to the patient's caregiver at specific points in their patient's illness. For example, the carers were referred to bereavement support when the patient was admitted to hospice care and when the patient was deemed to be near death.

Yet, my experiences suggested that these were two of many significant events which impacted on caregivers and underpinned their individual experiences of becoming and being a caregiver. My interactions with caregiver's thus far had led me to believe individual responses tended to vary in line with the practical, emotional and logistical impact of illness on their lives.

Although loss was a central theme to many of the carers' experiences, there were distinct differences in how they each 'storied' their experience, which suggested that factors other than the course of physiological illness deterioration determined the experiences of individual caregivers'.

These experiences gave rise to several questions, and on reflection, I realise that I had held certain assumptions relating to how carers take on the role and responsibilities of becoming a caregiver and how their support needs may or may not unfold along the same illness focussed trajectory as the patient's illness. These are the questions which have shaped my career as a researcher.

1.2 Who is a carer?

The term 'carer' is one that is often used to identify the person providing care in the patients' medical records or nursing notes. Though it is not a term given exclusively to family members, family caregivers are the primary source of support for many patients receiving palliative care (Sepulveda et al., 2002). Research has shown that the experience of caregivers is fundamentally related to the experiences of the patient (Wittenberg-Lyles, Demiris, Oliver, Parker and Burt, 2011). Throughout this research I use the term 'caregiver' to refer to the

participants in the research who were providing care and other caregivers I met who were providing care to a patient with palliative care needs. Many who assume this responsibility do not identify with the title of carer especially when they are caring for a friend or family member (Morris and Thomas, 2001; Hardy, 2012).

Within the context of palliative care, family caregivers or carers are defined as a relative, friend or partner who has a significant relationship with the patient and who provides physical, psychological and social support for them throughout their illness (Thomas, Hudson, Trauer, Remedios and Clarke, 2014). The Care Act (Penhale, Brammer, Morgan, Kinston and Preston-Shoot, 2014) describes a carer as:

> *Someone who helps another person, usually a relative or friend, in their day-to-day life. This is not the same as someone who provides care professionally, or through a voluntary organisation.*

The Department of Health document; *Recognised, Valued and Supported: Next Steps for the Carer's Strategy (2010)* aims to support those with caring responsibilities by encouraging them to recognise the important role they play in the caring process. The strategy also encourages involvement from the patient's and caregiver's wider family members and social groups which would help to minimise the amount of strain on individual caregivers. Engaging with others within and without the caring environment also helps the caregiver to establish and maintain important social networks.

Many do not acknowledge their role or value the contribution they make because they are protective of their role as spouse or family member (Morris and Thomas, 2001). They are often reluctant to identify with a term that infers they are caring out of a sense of responsibility or duty (Hardy, 2012). More frequently, those who provide substantial care for the patient will use familial labels to identify their role, for example wife, husband or partner. This is important to them because for some, the responsibility for caring emerges in an active and informed way (Hardy, 2012) out of a sense of commitment (or duty) to the patient, and because of their relationship rather than being something they feel obliged to do. This is especially true when providing care for a spouse at home, where acts of caring are expressed in countless ways and often beyond the level of consciousness. This study focusses on the family members

of patients who were providing care for a patient referred to the services of the Specialist Palliative Care Team.

1.3 What is palliative care?

The word palliative originates from the Latin word palliare meaning 'to cloak' which describes an approach to nursing that differs from curative care in its specific focus on the quality rather than the preservation of life. For clarification purposes, palliative care is a branch of medicine which differs from curative medicine in its intent. Curative care is oriented towards treatment where the medical approach to healthcare relies on scientific and analytical knowledge. In curative medicine, treatment decisions are based on the diagnosis of the patient's symptoms and the elimination or interference of the cause of illness. Within a curative approach medical staff would not automatically factor in the patient's or caregiver's psychological or spiritual health. Palliative care is offered to patients who have a disease or illness which is not suitable for or has not responded to a curative approach. In palliative care, no action is taken that will slow down or speed up the patient's death. However, treatment may be offered which would restore the patient's functional condition whenever possible. Palliative care, therefore, is concerned with the relief and pain of patient suffering including the pain and suffering of their friends and wider family members (Wittenberg-Lyles et al., 2011).

There remains a lack of consensus about the definitions of primary and palliative care (Hardy, 2012; Fallon and Smyth, 2008; Riley and Ross, 2005) with different terms used to describe the various stages of illness and care provision. The *2008 End of Life Strategy* (DH, 2010a) outlined the terminal nature of palliative care by defining its offer as:

> *Support for the patients, friends and families of individuals affected by advanced, progressive and incurable illness to help them to live as well as possible until they die.*

In 2007, the World Health Organisation (WHO) issued their global definition of palliative care which included the physical, spiritual and psychological symptoms of chronic illness. In recognition that illness may became more difficult to manage as the patient's illness progressed, WHO stressed the need for palliative care to be applied as soon as possible in the patient's illness rather than when the patient's condition becomes chronic or terminal.

1.4 The referral pathway into palliative care

Referral to palliative care is not always associated with a move from one type of care to another, though it does represent a critical juncture in care provision which forces caregivers to appraise care objectives. This has been hypothesised as a crossroads in the experience of caregivers (Schulman-Green et al., 2004; Sutherland, 2009).

The point at which patients are referred may be triggered by a number of factors such as medication review for the patient, respite care, or in today's changing landscape of surgical procedures, palliative care can be offered in conjunction with surgery for symptom control. Schulman-Green (2004) observed the timing of admission to palliative care services as an important factor in determining the patient's and caregiver's experiences and notes that late referral to services has been associated with a negative effect on patients and family members. For those caring for an individual at home, this transfer of care to a different setting forces a shift in the emphasis from caring for an ill person to supporting a dying person. This change of focus is likely to be met with an array of responses (Schulman-Green 2004). Certain factors can blur the lines for patients and caregivers between when treatment is curative and when there is little or no hope of a cure, but care or treatment is continued, nonetheless. Some of the reasons for the uncertainty have been highlighted as a lack of consistent clarity in conversations between clinicians and caring dyads (Fadul, Elsayem, Palmer, , Del Fabbro, Swint and Li, 2009) as well as the carer's own fluctuation in levels of acceptance that the patient may be reaching the end of their life (Schulman-Green, 2004). Aside from the caregivers' levels of acceptance and despite a drive to 'normalise' death, it is still common for caregivers to request that medical staff do not share what they consider to be negative information or tell the patient when the end of their life is imminent. It may be that they prefer to draw on their knowledge of the patient and tell them in a way that will lessen the impact of the news, or it may be that they do not wish the patient to know. There is a powerful death-denying ethos in many societies within the UK (Noble, Kelly and Hudson, 2013).

The meanings individuals attach to the introduction to specialist palliative care services can vary widely and may depend on their experience of palliative care in the past. For many family members, the referral of a loved one to palliative

care forces them to confront the impending death of the patient. This juncture in the caring process is acknowledged by researchers as a distinct period in the caregiver's journey (Lowson, Hanratty, Holmes, Addington-Hall, Grande and Payne, 2013; Ewing and Grande, 2013) where both the caregiver and patient must adjust to significant illness related changes which call for a revision of treatment options and priorities.

1.5 Providing care at home

The End-of-Life Care Strategy (2010) and the *Palliative Care Funding Review (*Hughes-Hallett, Craft, Davies, MacKay, Nielsson, 2011*)* are key documents which take into account the increase in the demand for home-based carers. The kind of care provided by the caregiver at home can often be protracted and complex, involving the learning of new skills and responding to the changing condition of the patient. The fluctuating nature of the patient's condition and providing care around the clock places a significant strain on caregivers who provide care in their home, often without a break and without the level of emotional detachment offered to professionally trained caregivers. The presence of medicines and medical equipment in the home can change the way occupants experience their lived space, restricting their movements and disrupting the general feeling of 'homeliness' many of us take for granted in our homes (Sarbin, 2005).

Caregivers may not anticipate at the beginning of illness that the patient's functional condition will deteriorate to the point where caring would place them under practical and emotional strain. For those who use or have access to paid carers in their home, the arrival in their home of formal carers and community healthcare staff at unspecified times during the day can be disruptive to the established and familiar routine of the family home.

1.6 Caregivers in the UK

A polling report published by Carers UK (2019) points to the increase in the number of carers since 2011, suggesting there may now be as many as 8.8 million adult carers in the United Kingdom. Not all of these caregivers will be accessing Specialist Palliative Care Services though predicted demographic changes are set to result in an increase in the number of people accessing these services, as individuals live longer with more complex diseases and require increasing access to social and health care services for longer

(Gardiner, Brereton, Frey, Wilkinson-Meyers and Gott, 2014; Ewing and Grande, 2018).

Early awareness of demographic changes and the impact on healthcare was the foundation for the publication of the 1998 Department of Health White Paper, *Caring for People* (Langan, 1998). This paper highlighted the then government's plans for health service delivery by drawing attention to a likely increase in the demand for essential services. There were implications for voluntary organisations also where there was a predicted increase in the demand for volunteer services to care for vulnerable people living in the community. As a result of this paper, responsibility for vulnerable groups was effectively shifted from central government towards more informal networks of family, friends and neighbours. This transfer of 'community care' to 'care in the community' had an impact on those providing unpaid care for a family member who came under increasing amounts of strain as they cared for sick and dying relatives. In the UK, there is a governmental move towards supporting patient preferences at the end of life which includes their choice of where to die. For many, this will be in their own home (Williams and McCorkle, 2011) or a familiar place surrounded by friends and family. Whilst this move may lessen the demands on an already struggling health service in terms of bed occupancy (Robinson, Giorgi and Ekman, 2012) it is likely to result in the strain being transferred onto community and hospice services and in many instances, would impact heavily on family caregivers.

The characteristics of future caregivers is also due to be affected by demographic trends and wider changes within society. For example, the decline in birth rates in proportion to an increasingly ageing population means there will be fewer family members to provide care for elderly relatives who live longer with illnesses that would once have shortened or ended their life (Rhodes and Shaw, 1999).

Changes in retirement age mean that many people continue to work full or part time alongside caring for family members throughout illness. This could impact on the number of family caregivers who are not working and therefore available to provide care. Knighting, O'Brien, Roe, Gandy, Lloyd-Williams and Nolan, (2015) refer to the 'sandwich generation' as a growing number of people who find themselves providing care for parents as well as their own children or

grandchildren. Those who are in employment face different challenges as a Carers UK press release in April 2015 points out how almost 2 million people leave their job to care for a spouse or family member with health needs. Some caregivers are able to employ private care companies in place of family members who have work commitments (Knighting et al., 2015). However, this kind of care can be costly and employing paid caregivers may be one of many difficult financial choices' caregivers are faced with (Gardiner, Brereton, Frey, Wilkinson-Meyers and Gott (2014).

1.7 The value of caregivers to the UK economy

In 2015, the contribution made by caregivers represented a saving to the UK economy of £132 billion because they provided care for people who would otherwise be accessing NHS or social services (Robinson et al., 2012). Their contribution was recognised at policy level by *The End-of-Life Care Strategy (DOH, 2010)* which affirmed the centrality of the role and recognised that the needs of the caregiver and the needs of the patient often differ at the end of their life. The document recommends that that the caregiver's needs be individually assessed and documented by multidisciplinary teams involved in end-of-life care. The strategy also encourages involvement from wider family members and social groups who are often able to provide practical and emotional support to the caregiver, especially when professional support is more difficult to access, for example out of normal working hours (King, Bell and Thomas. 2004).

These aims mirror those of the person-centred principles of care expressed earlier by the World Health Organisation (2010) which seek to ensure caregivers are offered and have access to appropriate information and support in line with their own needs rather than the medical needs of the patient which unfold according to their particular disease progression. *The Palliative Care Funding Review (2011)* acknowledged the unique nature of interventions in supporting all caregivers. However, in this document, the caregiver's needs are classified as closely relating to distinct phases of the patient's illness (stable, unstable, deteriorating and dying). From my own observations and experience of working with caregivers, the needs of the caregiver are often closely interwoven with the deterioration of the patients' illness but there are other historical, social and cultural influences which drive the caregiver's experience

and these may impact on the kind of support they need at an individual level. Family members experience considerable disruption in their own lives because of caring which affects their physical and psychological wellbeing. Though their caring experience takes place in a medicalised environment, their own lives are not neatly compartmentalised and, in this sense, assessing their needs according to the patient's phase of illness does not take into account the inherent fluctuations in the wider sociocultural world of the family caregiver (Timmermans, 1994; Ewing and Grande, 2018).

1.8 Recognising the needs of individual caregivers

A document published by *The Department of Health, (2010*) Recognised, Valued and Supported: Next Steps for the Carers Strategy went a stage further in recognising the needs of caregivers by emphasising the importance of supporting those people with caring responsibilities by giving them greater access to tailored support which would help them to maintain their own physical and psychosocial needs during the patient's illness. This included helping to support them to stay in employment if they chose. In 2014, an independent review of the Liverpool Care Pathway for the Dying Patient (LCP) led to the publication of the document *One Chance to Get It Right (2014)*. This publication, by the Leadership Alliance for the Care of Dying People, highlights the importance of a holistic package of care for the patient, which includes the need to recognise and actively explore the individual needs of informal caregivers involved in caring for patients at the end of the patient's life.

1.9 Assessing the needs of caregivers

Since 1999, local authorities have been required to offer a carers' needs assessment to all people who provide substantial and regular care to a family member with health needs. The aim of this assessment was to determine if the person providing care was willing to continue to provide care and whether, or not they were entitled to be paid for caring.

In 2006, the government produced the Gold Standard Framework for palliative care which aims to locally organise and operationally enhance the quality of life for patients and their carers towards the last years and months of life. The framework offered a care plan to every patient and caregiver with provision to ensure the services offered meet the needs and preferences of those involved. In 2014, *The Care Act* (Penhale et al., 2014) was revised in a way which

represented an overhaul to current legislation regarding social care in England. Carers UK welcomed this adjustment to legislation which awarded unpaid caregivers the same legal rights to care as those with documented care needs. This change from the previous Care Act policy meant that in selected local authorities, only caregivers who were judged to be providing 'regular and substantial care' were entitled to have their needs assessed. However, there was no legal duty of care on behalf of local authorities to assess caregivers needs nor to provide care if assessed as needing it.

Under the 2014 act, caregivers are entitled to have their individual needs assessed by the local authority regardless of the needs of the patient. The assessment is not automatically carried out when the patients is diagnosed with chronic illness and there is no provision for self-referral for a needs assessment. Caregivers may be referred via a third party, for example a GP or a member of the patient's medical team.

The aim of the assessment is to assist carers in their caring role and enable them to continue in the role for as long as possible. The needs of carers are assessed by the local authority based on the impact the caring role has on their own physical and psychological wellbeing. Three specific conditions are considered when assessing whether the caregiver satisfies the need to be supported in their role.

Condition 1. The need for support arises out of providing 'necessary care' for an adult. 'Necessary care' is defined as support which assists the adult to carry out activities of normal daily life they would be unable to carry out without the support of the carer.

Condition 2. The carers physical or psychological health is deteriorating or at risk of deteriorating or they are unable to provide care because of one of the following reasons:

> i) The carer is unable to provide care for an adult without assistance.
>
> ii) Providing care causes the carer distress or anxiety.
>
> iii) The carer can provide care without assistance but doing so would endanger the life of the carer or the person requiring care.

Condition 3. Because of being unable to provide care, the carer's wellbeing is significantly impacted.

In this assessment, the caregiver's needs are assessed separately from the patient and the information supplied by carers helps the local authority to determine which level of support the carer and patient will be awarded. Depending on the level of support awarded (low, medium or high) carers are provided with a support plan, personal budget or direct payments as well as signposting to clear and accurate information about other sources of support. The assessment does encourage carers to look forward by enquiring about a range of circumstances which may or may not arise but which may affect their research question needs in the future. Though the assessment is carried out just once, in the event of the carer's wellbeing deteriorating to the extent that their ability to provide care is impacted, the carer themself may request a reassessment of their needs in the light of such changes. Anticipating future need can presents a problem for many carers but especially for family carers who provide round the clock care, often in their own home. Added to this, it can be especially difficult to anticipate changes in the level of demand when providing care for a palliative care patient. Patients with palliative care needs frequently experience fluctuations in illness symptoms and their condition may deteriorate rapidly, especially towards the end of their life. It may be difficult for carers to notice the impact that providing care is having on them and their own health until it is too late.

The caregiver's own ability to provide care is also likely to be impacted by a myriad of possible factors outside of the caring scenario which were already in place before the onset of the patient's illness. Such factors may include the caregiver's current and historical physical and psychological health status, the needs and demands of wider family members as well as the caregiver's financial and or employment status. The referral to palliative care may be viewed by caregivers and family members with pessimism and this has been noted as a common reason for delays in referral to palliative care services for some patients (Schulman-Green, 2004)

It can be difficult for caregivers to hand over their caring responsibilities to an organisation or service such as a hospice or specialist community palliative care services (Schulman-Green, 2004). Changes in caring focus can be difficult for caregivers to adjust to and there are certain aspects of palliative care that distinguish it from other nursing approaches. For example, this type of care is

primarily guided by patient and family priorities, by balancing the physical and psychological needs of those involved and incorporating them into an empathetic, multifaceted care package to prepare them for the task of caring (Cagle and Kovaks, 2010). This is a change for caregivers who maybe had not perceived themselves as needing care but rather as having been tasked with managing the illness situation (Molyneaux, Butchard, Simpson, and Murray (2010)

1.10 Increasing trends towards dying at home

As previously stated, the functional condition of palliative care patients is prone to fluctuations throughout their illness. Some patients remain able to care for their own needs with very little support from a caregiver for a long time before their illness progresses and the amount of input they need increases. It may not be apparent to those who are caring for them how much the amount of care they provide is increasing until it begins to impact on their own wellbeing. In the UK, there is a government move towards supporting patients to stay at home as long as possible (Williams and McCorkle, 2011). Many patients wish to be cared for in a familiar place surrounded by friends and family and this has led to an increase in the demand for home-based care with a subsequent increase in the demand on people to care for them. This is often a spouse or family member (Ashworth and Cheung, 2006). Most palliative care patients want to remain in their own homes until their death, and the caregiver is compelled to make a decision about whether they are willing or feel capable to care for them at home until they die.

1.11 Tools to address caregivers' needs

A number of evidence based tools have been developed with the aim of providing a framework to identify the direct and indirect needs and difficulties of caregivers over the course of the patients illness trajectory (Ewing, Brundle, Payne, and Grande, 2013, Aoun, Deas, Kristjanson, and Kissane, 2017; O'Brien, Jack, Kinloch, Clabburn and Knighting, 2019). Two of the tools are limited in terms of their applicability because both are designed to explore the needs of individuals caring for patients with one specific illness. (Aoun et al., 2017; O'Brien et al., 2019). Within the tools also, there is a tendency to treat caregivers as a homogeneous group. This limits the ability of the tool to measure the needs and difficulties of caregivers with different culturally driven

views and perspectives of health, illness and death (Ewing et al., 2013). A further issue identified was that implementing the tools in specific healthcare settings does require training staff to use the tool to capture the views and perspectives of individual caregivers and this has been a barrier to the tools' use. However, these tools are an improvement on the tick-box approaches to assessing caregivers' needs and difficulties which are designed around the assumption that their needs and wants of caregivers are already known (Zarit, Reever and Bach-Peterson, 1980). My own opinion is that such interventions would not be sensitive enough to capture how widely individual caregivers' needs are likely to vary.

1.12 Summary and rationale for the current study

It is widely acknowledged that different illness vary in terms of their predicted course of progression (Morris and Thomas, 2001) because their caregivers' experience is closely enmeshed with the patients', certain points in caring have been put forward as evidence of a transition for the caregiver (Schulman-Green et al., 2004; Sutherland, 2009). What current research has not considered, however, is that the caregivers' experience may not unfold along the same predictable course of the patients' illness trajectory. Though the caregivers are enmeshed in an illness experience, they are also in a constant process of adapting to influences that lie outside the illness scenario and these may impact on them in highly idiosyncratic ways. It is possible that there are multiple episodes of transition in the fluctuating course of the patient's illness (Du Benske et al., 2008; Duggleby et al., 2010).

Having highlighted the growing number of caregivers in the UK as well as the contribution they make towards supporting patients with palliative care needs, I propose to explore individual caregivers' unfolding perceptions and experiences at critical points in their caregiving journey, to provide a more in depth understanding of their experience.

The focus of this study therefore is a longitudinal qualitative study of the Family Caregivers' Experiences in the Palliative Care Context.

Chapter 2 – Literature Review

2.1 Introduction

The Introduction chapter drew attention to the unique role played by family caregivers within palliative care. Caregivers providing care for a family member with chronic or terminal illness occupy a unique position in specialised palliative care settings because of their position as both provider and recipient of care. The experience of becoming and being a caregiver brings unique challenges for family members. This is because the physical demands of providing care for a patient with palliative care needs is often extraordinarily time consuming, as well as being physically demanding. Added to this, the emotional toll of providing care with no formal training, and without the emotional detachment afforded to qualified medical staff, makes family caregivers especially vulnerable to psychological strain (Galvin, Todres and Richardson, 2005; Andrews and Seymour, 2011; Baile, Palmer, Bruera and Parker, 2011; Abma, Oeseburg, Widdershoven, Goldsteen, Verkerk, 2005; Ewing and Grande, 2018). The provision of support by a range of services is a contributory factor in supporting caregivers and helping them cope and adapt to the role. Indeed, this aspect of their experience has been seen to play a key role in whether or not they continue to provide care for the patient at home up until the time of the patients' death (Ewing and Grande, 2018).

The aim of this chapter was to provide a review of current knowledge and literature relating to the experience of being a caregiver for a family member accessing palliative care services over the course of the patients' illness. This process assisted me in identifying gaps and inconsistencies in knowledge of this area, which provided a foundation for the development of the research question, aims and objectives. In the first section, I have described the search strategy used to select the articles in this review. Following this, I have given a review of theory, research and literature underpinning the current knowledge base in relation to how the experiences of family caregivers change or stay the same over time.

2.2 Review approach

There currently exists a wide range of overlapping literature review approaches for use across the disciplines of clinical, nursing and social science research (Hawker, Payne, Kerr, Hardey and Powell, 2002). The intersecting of

boundaries across disciplines can act as a barrier for some researchers when selecting an appropriate search strategy (Grant and Booth, 2009). Health researchers are challenged with accessing the diverse and often complex healthcare literature to compile a body of theoretical evidence which gives a broad outline of the research area (Dixon-Woods, et al., 2006a).

Within this research, I aimed to choose a review which would assist me developing the aims and objectives of the study by gathering a body of research most closely relating to the experiences of caregivers who provide care for a family member throughout the course of terminal illness. In a typology of reviews, Grant and Booth (2009) identified 14 review types and methodologies which highlight the scarcity of reviews currently utilised in healthcare research. Because there were time constraints in this research, a systematic review of the literature would have been too time consuming. I therefore selected an approach to utilise elements of a systematic approach (Dixon-Woods et a., 2006; Johnson, Tod, Brummel and Collins, 2015). This provided me with a template for the synthesis of literature relevant to the topic area. The critical integrative synthesis (CIS) approach permits the combination of papers employing a wide range of methodological approaches. This was of value in this review as the subject area incorporates a wide body of literature employing both qualitative and quantitative research methodologies. According to Dixon-Woods et al., (2006a), within a CIS approach, it is possible to bring together articles from diverse methodological approaches and combine them to identify key ideas and concepts. The selected articles provided a framework for the iterative organisation and development of themes which assisted in the identification of gaps and inconsistencies in existing research and policy literature (Cronin, Ryan and Coughlan, 2008). Johnson, et al., (2015) assert that the CIS approach helps the researcher to construct a fresh appreciation of the research topic from which to explore the literature.

2.3 Methods for literature search

2.3.1 Search strategy

I aimed to identify literature from a variety of sources to locate the evidence relating to family caregivers within the context of informed debate (Hawker et al., 2002). With this in mind, I drew on principles of PICO (Booth and Fry-Smith, 2003) wherein the Population was defined as "caregivers" and the Intervention

was characterised by the exploration of their experience during the time they interact with "palliative care services". Comparing their experiences across time, I aimed for an Outcome which would uncover incidences of change or stability in the caregivers' experiences across time.

A search of Medline, PubMed, ASSIA AND CINLAH databases was carried out to identify research literature, policy documents and publications from special interest groups, as well unpublished PhD theses. For each of the databases, a combination of key terms was used to capture the experience of being a carer and providing care for a family member while interacting with palliative care services throughout the patient's illness.

2.3.2 Search terms

In the initial stages of the search, the following key terms were applied to the search.

- "Carer*, "Informal Carer*," "Lay Carer*; "Caregiver*
- "Palliative Care", "End of Life Care", "Hospice care"
- "Longitudinal", "Cross-sectional", "serial interview research design".

I used the Boolean operators 'AND', 'OR' to combine the different features of my research question and enable me to identify literature most closely relating to the topic area (Cronin et al., 2008). On closer examination, much of the literature related to studies where the terms applied in a wide variety of contexts and settings which were not relevant to the research topic. Examples of these were articles which reported the findings of monitoring the nutritional status of the patient at end of life, assessing the cognitive awareness of palliative care patients, palliative care in social care settings and providing care for an elderly relative in a nursing home at end of life.

Johnson et al., (2015) warns that a broad search of the literature is likely to uncover a variety of papers which may not be applicable to the search topic area. Added to this, a review of every paper with even a tenuous link to the study topic is not thought to be realistic (Green, Johnson and Adams, 2006). Egan, MacLean, Sweeting and Hunt (2012) assert that while it is usual to use both general and specific terms in literature reviews, a reliance on terms which are too general may increase the risk of missing important evidence. This may impact on how the researcher formulates the research question, aims and objectives.

Hawker et al., (2002) highlight how terms used across different specialities often use discipline-specific words or terminology to describe particular experiences. This can present a challenge for health researcher whose study may be positioned on the boundary between clinical or nursing research and the social sciences (Hawker et al., 2002).

To capture the terms used across the areas relevant to this research project, I searched the National Library of Medicine's controlled vocabulary thesaurus, Medical Subject Headings (MeSH) terms in the MEDLINE ®/PubMed® database. MeSH headings assisted me in identifying frequently used subject headings within journal articles and books in the life sciences. Terms identified in the initial search were searched again combined with the Boolean operators 'AND', 'OR' to merge together the different features of the research question and identify literature closely relating to this research (Cronin et al., 2008). From here, I combined the MeSH heading terms in different ways to form word groupings that closely resembled concepts fundamental to the research question, before running the search again using the following, more specific terms.

- "Carers" or "Family caregivers" to identify studies of individuals who provide care for family members who need daily one-to-one care throughout chronic illness or disease.

- "Palliative care" or "Community palliative care" or "Hospital palliative care" to identify articles relating most closely to a branch of medicine focussing on the ease and suffering of patients in the advanced and terminal phase of their illness (WHO) (2002) and promoting the quality of life for the patient and their family.

- "Longitudinal Studies" or "Prospective studies" or "cross sectional studies" to identify literature where individuals are investigated or observed with the aim of exploring how they are impacted by change over time.

These terms were applied across all electronic databases with the following inclusion and exclusion criteria to further refine the terms of the search and narrow the focus of the review (Hawker et al., 2002).

- Date of publication between 1990 and 2018 - these dates were selected because, according to Heaton (1999) the needs of caregivers began to

be recognised as playing an important part in the future of health and social policy legislation in the 1990's.

- Literature in English language only.

Added to this, I set up an alert on each database to ensure I would be informed of new research in these areas between the time of the literature search and the write-up of the thesis. Figure 1 presents the number of articles identified from a search of all four databases.

Figure 1. Data Extraction

Database	Search terms	Limits	Results
Medline	Carers OR Family caregivers AND Palliative care OR Community Palliative Care OR Hospital Palliative Care OR Hospice care AND Longitudinal studies and Prospective studies OR Cross-sectional studies.	• Published between 1990 and 2018 • English language	252
PubMed	Carers OR Family caregivers AND Palliative care OR Community Palliative Care OR Hospital Palliative Care OR Hospice care AND Longitudinal studies and Prospective studies OR Cross-sectional studies.	• Published between 1990 and 2018 • English language	1279
ASSIA	Carers OR Family caregivers AND Palliative care OR Community Palliative Care OR Hospital Palliative Care OR Hospice care AND Longitudinal studies and Prospective studies OR Cross-sectional studies.	• Published between 1990 and 2018 • English language	167
CINLAH	Carers OR Family caregivers AND Palliative care OR Community Palliative Care OR Hospital Palliative Care OR Hospice care AND Longitudinal studies and Prospective studies OR Cross-sectional studies.	• Published between 1990 and 2018 • English language	720

After completing a thorough search of electronic databases, I explored the contents of relevant online journals accessed via the University of Huddersfield and Sheffield Hallam University websites. Johnson et al., (2015) advise that limiting a search to electronic databases is unlikely to identify literature published from within all related online journals. Journals searched included Health *and Social Care in the Community: BMJ Supportive and Palliative Care, Qualitative Health Research* and *the International Journal of Palliative Medicine.* Finally, authors and citations identified in specific journal articles were also reviewed to maximise the probability that all published and unpublished

research and literature relevant to the area would be identified (Hawker at al., 2002).

After removing all duplicates, the articles were searched by title and assessed in terms of relevance to the research area. Literature which did not relate to the topic of exploring the experience of caregivers in palliative care settings was subsequently removed (Johnson, 2015). Remaining articles (n=283) were appraised according to the articles' relevance to the research area (Hawker at al., 2002). The process of appraisal is detailed in the Prisma chart (Figure 2)

Fig 2 Prisma chart

Appendix 9

PRISMA Flow Chart (adapted)
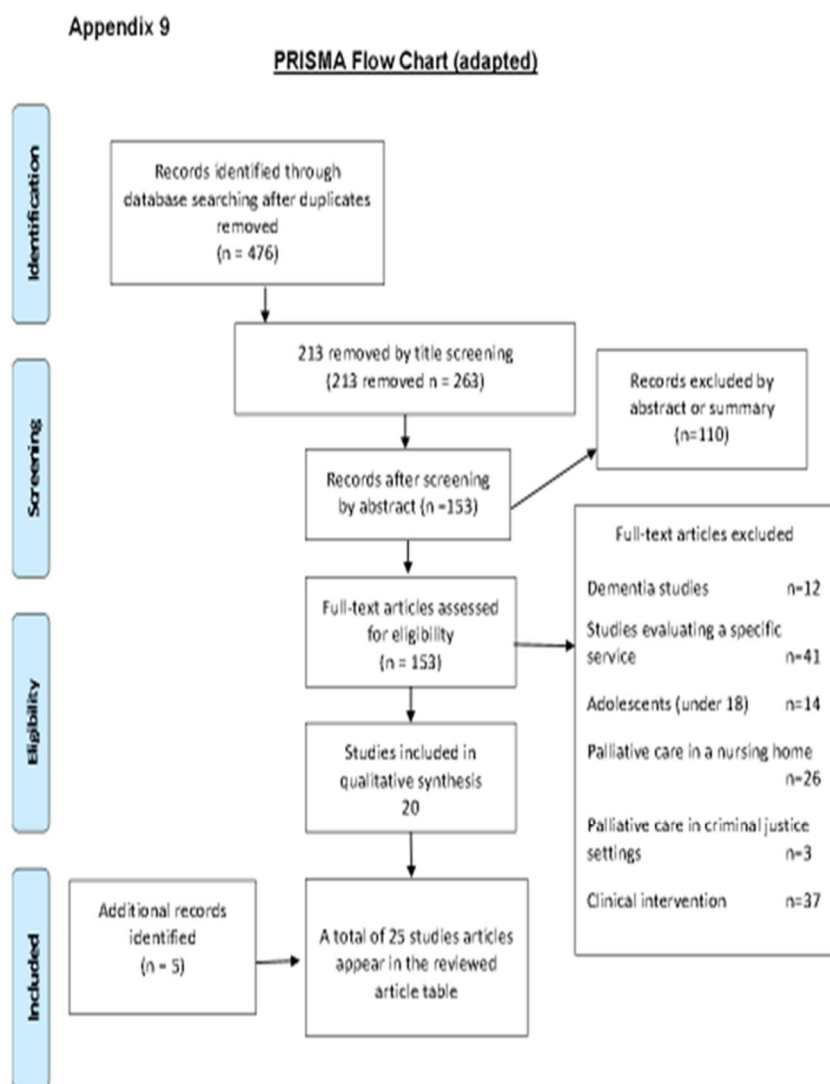
2.4 Study selection

In total, 25 articles from a range of industrialised countries were selected for a final review. Seven were from the USA and the UK, two were from Canada, one from Australia and one from Sweden. Six review articles were included in the review comprising a review of transitions in healthcare (Kralik, Visentin and van

Loon, 2006), a review of gaps and future priorities for supporting caregivers in end of life care (Grande, Stajduhar, Aoun, Toye, Funk, Addington-Hall, Payne and Todd, 2009), a scoping review of literature relating to transitions in palliative care (Marsella, 2009), an exploration of how caregivers understand transitions in palliative care (Blum and Sherman, 2010), a review of literature surrounding family caregiving (Fletcher, Miaskowski, Given and Schumacher, 2012) and a review of the self-reported unmet needs of patients and caregivers accessing home based palliative care (Ventura, Burney, Brooker, Fletcher and Ricciardelli, 2014). The remaining articles were made up of qualitative and quantitative studies and these were reviewed narratively in terms of how they made known the changing perceptions and experiences of caregivers in palliative care settings.

2.5 Review of qualitative studies

The qualitative studies reviewed included an article by Brown and Stetz (1999) who collected in depth interviews three times over four months with twenty-three family caregivers. The study used a grounded theory approach to develop a model of providing care for a patient with either AIDS or advanced cancer in the terminal phase. Schumacher et al (2006) also adopted a grounded theory approach to inform the development of a model of how family caregiving skill is developed. This study formed part of a larger study which aimed to systematically assess the skills of family caregivers for patients receiving treatment for cancer. Duggleby, Penz, Goodridge, Wilson and Liepert, Berry, Keall and Justice (2010) interviewed patients with advanced cancer, bereaved family caregivers and health care professionals to develop a theory of transitions applicable to rurally dwelling patients and their family carers. Penrod, Hupcey, Baney and Loeb (2010) interviewed former and active caregivers of patients with a range of illnesses to develop case studies describing differences in end-of-life caregiving trajectories. The aim of the study was to develop a model which would guide palliative care nurses in providing support to end of life caregivers.

Of the studies whose aim was to explore caregivers experiences across time, Donovan, Williams, Stajduhar, Brazil and Marshall (2010) conducted a longitudinal case study which aimed to capture how culture influenced the perceptions of individual family caregivers providing care at the end of life.

Hupcey, Fenstermacher, Kitko and Penrod (2010) conducted twelve interviews with twenty-four spousal caregivers over twelve to eighteen months to explore how wives' managed changes in their husbands' heart failure related illness as well as their own caring associated needs during the time they were providing care.

Cavers et al (2012) collected data from caregivers of patients with glioma over a two-to-five-year period. The study included interviewing participants before the patient's illness was diagnosed and through to the post bereavement phase of caregiving. Janze and Henrikson (2014) conducted two interviews with three out of six participants who were providing care at home for a patient with palliative care needs through not in the terminal illness phase. The study aimed to gather the caregivers' stories about how they prepare for caring against the backdrop of an awareness of the patients' death. An ethnographic approach was conducted over an eleven-month period by Hurley et al (2014) alongside single interviews with 28 caregivers and staff in a single hospice. The study uncovered points in the patient's illness where caregivers reached a crisis in their perceived ability to cope with providing care. Carduff, Finucane, Kendall, Jarvis, Harrison, Greenacre, and Murray (2014) conducted focus groups with 10 family caregivers to explore barriers to being a family caregiver. The study identified the points at which point individual carers recognised their caring status, what support was available to help them and what support was available to them to maintain their own wellbeing during the caring process.

A single interview approach was used by Schulman-Green et al (2004) to explore how participants transitioned between home and hospice care. Focus groups with bereaved caregivers who had been enrolled in a Hospice at Home programme were once conducted by Ewing and Grande (2013). These were used to develop an assessment tool which to measure the changing needs of caregivers providing care for a patient with terminal illness at home. This was followed by a mixed methods study to validate the tool by collecting data from a sell-assessment booklet which was completed by active caregivers twice over a four-week period. Lowson et al (2013) conducted single in-depth exploratory interviews with caregivers over 75 years old who were caring for patients with a range of illnesses. The study aimed to understand the patients' perspectives of the family caregiver role as they transition between different settings in the last

year of their lives. As part of a mixed methods approach, Morris and Thomas (2001) interviewed caregivers to explore wider understandings of the carers place in the cancer situation. Hurley, Strumpf, Barg and Ersek (2014) analysed observations and interviews with ten family caregivers in an ethnographic study to uncover transitions in caring triggered by an illness related crisis which left the caregiver feeling less competent to provide care for their family member.

Those qualitative studies available focussed on a particular aspect of the caregiving experience at certain points in providing care in a given context or for a patient with specific illness related needs. There was, however, a lack of longitudinal qualitative carer-focussed studies to investigate the unfolding perceptions and experiences of individual caregivers over the course of the caregiving experience.

In terms of the methodological quality of the qualitative studies, these were critically appraised using McMaster Critical Review Form – Qualitative studies (Version 2.0) (fig 3)

Fig 3 McMaster Critical Review Form – Qualitative studies (Version 2.0)

	Brown & Stetz(1999)	Morris, S. M., & Thomas (2001)	Schulman-Green et al (2004)	Schumacher et al (2006)	Duggleby et al (2010)	Donovan et al (2010)	Hupcey et al (2010)	Penrod et al (2010)	Cavers et al (2012)	Ewing and Grande (2013)	Lowson et al (203)	Carduff et al (2014)	Janze and Henrikson (2014)	Hurley et al (2014)
Study purpose														
Was the purpose and or research question stated clearly?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Literature														
Was relevant to background	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

literature provided?														
Study design														
Was a theoretical perspective identified?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Sampling														
Was the process of purposeful selection identified?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Was sample done until redundancy in data was reached	NR	NR	.✓	✓	NR	NR	✓	NR	NR	NR	NR	NR	✓	NR
Was informed consent obtained?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Data collection														
Clear and complete description of the site	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Clear and complete description of the participants	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Role of the researcher and relationship with the participants	✓	✓	✓	✓	NR	✓	✓	✓	✓	✓	✓	✓	✓	✓
Identification of assumptions and biases of the researcher?	NR	NR	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

Procedural rigor was used in data collection strategies	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Data analysis														
Data analyses was inductive	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Findings were consistent with and reflective of data?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Decision trail developed?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Process of analysing the data was described adequately?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Did a meaningful picture of the phenomena under study emerge?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Overall rigour														
Was there evidence of the four components of trustworthiness?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Credibility	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Transferability	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Dependability	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Confirmability	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	

Study conclusions and implications														
Conclusions were appropriate given the findings	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	
The findings contributed to theory development and future practice or research	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	

2.6 Review of quantitative studies

In a longitudinal quantitative study, Burns, Broom, Smith, Dear and Craft (2007) issued individual questionnaires to 136 carers and patient dyads to explore their paired responses and evaluate where their understandings of palliative treatment and goals were similar or different. While DuBenske, Wen, Gustafson, Guarnaccia, Cleary, Dinauer and Mctavish (2008) invited 182 current or former caregivers to complete a checklist of their needs to uncover how their needs differed at the time of the patient's treatment, end of life and post-patient death period. Individual interviews using survey methods were used in a study by Burns, Abernethy, Dal Grande and Currow(2013). Participant responses were used as evidence for identifying the number of invisible caregivers involved in providing care for a patient at the end of life. A study to validate the Carer Support Needs Assessment Tool (CSNAT) was conducted by Ewing, Brundle, Payne, and Grande (2013). This involved issuing an evidence-based intervention tool to 225 adult carers of patients accessing palliative care services. Participants were surveyed using a self-completed questionnaire at baseline and again four weeks later. This measured the carers evaluations of their own wellbeing, stress levels, their positive or negative appraisals and their preparedness to continue caring. The methodological value of the quantitative studies was critically appraised using the McMaster Critical review form – Quantitative studies * (Fig 4)

Fig. 4 McMaster Critical review form – Quantitative studies *

	Burns et al (2007)	DuBenske et al (2008)	Burns et al (2013)	Ewing et al (2013)
Study Purpose				
Was the purpose clearly stated?	✓	✓	✓	✓
Literature				
Was relevant background literature reviewed?	✓	✓	✓	✓
Sample				
Was the sample described in detail?	✓	✓	✓	✓
Was the sample justified?	✓	✓	✓	✓
Outcomes				
Were the outcome measures reliable?	✓	✓	✓	✓
Were the outcome measures valid	✓	✓	✓	✓
Intervention				
Intervention described in detail?	✓	✓	✓	✓
Contamination was avoided	NA	NA	NA	NA
Co-intervention was avoided	NA	NA	NA	NA
Results				
Results are reported in terms of statistical significance?	✓	✓	✓	✓
Were the methods of analysis appropriate?	✓	✓	✓	✓
Clinical importance was significant?	✓			
Drop-out numbers reported?	NR	NR	NR	✓
Conclusions and implications				
Conclusions were appropriate given study methods and results?	✓	✓	✓	✓

*Key questions from the McMaster Critical review form – Quantitative studies have been reported. In fig 4 ✓ denotes criteria is met within the study and × denotes the criteria was not met. Abbreviations = NR = not reported and NA = not applicable

All articles were subsequently imported into RefWorks, an electronic reference management database accessed via Sheffield Hallam University. A summary of each article was detailed in RefWorks and these were synthesised in an iterative fashion by assigning themes and subthemes to the selected literature. These provided background and context for the development of this research. Articles were tagged in RefWorks under the created themes and subthemes for later ease of retrieval. Fig 5 details the reviewed articles using a quality appraisal tool adapted from Hawker et al., (2002). Data within the table is appraised in terms of the title, sample and location, methodological approach, aims, findings and recommendations

Fig 5 Table of Reviewed Articles

Year	Author and title	Sample and location	Approach	Aims	Findings
1999	**Brown, M., & Stetz, K.** The labour of caregiving: A theoretical model of caregiving during potentially fatal illness.	USA	In depth interviews with 26 family caregivers of people with AIDS or advanced cancer over a 4-month period. Constant comparative analysis was used to analyze the data.	To explore the influence that chronic and potentially fatal illness has on the caregiving process over time.	A substantive theory was developed within a core theme. The labour of caregiving comprised four phases which were, becoming a caregiver, taking care, midwifing the death, and taking the next step. The core theme encapsulates how the issues and tasks associated with caregiving vary in each phase. The role of the caregiver is to contribute to the patients' quality of life which was most evident when illness began as well as at the time of the patient's death.
2001	**Morris, S. M., & Thomas, C** The carer's place in the cancer situation: where does the carer stand in the medical setting?	UK	Mixed methods using postal questionnaires and interviews with patients and carers as well as health personnel involved in	To further understandings of what it means to be the main carer of someone with cancer and explore how	Carer involvement is a process, of 'carerhood' rather than a static phenomenon with carers adopting different positions at different times and under different circumstances. When the

| | | | cancer services at four hospitals.

Patients with a cancer diagnosis were interviewed close diagnosis, end of first treatment, first recurrence or the move to palliative care only. Caregivers were identified by the patient and interviewed once after the patients' interview. were interviewed once as a follow up after the patients' interview. | carers negotiate their place in the cancer situation, and medical setting? | carer is accepted and validated by others in the cancer scenario, taking care of their own and the patients' needs is easier. |
|---|---|---|---|---|---|
| 2004 | **Schulman-Green, D., Mccorkle, R., Curry, L., Cherlin, E., Johnson-Hurzeler, R., & Bradley, E.**

At the crossroads: Making the transition to hospice | USA | In depth interviews analysed using constant comparative analysis with 12 caregivers of different ages, genders and kinship relationships purposely selected from a hospice in Connecticut | To develop an in depth understanding of the common experiences of caregivers in transition into hospice care. To investigate factors which may result in a delay in hospice enrolment from the perspective of the caregiver. | Analysis identified three themes which pervaded the family caregiver accounts of being in transition to hospice care. (1) Caregivers' acceptance of the patients impending death (2) Challenges in negotiating the health care system across the caregiving journey. (3) Changes within patient and family dynamics. Overall, the study portrays the complexity of the transition from home to hospice care for the caregivers' perspective. Suggests these complex dynamics contribute to a delay in enrolling to hospice care. Further suggests that services can play a role in helping caregivers navigate this |

					important crossroads in their journey.
2006	**Kralik, Visentin and Loon** 'Transitions: a literature review'	Review of relevant literature to describe transition and identify the role of nurses in facilitating transition the CINAHL, Medline, Sociofile and Psychlit databases were accessed for papers published between 1994 and 2004.'	Literature review exploring how the word transition u sed in healthcare literature?	Report on the literature which explores how the term transition is used in the health literature	The word transition is used extensively demonstrating it is an important concept in the health literature. Definitions of the term varies according to the discipline in which it is used. It is generally agreed across all disciplines that transition as a term encompasses how individuals respond during a period of change. Transition takes place over time and this includes change and adaptation from a developmental, personal, social situational or environment perspective. There is renewal of the individuals' sense of self during transition which is best explored longitudinally, comparatively and or using longitudinal cross case analysis of data.
2006	**Schumacher, Beidler, Beeber and Gambino** A transactional model of family caregiving skill	USA Semi structured interviews with 44 caregiver/patie nt dyads and 63 individual caregivers.	Qualitative research used to inform model of family caregiving skill	Study aimed to develop a model of caregiving skill using a qualitative research approach.	A transactional model of family caregiving skill incorporating the concepts of illness situational demands, patterns of care caregiver responses and patient reactions. Model did not explore the social networks or how these influenced the caregivers' experience. Relationships between the caregiver and health professionals were not assimilated into the model though this area is recognised as a complex field and was said to be

					out ft he remits of this study.
2006	**Burns, Broom, Smith Dear and Craft (2007)** Fluctuation awareness of treatment goals among patients and their caregivers: a longitudinal study of a dynamic process.	Australia Questionnaire completed by 186 patients and 136 carers at baseline.	Participants were then followed through medical notes or in some cases, interviews at later dates. Questions related to perceptions of treatment intentions and paired responses evaluated for congruence	To explore individual patients and carer perceptions of treatment intentions (curative or palliative) by evaluating paired responses for similarity in each dyad	Patients and their carers have differing understandings of treatment goals and intentions. Differing awareness and appreciation of approaching death may have related to differing understandings about what palliative care is. There is a distinct medical approach to the problem and solution which may be the result of clinical encounters with oncologists who consult with carers and patients but not always together.
2008	**DuBenske, Wen, Gustafson, Guarnaccia, Cleary, Dinauer and Mctavish** Caregivers differing needs across key experiences of the advanced cancer disease trajectory	Wisconsin 159 female caregivers of patient with a variety of cancer related diagnoses	The authors developed the Cancer Caregiver Needs Checklist for this study. This was completed by 182 current or former caregivers of patients with advanced cancer. The checklist explored the differing needs of caregivers across specific key experiences within the broad stages of illness identified from a search of the literature.	Article was a response to current literature which focusses on capturing the caregivers needs across broad stages of illness trajectory. These stages are thought to be too broad assist with the targeting of interventions. Sought to examine the needs of caregivers across a range of illness-related transition experiences within the advanced cancer disease trajectory.	Acknowledges that, the more thoroughly individual carers needs are defined the more effective educational interventions will be. This study compared information needs across the treatment, end of Life, and post-patient death period. Findings indicated that information needs were significantly different during these times.

2009	**Grande, Stajduhar and Aoun Toye, Funk, Addington-Hall, Payne and Todd (2009)** Supporting lay carers in end of life care: current gaps and future priorities	Review of international research	Presents an overview of carer literature with a summary of future priorities as well as gaps and flaws in existing literature.	Evaluation of research in relation to how policy aims to support carers to provide end of life care and death at home.	There is extensive amount of research into the undesirable effects of providing care from the caregivers' perspective. However, there is a lack of empirical longitudinal research to explore how their effects can be avoided. Current carer support is dominated by 'react and repair' approach to identifying crises and interventions. Approaches must be sensitive to carers' specific concerns to improve uptake of intervention tools. Argues for an approach to supporting carers which emphasise the positive aspects of caregiving. More longitudinal research incorporating user involvement is needed.
2009	**Amanda Marsella** Exploring the literature surrounding the transition into palliative care:	Scoping review of Canadian literature.	Scoping review of 28 articles which explore transitions in palliative care	Conducted in response to an increase in the frequency of transitions in the Canadian healthcare system. Yet the subject of transitions in healthcare has been overlooked	Three key areas were identified as complicating the transition. These were the fundamental nature of transition, the timing of transitions and the lack of information .
2010	**Duggleby, Penz, Goodridge, Wilson and Liepert, Berry, Keall and Justice** The transition experience of **rural older**	Canada	Grounded theory approach, 27 open-ended interviews with older rural persons and 10 bereaved family caregivers. Four focus group	Aimed to 1, explore the transition of rural dwelling elderly people from the perspectives of the deceased patient, their	Elderly patients and their caregivers in rural locations experienced multiple complicated transitions in their environment, roles/relationships and their psychosocial health. These transitions had a

	persons with advanced cancer and their families: a grounded theory study		interviews with 12 palliative care health care professionals	caregiver and health professionals and 2, Develop a theory of transitions applicable to these patients and their families.	disruptive influence on their lives and those of their caregivers. This left them feeling distressed and uncertain. . A theory of "Navigating Unknown Waters" incorporated the process of coming to terms with their situation, connecting, and redefining normal. Timely communication, provision of information and support networks facilitated this process. The theory can provide a framework for future studies to help deliver end-of-life-care in rural populations and improve health care provides appreciation of the psychological processes involved in adapting to transitions
2010	**Blum and Sherman** **Understanding the Experience of Caregivers: A Focus on Transitions**	Current and past literature relating to patients with cancer and their caregivers.	Review of current literature	Bringing together current thinking around the trials and advantages of caring for a family member through a cancer disease trajectory.	Many caregivers are not prepared for the burden of caregiving. This can lead to self-neglect of their physical and psychological needs and often results in illness as they become overwhelmed with the role of being a caregiver. Not all carers perceive burden in the same way or to the same degree and individual support is thought to be critical to supporting them throughout the illness experience. Whilst nursing orientated the article does explore the individual nature of disease pathways when experienced by caregivers. Recommends mentoring/ coaching for patient and caregiver to help them recognise their own meanings through the

					transition process. The study is illness focussed primarily but
2010	**Donovan et al (2010)** The influence of culture on home-based family caring at end of life: A case study of Dutch reformed family caregivers.	Canada	Longitudinal study with between two and five semi-structured interviews lasting one to three hours conducted with five family caregivers during caregiving and bereavement. Interviews were conducted in the home with observation of the home caring context recorded as photographs and kept in research field notes.	Develop a better understanding of the effects of cultural factors and how this influences the caregiving experience of end-of-life caregivers within the Canadian health care system.	Highlights the importance of considering individual social and cultural influences and how these may impact of family caregivers. Three themes relevant to the group were cultural attitudes towards care, religious beliefs and coping, and culturally informed care-seeking behaviours. These themes were strongly associate with the religious and ethnic identities of the participants which strengthened their links to the community in which they lived. Personal coping strategies were based on a strong faith and perceived adequacies in terms of formal and informal support. These contributed to their success and possibly served as a buffer against caregiver burden
2010	**Hupcey et al** Achieving medical stability: Wives' experiences with heart failure	USA	Instrumental case study approach with 26 wives of husbands who were admitted to a regional cardiac centre with acute heart failure	Gather the perspectives of wives of patients with heart failure to develop an understanding of the experience of living with heart failure from the perspectives of wives.	Wives were thought to be looking ahead to what is described as the next period of medical stability. However, the medical instability of the patient resulted in emotional instability for the caregiver. There were clear differences noted around the age and economic status of the wives. Recommends improved information for caregivers with an acknowledgment that the trajectory has a dynamic element to it.

					There were financial implications and the impact of these were worse in low-income families of those with a lack of social support Findings recommend new conceptualisations of trajectories in this condition especially as life-prolonging treatments become more readily available for these patients. This will add another dimension to illness experience.
2010	**Penrod, Hupcey, Baney and Loeb** End-of-life caregiving trajectories	Not stated	Instrumental case studies using grounded theory with 46 unpaid informal caregivers (9 male and 37 female) at the end of life for patients with varying disease type across three distinct end-of-life trajectories. These were expected death mixed death and unexpected death trajectories.	To describe the differences in caregiving trajectories as portrayed by family caregivers providing end-of-life care. To understand archetypal caregiving trajectories and guide nurses in supporting caregivers towards the end of the patient's life.	. Themes uncovered were • Sensing a Disruption • Challenging Normal • Building a New Normal • Reinventing Normal. The course and duration of the phases varied according to the caregivers' response to the patient's death trajectory. Recommendations include holistic integrated pathway which is based on the caregivers' own perspectives by exploring their unfolding experiences. Specifically notes that caregiver trajectories are not driven by disease but the anticipation of death. The article acknowledges the power that nurses have in helping to make the transition a smooth one for caregivers

| 2012 | **Cavers, Hacking, Erridge, Kendall, Morris and Murray**

Social psychological and existential wellbeing in patients with glioma and their caregivers: a qualitative study | UK | Longitudinal study with patients and carers pre diagnosis, at the start of treatment, post treatment and at 6 months follow up. Qualitative interviews overed a 2-year period 5 of the interviews were conducted post bereavement. | To understand the multidimensional experience of patients with glioma as they moved between diagnosis to the terminal phase of the disease. | Social psychological and existential distress was seen prior to the patients' diagnosis. There was evidence of physical; and social decline with distress in the participants psychological and existential outlook was most acute around the time of diagnosis and after the first treatment phase. The availability of support and family resources in terms of their resilience and the emotional support hey provided determine how the course of each participants trajectory. The study sought to understand issues faced by patients and caregivers as a way of understanding what kind of support they need. Findings brought out ways that clinicians could care for patients and caregiver dealing with glioma beginning pre diagnosis. Understanding the trajectory of the patient and caregiver will assist healthcare professionals to predict their needs throughout illness and support them sensitivity throughout the patient's illness. |
| 2012 | **Fletcher, Miaskowski, Given and Schumacher**

The family caregiving experience: An expanded and updated conceptual model | Draws on international research articles. | Update and model of the family caregivers experience drawing on ideas from research within cancer family caregiving between 2000 and 2010. | Put forward a revised conceptual model of the family caregiving experience which incorporates 3 elements. | Suggest that context and trajectory have a joint impact upon the well-being of the patient and the caregiver. The conceptualisation of the dynamic relationship between these concepts had become more complex in the last two decades. There is mixed |

				Stress, Context and Trajectory.	evidence on the relationship between the patient's disease stage and the amount of strain the caregiver experiences. Suggests a conceptualisation that reflects the day to day experiences of patients and carers as opposed to biological illness markers. Recommends the use of longitudinal design in relation to family caregiving particularly as it relates to changes in caring contexts.
2013	**Burns, Broom, Smith Dear and Craft** Uncovering an invisible network of direct family caregivers at the end of life: A population study.	Australia	Individual interviews using survey method approach for a population study.	A study of the population with a view to defining individuals who provide care at the end of life and identify those who provide care within an illness scenario.	Advocates for a change in medical records which would identify the extent of the involvement of those who provide differing levels of care. Would also acknowledge caregivers and potential caregivers as part of the wider team. This would be a change from the current practice which records only one person who is identified as the main carer within the patient's medical records.
2013	**Ewing and Grande** Development of a Carer Support Needs Assessment Tool (CSNAT) for end-of-life care practice at home: A qualitative study	UK study with carers enrolled in Hospice at Home programme	Qualitative interviews with focus groups consisting of around 4-6 carers	To gather caregivers' perspectives of the support they need while providing end-of-life care at home and to develop a support needs assessment tool for use in everyday practice	Direct support needs highlighted which are thought to relate the carers own needs during the process of providing end of life care in the home. Among these were the caregivers need to contribute their own perspectives and requirements to understand the significance of clinical changes. The study provided a template for the development of a tool to

					assess caregivers changing needs.
2013	**Ewing, Brundle, Payne, and Grande** The Carer Support Needs Assessment Tool (CSNAT) for Use in Palliative and End-of-life Care at Home: A Validation Study	UK Family carers in different Home for Hospice Home care settings	Mixed methods used to validate the Carers Support Needs Assessment (CSNAT) tool Measured needs of 225 adult caregivers of patients from six U.K. Hospice Home Care services using CSNAT and qualitative feedback on the Carer Support Needs Assessment Tool (CSNAT) . Feedback sought from 10 pilot caregiver interviews a well as the professional and Caregiver Advisory Group. Caregivers were surveyed at baseline and at four-week follow-up using self-completed questionnaires.	Validation of the CSNAT as a practical tool to assess the support needs of carers are lacking. To address this gap, the CSNAT was developed as a brief evidence based tool to support assessing the carers support needs which is suitable for everyday practice.	The pilot study grouped items relating to items supporting caregivers in providing care for the patient on one page. Items relating to personal support for the caregiver themselves were grouped on a different page. Some of the caregivers disregarded support for themselves by completing "no" as a response for each item on the personal support page. Following this, all the items from both groups were mixed to encourage caregivers to consider all the support domains. The findings indicated that the CSNAT has good face, content, and criterion validity. Scores showed clear and consistent positive correlations with strain and distress and negative correlations with preparedness for caregiving and global health. There also were clear correlations with help with activities of daily living and some relationships with positive appraisals and symptom burden.

| 2013 | **Lowson, Hanratty, Holmes, Addington-Hall, Grande, Payne, and Seymour, Jane**

From Conductor to second fiddle: Older adult care recipients' perspectives on transitions in family caring at hospital admission | UK | Exploratory semi structured interviews with 15 patients and 12 patient and caregiver dyads. | To explore the meanings of family caregivers by drawing on perspectives about the impact of illness on the family relationship dynamics. | Using the metaphor of an orchestra, family carers were depicted as 'conductor' within the home settings on the basis they are a consistent and reliable presence. Added to this, the took charge of ensuring the smooth running of the patient's care and wellbeing as well as managing the home and other responsibilities such as employment. Conversely the family carer was depicted as 'second fiddle' to formal care staff in other care settings though the carer role was still maintained within the limitations and boundaries of the particular care setting. Patients viewed the support and continuity provided by family carers because they were already very familiar with their needs. |
| 2014 | **Carduff, E., Finucane, A., Kendall, M., Jarvis, A., Harrison, N., Greenacre, J., and Murray.,S(2014**) Understanding the barriers to identifying carers of people with advanced illness in primary care: triangulating three data sources | UK | Three data sources – a review of the caregiving literature; a workshop with end-of-life care researchers and a focus group with carers and health professionals. Carer focus groups were analysed with a constructionist approach. | Explore strategies for, identifying carers in primary care in particular why carers tend not to identify themselves as a carer or ask for support in the caring role. | The role of carer is often undertaken in a gradual way and frequently outside the carer's own awareness. Many identify with familial titles for example wife, sister or daughter rather than the tittle of carer. The carers position in healthcare settings is often uncertain meaning they perceive their role and where they were in the illness caring trajectory differently. This influences how, when and from where they sought help. Carers sometimes felt they did not need help at the time they were asked, yet a later crisis in the caring situation may |

					have been preventable if support systems had been put in place earlier. The article highlights how important it is to identify carers, and at the same time, empower those who remain hidden. Intervention early in the illness is needed to prevent carers from reaching crisis point where their physical and psychosocial wellbeing is affected. The needs of carers should be Health and social care professionals should be altered to recognising the needs of carer who may not identify themselves as a carer.
2014	**Janze and Henrikson** Preparing for palliative caregiving as a transition in the awareness of death: Family carer experiences.	Sweden	Interviews with 6 caregivers for patients with a cancer diagnosis who were caring at home and not in the palliative care phase when the study began Descriptive and interpretive design with qualitative content analysis	To explore family caregivers´ experiences of preparing for caregiving from the perspectives of their partners using stories	The sub themes of living with uncertainty and focussing on the present and preparing for caregiving while transitioning into new roles described the process caregivers experience against the backdrop of willingly or unwillingly preparing for the patient's death. Awareness of the patients' death was an ever-present thread which ran through the experience for caregivers.
2014	**Hurley et al** **Not quite seamless: transitions between home and inpatient hospice**	USA	Ethnographic approach using observations and interviews to explore the beliefs and practices of patients, caregivers, and a hospice interdisciplinary team in a large hospice agency	To uncover trigger points where transition was less than seamless based around the individual perceptions of the carers perceived levels of competency and ability to provide care.	Findings suggest transitions were triggered by a particular illness crisis as well as the caregiver's ability to cope with the crisis. The research suggests that future research should address the utilization of hospice services and how this meets with patient preferences to ensure that transitions meet with the

					needs and wishes of the whole family.
2015	**Gardiner, Ingleton, Gott and Ryan** Exploring the transition from curative care to palliative care: a systematic review of the literature	Review of literature within UK settings	The study identified 12 papers for review. Twelve were of cancer and one heart failure. All explored patient and carer perceptions.	Aimed to provide a systematic review of evidence relating to the transition from curative care to palliative care within UK settings	The review highlighted the importance of continuing care. From both the patient and caregiver perspective, a key component of improving the transition to palliative care experience was continuity of care. This was said to be critical in terms of how satisfied with services delivery they were. The involvement of multiple agencies had a disruptive effect on this experience for patients and caregivers There is work to be done in terms of defining the concept of transition when relating to palliative care as there may be multiple transitions in this experience. This means the transition concept does not adequately capture palliative care experience fully. Introducing palliative care early in the patients' illness trajectory would be present an ideal opportunity to incorporate a phased transition to palliative care.
2014	**Ventura, Burney, Brooker, Fletcher AND Ricciardelli**	Review of nine qualitative studies, three	Systematic review of empirical studies	Recognizing that home based palliative	The finding that patient and carer unmet needs

		quantitative studies and three mixed design.	which explore the self-reported unmet needs of caregivers of home-based palliative care.	care services are the main approach to delivering palliative care in the UK. The aim of this review was to explore and describe the literature around the topic of the unmet needs of palliative home care patients and carers	are similar has implications for interventions that could be developed to address these needs. As well as addressing patient and carer issues separately, it appears likely that programs or information sessions to help the patient and caregiver dyad could benefit them both. One of the most prominent issues experienced by patients and carers was that staff were not communicating effectively, and patients reported that doctors had little time for them and were therefore unable to listen to their concerns. Patients and carers needed to talk about the illness with someone, but this service was not offered to them. The need for assistance with household tasks, and financial support were also common areas of unmet need for patients and carers Recommends that standards of care across home based palliative care settings should adopt a more holistic focus if they are to meet the psychosocial needs of patients and carers.
	Home-based palliative care: A systematic literature review of the self-reported unmet needs of patients and carers				

2.7 Presentation of review findings

Studies of the family caregiving experience is international in scope. The aim of this review was to gain a global perspective on the family caregivers' experience of providing care for a patient accessing palliative care. For explanation purposes, the term palliative care is used in this study to refer to a treatment-oriented branch of medicine which is a subspeciality of primary care. Palliative care differs from primary or curative medicine in that, within primary

care, the approach to health care relies on scientific and analytical knowledge. In palliative care, the focus of care planning is on the preferences and values of the patients and their family, but this does not include taking any action which would impede or accelerate the patient's death. However, this may include returning the patient to their functioning capacity wherever possible.

In total, 26 articles from a range of industrialised countries were selected for a final review. Seven were from the USA and the UK, two were from Canada, one from Australia and one from Sweden. Six review articles were included in the review including a review of transitions in healthcare (Kralik, Visentin and van Loon, 2006), a review of gaps and future priorities for supporting caregivers in end of life care (Grande, Stajduhar, Aoun, Toye, Funk, Addington-Hall, Payne and Todd, 2009), a scoping review of literature relating to transitions in palliative care (Marsella, 2009), an exploration of how caregivers understand transitions in palliative care (Blum and Sherman, 2010), a review of literature surrounding family caregiving (Fletcher, Miaskowski, Given and Schumacher, 2012) and a review of the self-reported unmet needs of patients and caregivers accessing home based palliative care (Ventura, Burney, Brooker, Fletcher and Ricciardelli, 2014).

This review presents literature which most closely relates to caring for a family member with terminal illness and accessing palliative care. This involves using themes and subthemes to highlight important aspects of their experience which influences their caregiving experience. In this process, I will reflect on the strengths and weaknesses of the research and critique the methodology used. Finally, I will outline how this review assisted me in developing and framing the research question, aims and objectives. The value of capturing the caregivers' journey over time is widely acknowledged in the literature (Morris and Thomas, 2001; Shulman-Green 2004; Du Benske 2009; Hupcey, 2010; Williams and McCorkle, 2011; Cavers, Hacking, Erridge, Kendall, Morris and Murray, 2012; Penrod, Hupcey, Baney and Loeb, 2010; Ewing and Grande 2013; Hurley, Strumpf, Barg and Ersek, 2014; Janze and Henrikson 2014). Much of the research conceptualises the caregivers as being in a process of transition and yet there remains a level of uncertainty around the applicability of this model when it applies to individuals who provide care for people enmeshed within an illness scenario (Kralik et al., 2006).

Because the health of patients with terminal illness fluctuates, there are frequent changes to patient treatment plans as well as the context of their care. Patients are referred to palliative care services for a variety of reasons where their care may be delivered by individuals or teams of especially trained staff in the patients' home, in a hospital or as a day or inpatient in a hospice. Further to this, in the changing landscape of surgical procedures, many patients undergo surgical procedures for the relief of their pain or to alleviate symptoms of their illness in conjunction with their care.

2.8 Transitions in healthcare

The experience of being a caregiver for a patient with terminal illness takes place in a highly medicalised context, leading several authors to hypothesize that the patients' disease or illness trajectory will define the course of the caregivers' experience. Thus, the term 'transition' has been used to describe times or points of change in the caregivers' experience within the literature. For example, Bridges (2003) theorises points of transition as times of both circumstantial and psychological change. Kralik et al., (2006) describe transitions in health as a period of change where people redefine themselves while, at the same time, incorporating new and changing conditions into their world. The effect of health transitions upon individuals is highlighted in a study by Lowson et al., 2013) who use the metaphor of an orchestra to portray the different roles and positions taken by individual caregivers in different healthcare contexts and settings. Within this article, during the time caregivers are providing care at home they are tasked with taking responsibility for organising and coordinating the patients care, and this is compared to the role of a conductor in an orchestra. By contrast, when the patient is transferred into care in a medical setting, the caregiver's role in decision making and providing care is greatly condensed. This point in caring is conceptualised as taking on the role of 'second fiddle' in the same orchestra. This can be difficult for caregivers because this is typically a time when they are especially focussed on being the patient's advocate and striving to minimise fragmentation in their care delivery.

Historically, support for caregivers who access palliative care services has been targeted around the stages and phases categorised according to several factors. For example, specific illness trajectories such as cancer (Du Benske et

al., 2009; Blum and Sherman, 2012; Cavers et al., 2012, Carduff, 2014) or heart disease (Boyd et al., 2009). Other research aims focus on changes in illness and treatment goals (Schulman-Green, McCorkle, Curry, Cherlin, Johnson-Hurzeler and Bradley, 2004; Marsella, 2009; Blum and Sherman, 2010; Donovan et al., 2010; Fletcher et al., 2012). It could be said that illness or disease may be just one of many factors which influence the course of the caregiver's experience during the time they provide care for patients over time. The term 'transition' has been widely used to denote times of change from one state or set of circumstances, contexts or settings. A definition of health-focussed transitions has been offered by Kralik, Visentin and van Loon, (2006), who claim this period of change is a time where individuals in transition redefine themselves while adapting to new and unfamiliar circumstances. Bridges (2003) explores the concept of transition in more detail by underscoring the difference between circumstantial change and psychological transitions. According to this theory, change is considered as a shift or alteration in circumstances which may be deliberate but can also be enforced as a result off a shift in situation. By contrast, transition is described as a psychological process through which individuals incorporate change into their lives. Applied to the experiences of caregivers, the unpredictable period of change and adjustment which accompanies caring for a person with terminal health needs may encompass multiple episodes of change and transition within one experience (Du Benske et al., 2009; Duggleby, Penz, Goodridge, Wilson, Liepert, Berry, Keall and Justice, 2010). The term 'transition' has been used as a framework in which to investigate the vulnerability of people affected by changes in healthcare contexts (Shulman-Green, 2004; Marsella, 2009; Duggleby et al., 2010; Blum and Sherman, 2010; Gardiner, Ingleton, Gott and Ryan, 2015). This suggests the term is an important concept in healthcare transition literature. In the next section, I will explore some of the ideas which underpin the family caregivers' experience of becoming and being a caregiver.

2.9 Models of caregiving

It is recognised that some points in the patient's illness will require more in terms of adjustment on behalf of the caregiver than others (Kralik, 2006). Conceptual models provide an account of a system and concepts which help to build an understanding about how the system works.

Early models of family caregiving were framed by the caregivers' perceptions and responses to the demands of the caregiving scenario. A model of providing care for chronically ill family members was developed by Weitzner and Haley (2000) to explore the extent the to which primary and secondary caregiving stressors impact on the caregivers' physical or psychological wellbeing. In this model, primary stressors are conceptualised as illness-related factors, including the patients' functional condition as well as their emotional and behavioural response to illness. Secondary stressors are regarded as the spill-over effects of caregiving, which include relationship dynamics, disruptions to the caregivers' routine, issues associated with employment and the economic effects of providing care, as well as increasing fatigue from the growing demands upon their time and energy. Drawing on studies of the stress coping model, the extent to which a caregiving stressor impacts on the individual caregivers' physical and psychological wellbeing is thought to be influenced by the factors outlined in figure 6.

Figure 6. Factors mediating the impact of stressors on caregiver wellbeing

- **How individual caregivers evaluate the demands placed upon them during the caring period.**
- **The caregivers' individual stress and coping strategies.**
- **How satisfied the caregiver is with the level of support available to them from healthcare services**
- **How the caregiver evaluates and uses the support available to them from their own social networks as well as the extent to which this diminishes over the course of the patient's illness.**
- **The caregiver's feelings and perceptions of the burden placed upon them, including feelings of resentment.**
- **The individual disposition in terms of their tendency towards optimism or pessimism.**
- **Their own evaluation of the quality of their relationship to the patient's.**

The model proposed considers the extent to which factors developed from the stress coping model drive the caregivers individual experience. By understanding the relationship between individual factors, the model provides a framework for understanding the caregiving experience from the caregivers' own unique perspective. A possible limitation of the model is the use of a stress process model, originally developed for Alzheimer's disease patients and here assumed as a fitting foundation for viewing the process of caring for patients

with other chronic diseases such as cancer. Previous research has argued for studies with a greater emphasis on the positive aspects of caregiving. These are said to help caregivers in developing new skills and prepare them for the caregiving journey (Grande, 2009). A study by Blum and Sherman (2010) reports on the sense of satisfaction and reward participants gained as well as developing a sense of mastery and life satisfaction when adopting the caregiving role. Many caregivers use positive coping styles and maintain a positive attitude to their role of caregiving (Cavers et al., 2012).

Other models focussed on the dyadic nature of the caregiving role, for example, caregiving during potentially fatal illness, a model developed by Brown and Steltz (1999) explores how the process of becoming a family caregiver unfolds while caring for a patient with chronic and potentially fatal illness. Using qualitative and quantitative data collected over time from caregiver groups, the model describes the physical emotional and cognitive process experienced by family caregivers in four phases, which begin with the diagnosis of illness and end after the patient's death. The complexity of choosing to take on the commitment to care is emphasised within the process where caregivers adapt and assume the role of caregiving. This draws attention to certain aspects of caring which occur alongside the number of everyday tasks associated with the role. For example, in phase one, the participants described facing the reality of illness, which implies effort, focus and the existence of sorrow, before the decision to take on the role of caregiver has begun. Facing the reality points to the myriad of ways by which the decision to assume the role of caregiver is arrived. For the study participants, these included a lack of choice, a genuine affection for the patient or the caregiver's commitment to a role. The relational element of the role played by caregivers, rarely seen by others, is revealed in this model, highlighting how caregivers are not observers or overseers of the patients' death; rather they actively strive to create the death experience desired by the patient. The ongoing cognitive, emotional, and physical work involved in caregiving is brought together in four phases which encapsulate the core theme of the labour of caregiving. An outline of the four phases is detailed below.

Phase 1. *Becoming a caregiver* involved the caregivers facing the reality of the patient's illness and deciding to take on the caregiving role. During this phase,

caregivers began to develop skills and expertise in care delivery. Those new to the caregiving role experienced feeling of uncertainty and inadequacy in being able to fulfil the role. Perceptions were seen to vary between accepting the illness and hoping for a good outcome in the future. Having access to financial and practical resources form care providers to help them fulfil their role had the most influence on how prepared caregivers felt the face the future.

Phase 2 *Taking care* refers to managing the illness and preparing for the patient's death. This phase consolidates the caregivers' acceptance of illness by adapting their environment. This may involve making alterations or moving to a different location to facilitate better care of the patient. Family relationships change by being strengthened for some, while for others, family dynamics were strained as caregivers at this stage came to accept the limitations of their own physical and emotional resources. Caregivers at this phase negotiated healthcare services to meet the needs of the ill person and this included seeking support and information for themselves to improve their ability to provide care.

Phase 3 Midwifing the death involved taking responsibility for coordinating the final days and hours of the patient's life. This was said to be a profoundly emotional experience where caregivers waited and hoped for a 'good death'.

Phase 4 Taking the next step highlights the complexity of the caregiving role when, after the patient has died, the caregiving role is brought to an end through a process of informing others of the patient's death and carrying out the wishes of the deceased person. This period of adjustment involved building a life away from caregiving and some caregivers expressed a sense of relief at this stage, though many continued to reflect and reassess their actions and re-examine the caregiving experience.

Elements of this model remain of interest to healthcare researchers today. For example, the financial cost of caregiving (Hupcey, 2010; Blum and Sherman, 2010; Ventura et al., 2014; Hurley et al., 2014; Janze and Henrikson, 2014; Ewing and Grande, 2013). Negotiating access to healthcare services was noted as being challenging in a study by Schulman-Green (2004). Other researchers draw attention to the importance for caregivers of having consistent and dependable access to support in the form of information and advice from palliative care staff (Penrod et al., 2010; Cavers et al., 2012; Grande et al.,

2013; Hurley et al., 2014; Ventura et al., 2014; Gardner et al., 2015). My own view is that it is clear that the Brown and Steltz (1999) theory is important because it tells us that some elements of the caregiver's experience is enduring over time. However, it is limited in its focus on the, taking care, element of the caregiver role at different stages of illness.

A transactional model of cancer family caregiving skill was developed by Schumacher, Beidler, Beeber and Gambino (2006) which aimed to develop a model of caregiving using qualitative research by interviewing individual caregivers and patient and caregiver dyads. The model considers the demands of the illness situation, caregiver and patient responses to illness and individual patterns of caregiving. Caregivers were providing care for patients with a range of cancer diagnoses. The findings indicated that caregivers develop skills by closely monitoring changes in the patient's verbal and non-verbal behaviour and make changes in their caring approach based on their observations. Based on their unique relationship with the patient, caregivers adapt their caring approach to take account of the patient's physical condition as well as their knowledge of the patient's own disposition to maintain the patient's psychological and spiritual well-being. In this sense, caregivers are well placed to work closely with healthcare services to negotiate targeted and timely interventions based on the holistic needs of the patient.

A particular strength of the study was the amount of data collected from 107 semi-structured interviews with caregivers. However, generalisability of the study finding may have been limited by the collecting of data from one cancer hospital. As the field of caregiving research grew and expanded, the model was later expanded to explore the interactive nature of individual concepts within the model (Fletcher et al., 2012) which focusses on one aspect of this model. Though it is recognised that the patient carer relationship is a key aspect of the experience which supports the wellbeing of both parties, the author stresses that other elements of the model are worthy of exploration. A number of authors have explored how family caregivers experience caregiving over time through their research in applied strings. Many of these are dominated by stage or phase-based models which resonate with transition literature. I will now explore how some of these studies have furthered understanding in this important area of research. In a study which explored the experience of caregivers of patients

with one of four cancer types, Morris and Thomas (2001) used the term 'journey of illness' to depict the caregivers' transition as a 'shifting process of carer-hood'. Interviews were conducted with 79 patients and caregivers accessing cancer services once at one of four points.

1. the diagnosis of illness
2. the end of the first treatment
3. the first recurrence
4. the referral to palliative care.

These points in illness are theorised as critical moments in the cancer experience. The journey describes the caregiver's involvement as a process rather than a single occurrence in that they adopt different perspectives at certain points under different conditions. At some of the points named as critical, their needs are the same as the patients, while at others they may differ. The data for this research was collected via postal questionnaires and single one-to-one interviews which were analysed together using content analysis. Some of the interviews were conducted with the patient and caregiver together, while others were with the caregiver on their own. Analysis of interviews also incorporated data from interviews with health professionals, and this may have impacted on the analysis of data because professionals may have a different perspective of what constitutes a critical point in illness or caregiving to the caregiver. The role of health professionals in helping the caregivers recognise the importance of their contribution in the caring arena was highlighted in this research, and the article makes some interesting points about how caregivers position themselves with regard to being the patient's caregiver in a medical arena. A limitation of the study was that caregivers' experiences were explored at points in the patient's illness which were pre-conceived as crucial for the caregiver also. This may have limited the findings in that it missed other critical points in carer-hood which were influenced by factors other than the patients' illness and which impacted on caregivers in highly idiosyncratic ways. In addition, the participants were white middle class heterosexual spousal caregivers. It is possible that the findings would have been altered if other kinship relationships had been represented.

2.10 Caregiving across time

Providing care for a terminally ill family member in the home is a key event in the life of caregivers. Individuals living with chronic illness are acknowledged as being in an unpredictable process which may include movement in any direction This has been recognised by transition theorists, such as Kralik (2006) as distinct from other kinds of caregiving experience. Fluctuations in the patients' illness was termed as a transition in a study by Du Benske et al., (2009) who surveyed the needs of 159 female and 24 male caregivers across the broad stages of illness. The study focussed on identifying the information needs of caregivers to identify opportunities for information interventions at ten key transition events in the cancer disease trajectory. This qualitative study relied on the self-reported information need of patients throughout the disease, however, caregivers are not always able to identify their own needs. This is especially true while the patient is still alive when the demand on their time is great and they are more closely attuned to the needs of the patient than their own. Added to this, the stages began at the start of treatment and ended after the patient's death, and these may have been too broad to distinguish the complexity of individual caregivers' needs. The study was limited by the recruitment criteria which was biased towards educated Caucasian females. This makes it difficult to identify other factors which may influence how caregivers experience transition, for example, gender, culture or socioeconomic status. The volunteer sampling of participants may have limited the findings towards caregivers with more time available, better coping skills or those with access to help from wider family members. These factors may also influence the information needs and caregiving experience of caregivers. The need to develop an in-depth understanding of the experiences of individual caregivers has been identified as a way to introduce timely and personalised support interventions for them. Three literature reviews in the review highlighted the need to develop a more in-depth understanding of the support needs of caregivers throughout the time they interact with palliative care services. Grande (2009) carried out a review of the international literature which provided an overview of the current research, drawing attention to where there are gaps which affect the support needs of caregivers, especially towards the end of the patient's life. This is important because it is recognised that caregivers often do not see themselves as being

the person with needs, nor do they acknowledge their own role as the patient's caregiver (Donovan, 2010).

Using an ethnographic approach, Hurley et al., (2014) observed ten caregivers and other family members involved in the patient's care, as well as members of the hospice multidisciplinary team, to explore the beliefs and practices during the transition between home and hospice care. The study identified 'trigger points' in caring, reflecting perceived levels of competency and the caregiver's evaluation of their own ability to provide adequate care. The transition experience was described as 'less than seamless' in terms of the caregiver's fluctuating levels of acceptance of impending death. The use of a single hospice was said to have allowed the collection of rich data, though this may have limited the generalisability of the study to palliative care transitions in other settings.

A perception of caregiving as a crossroads was suggested by Shulman-Green (2004) who explored the feelings and perceptions of caregivers immediately prior to patient accessing hospice care in the USA. The study theorises that caregivers, reached a crossroads in caregiving where they were faced with accepting the patient's death at the same time as navigating their way through the healthcare system. This point contributed towards a change in patient and family dynamics for caregivers as well as their own self-concept. The research highlights the need for healthcare services to provide individual holistic support packages for patients as well as caregivers who are both accessing services. Of the 12 participants in this research, five were children of the patient, one spouse, one sister, one niece, one sister-in-law, two daughters-in-law and one friend. This diversity in kinship may have contributed to the complex interplay among family members' relationships. Part of the caregivers' challenge when negotiating healthcare involved securing the most effective in accordance with the level of the insurance cover that was purchased for the patient in the USA.

A grounded theory study by Duggleby et al., (2010) aimed to gain a thorough picture of the transition experience by interviewing bereaved caregivers (n=10), patients with advanced cancer (n=6) and health care professionals (n=12). The study identified strategies by which patents and their caregivers found meaning and established hope in their situation across significant milestones in illness. The findings of the study highlight the profound effect on the caregiver's health,

identity, relationships, environment and daily activities. The geographic location of the study, however, may have limited the study's trustworthiness. Participants were recruited to the study from three different rural regions in Canada where access to resources was inconsistent, and this may have influenced how the participants and their families experienced transition. As with the research conducted by Morris and Thomas (2001), the data analysis incorporated the perspectives of health care professionals who may have identified different transition processes to the patients and their families.

In a quantitative longitudinal study of caregivers for patients diagnosed with a number of incurable malignant disease types, Burns, Broom, Smith, Dear and Craft, (2013) interviewed caregivers twice in a three-month period to explore their own and the patient's understandings of treatment goals. The study revealed there were differences in caregiver and patient perceptions of treatment goals, particularly around the non-curative focus of palliative care. The findings suggest that, although oncologists are continuing to engage in frank discussions with caregivers and patients separately, discussing the patient's impending death may be a more difficult conversation for the caregiver to have with the patient. The study highlights the important role that hospice staff can play in helping patients and caregivers to achieve the aim of 'a good death' for the patient and, in doing so, assist the caregiver in their bereavement process after the patient's death.

A series of studies provide information about factors which impact on caregivers in idiosyncratic ways, but which may not automatically relate to the patients' illness or other biomedical disease markers. For example, most of the early studies as well as more current research provide evidence to suggest caregivers draw upon aspects of the social and cultural world in which they are placed and live to make sense of their experience when providing care for patients with chronic illness (Donovan et al., 2010; Cavers et al., 2012; Fletcher et al., 2012; Burns et al., 2013; Ewing and Grande, 2013; Hurley et al., 2014, Ventura et al., 2014). In the following section, I will provide an outline of factors which were noticeable by the effect they had on shaping the experiences of caregivers in the literature. These factors are key in influencing the caregivers' experience of providing care across time.

2.11 Relationship dynamics

The diagnosis of terminal illness often has a transformative effect on the friends and family of the patient and their family caregiver, who face their own emotional responses to the patient's illness and functional decline. The topic of relationship dynamics and how they change during the illness has been noted in a number of studies (Shulman-Green, 2004; Cavers et al., 2012; Hupcey, 2010; Janze and Henriksson, 2014). It is not unusual for many members of one family to be involved in providing care for the patient. Schulman-Green (2003) reported how changed relationship dynamics marked one phase of the transition into hospice care for families said to be at a 'crossroads' in palliative care. In this article, the routines and habits of the family caregiver were changed as the patient's needs multiplied during illness. This resulted in strained relationships and limited communication with each other as they each tried to avoid discussing the end of the patient's life. A systematic review of the literature pertaining to the self-reported unmet needs of patients and caregivers draws attention to the sense of isolation caregivers experience as relationships on multiple levels are affected (Ventura, 2014). The review underscores how illness progression impacts on the caregivers' social world and limits opportunities for them to engage with people outside of the caring scenario. Many face interruptions in their work life and lose contact with work friends and colleagues (Morris and Thomas, 2001). Established relationship roles are prone to change when sons and daughters are forced to adopt a parental role in their relationships with their own parents (Schumacher et al., 2006). In a study of relationships between family members at the end of life, Burns et al., (2007) draw attention to where relationships between family members deteriorated when there was disagreement over proposed treatment plans. Many began to feel overwhelmed by the responsibility of looking after their family member and are challenged by taking care of the patient's needs night and day.

Two of the studies highlighted the impact of caregiving on the social world of caregivers. A study by Hupcey (2010) and Cavers et al., (2012) identified the way that caregivers frequently re-examined their relationships with others during the process of caring for the patient. This study highlights how, for many, socialising with others becomes increasingly difficult as the patient's condition deteriorates and the demand on their time increases. Cavers et al., (2012)

spoke of their faith and a relationship with the church. The participants drew on their religious or spiritual beliefs, and many said they felt reassured by the knowledge that they were able to place their trust in something outside of themselves. The friendships formed with others in their faith groups were a source of comfort for the carers, as were the depth of these relationships which were grounded in the shared beliefs and practices of their faith. A limitation of this study was the recruitment context, which was a small island in southeast Scotland. This does limit the study's findings to this geographic area, and it is not clear if the findings would have been different if participants from other national, social, ethnic or religious groups had taken part. In addition, the participants were all caring for a patient with a diagnosis of glioma and this further limit its applicability to caregivers of patients with other illnesses.

In a qualitative study of caregivers preparing for the caring role, Janze and Henrikson (2014) state that family caregivers prepared for caring in accordance with their awareness of the patient's death. The overarching theme of preparing for caregiving in awareness of death encapsulated how family caregivers focussed on the present while preparing for the future. The theme drew attention to the relationship between the patient and caregiver and how caregivers prioritised the needs of the patient. The patient's moods and responses to illness prompted carers to adjust their own attitude and position in caring impacting on the caregiver's psychological wellbeing.

A study by Morris and Thomas (2001) explored the experiences of 12 people providing care for a patent transitioning into palliative care. The complexity of this experience was described as the interaction between patients, caregivers, medical staff and palliative care services. Three themes were common to all participants in the study as they navigated their way through the palliative care service system and positioned themselves in the medical setting. The study draws attention to how caregivers are more likely to accept support from palliative care staff when they are convinced that doing so would not detract from the needs of the patient.

The initial stages of illness may not require the caregiver to adjust their lives in any significant way. In a synthesis of three data sources, Carduff et al., (2014) states that caregivers are likely to perceive their role in caring for the patient differently according to the stage of illness and may not see themselves as in

need of support in the early stages. The point of referral to palliative care services is acknowledged as a time when there will be a shift in awareness for many caregivers as they begin to accept the long term implications of their role (Shulman-Green, 2004; Blum and Sherman, 2010; Hurley, 2014; Gardiner et al., 2015).

2.12 Access to information

The caregivers' understanding of the patient's illness and how this relates to their changing illness needs is recognised as lessening the amount of caregiver distress and burden (DuBenske et al., 2008; Janze and Henrikson, 2014; Ventura et al., 2014). The study provides an understanding of how the caregivers' need for information will differ across stages of illness related needs, arguing that their needs should be comprehensively defined in order for educational interventions to be delivered effectively. The need for information appeared to be closely linked to a desire for guidance and education about the patient's illness and how to care for them over the course of their illness. A systematic review of the unmet needs of caregivers as they are referred to palliative care services points to a need for information and practical guidance with acquiring appropriate skills for long term caregiving (Ventura et al., 2014). Several authors recognise the importance of providing signposting to caregivers, together with sources of training and information, as a way of minimising their uncertainty about the illness deterioration and their own ability to provide care throughout illness. (Morris and Thomas, 2010; Hupcey, 2010; Grande 2009; Duggleby et al., 2010). The timing of information is said to be a simple way to welcome caregivers into the medical setting, which validates them as providers and users of care (Morris and Thomas, 2010). While participants in a study by Duggleby (2010) reported feeling shocked and uncertain when their family member was referred to community palliative care. Timely communication and information about the patient's illness was said to help alleviate their sense of uncertainty about the future and their lack of confidence in being able to cope with the patient's future needs. Consideration was given to the need to deliver information to caregivers appropriate to the patient's stage of illness. This was raised by a number of authors who comment on how nursing staff have the opportunity to deliver information to caregivers in a way which will enhance their understanding and

improve their acceptance of the patient's changing illness. This has been seen to improve the likelihood of them caring for their own needs alongside taking care of the needs of the patient (Morris and Thomas, 2001; Hupcey, 2010). A study by Duggleby et al., (2010) notes how caring in the home around the clock leaves caregivers vulnerable to higher levels of anxiety, especially out of normal working hours when accessing professional help or advice is more difficult. Participants in this study said they particularly valued support which helped them to adapt to the patient's changing health needs, had reliable open lines of communication with palliative care services and had strong family and community support networks. The study findings give the accounts of patients and caregivers in rural settings. The findings may have been influenced by data collection where patients and caregivers who take part in the interview were not related. So, this is a study of patients and families, not patients with their families.

2.13 Interactions with palliative healthcare providers

The psychosocial health and wellbeing of caregivers is fundamentally linked to the patients. Their experiences of accessing and interacting with palliative care services may be overlapping, but their needs may be different. It is recognised that there is a need to validate caregivers, care providers and users of palliative care services (Morris and Thomas, 2001).

A study of how caregivers fluctuate in their acceptance of the referral to palliative care may act as a barrier to their own and the patient's engagement with palliative care services (Schulman-Green, 2004). In a longitudinal study of the fluctuating awareness of treatment goals among patients and their caregivers, Burns (2007) observes that knowledge of imminent death does not equate to an acceptance of death on an emotional level. The study points to the distinctly medical approach to delivering information to patients and caregivers. It is suggested that this may be the result of consultations with clinicians and oncologists who discuss treatment goals with patients and with caregivers, but not always together. Though the study aimed to investigate the differences in understanding, this did not include an exploration of why some participants do not understand the goals of palliative care as clearly as others. Therefore, it was not possible for the author to explain the reason for the confusion. It was thought a major factor was location of the study, which was a geographically

large Australian state where unemployment had led to a collapse in close family and social relationships.

A systematic review of caregivers' self-reported unmet needs (Ventura et al., 2014) revealed caregivers' observations of service delivery were that they considered medical staff were overstretched and had little spare time to speak with them. As a result, caregivers generally felt unable to share their concerns or ask questions about the patient's care. Of interest is that the review uncovered how the desire for open communication with services was the most common unmet need of caregivers in the selected studies. Other needs which were highlighted arose from feelings of isolation when the patient's condition worsened, and they were forced to spend more time caring for the patient and less time interacting with others outside of the illness setting. The need to signpost caregivers to information about how to care for their own physical and psychological wellbeing was highlighted and this was a need which was frequently unmet (Ventura et al., 2014). The value of talking to other caregivers was highlighted but the need to talk to other caregivers was not available to them. Lack of support or tools for caregivers wishing to access one-to-one counselling or peer support groups was demonstrated.

In a review of the transition from curative to palliative, Gardiner, Ingleton, Gott and Ryan (2015) underscored the caregiver's need for continuing care, information and guidance to support them through this transition phase. The necessity of information featured strongly within this review, especially at key points in illness, for example home care, Du Benske, Wen, Gustafson, Guarnaccia, Cleary, Dinauer and McTavish (2008) or times when caregivers need to acquire special skills to provide care for the patient (Penrod et al., 2010).

There may be multiple changes in the place of care for patients with palliative care needs (for example from home to hospital, hospital to home and home to hospice). Several studies draw attention to the importance of how caregivers orient themselves to the different care delivery settings, suggesting this is an important area of caregiver research (Morris and Thomas, 2010; Blum and Sherman, 2010; Hupcey, 2010; Penrod et al.; 2010; Ewing and Grande, 2013). The studies raise questions about how caregivers can be made to feel more comfortable with these changes in caring focus and this is discussed later in this

chapter. Fostering collaborative relationships with nursing and medical teams by nursing staff presents staff with a way of supporting caregivers in practical ways and encouraging them to exercise self-care while providing care to the patient (Blum and Sharman, 2010). In a bid to address the paucity of available tools to measure the support needs of caregiver over time, Ewing and Grande (2013) conducted a qualitative study to uncover the specific needs of 75 adult caregivers referred to five separate hospice at home services in the UK. Data from focus groups and telephone interviews are used to assist the development of a tool which aimed to identify the practical, psychosocial and financial needs of caregivers and patients towards the end of life. The study identified the unique opportunity palliative care services have to support caregivers in a wider range of domains. Key amongst the caregivers' needs, was having access to a named person who could be contacted by the patient and caregiver in an emergency or when information about the patient's illness and medication was needed. Practical support with caregiving was said to be appreciated, though many said they would have liked to have received special training in how to safely lift and turn the patient manually and use a hoist when providing care in their home. Information about the patient's illness and what medications were being used was said to help caregivers understand the illness progression and prepare them for fluctuations in illness. The advantages of including caregivers as co-recipients of care in palliative care medical settings was identified by Penrod et al., (2010) whose study employed an instrumental case study design to explore variations in caregiving trajectories from the perspective of active and former caregivers. The study aimed to offer a guide for nurses to support people in clinical practice across common variations in end-of-life trajectories faced by caregivers. The findings are based on three distinct phases which are given shape by the caregiver's own perceptions of the patient's proximity to death. At these phases, the caregiver strives to achieve a sense of stability and normality towards the end of the patient's life. Whilst a theory of caregiver trajectories, which is driven by the caregiver's own lived experience, is welcomed, the study does raise several questions with respect to recruitment, data collection and analysis of data. For example. participants recruited were active and former caregivers and subsequently the data incorporated accounts of past and current caregiving. There is an assumption here that all the participants in the study

were describing the same experience of transitioning towards death. This could be problematic as those who were enmeshed within the caregiving experience at the time of their interview may focus on certain aspects of their role which had significance for them in the present. It is possible that those reflecting on having been a caregiver may have had time to reflect on their experience from a place of less stress and anxiety. Therefore, analysing the experiences of current and past caregivers in one dataset may have influenced the research findings. Other authors who focus on the transition process also draw attention to the important role of caregivers and the need for them to be welcomed into the medical arena (Shulman-Green, 2004). A study by Cavers et al., (2012) notes that where there is open collaboration and interaction with medical staff, caregivers felt more comfortable about seeking information to help them understand the patient's illness and training to assist in care delivery as illness progressed. A comprehensive review of family caregiving at the end-of-life points to a common finding in relation to caregivers who lack previous experience of dying or caregiving. These people are more likely to feel unprepared and lacking in knowledge or capacity to care for the patient. Qualitative findings revealed that being directly involved in the patient's care increases the confidence and coping abilities of family caregivers. Gardiner et al., (2015).

2.14 The caregivers' own needs

The face of caregivers is changing, meaning that individuals of all ages and stages of life are being tasked with managing the care of people who are terminally ill. The needs of caregivers often go unnoticed even by the individuals themselves. Taking care of their own needs was raised as a challenge for caregivers who are reluctant to accept support from nursing staff if it would diminish the level of support offered to the patient (Morris and Thomas, 2010). Certain needs have been identified as essential to wellbeing of caregivers, for example the need to establish cooperative relationships with all service providers was highlighted (Ventura et al., 2014). In a systematic review of the literature, attention was drawn to the self-reported unmet needs of caregivers providing care for a patient with palliative care needs in their home. The review points out that caregivers' value open communication and reliable access to services, though these two factors were the most identified as unmet. This was

reported as impacting on both patients and caregivers in a negative way. Articles in the review relating to the psychosocial needs of caregivers included the need for practical help with mobility and childcare issues where appropriate. The articles in the review pointed to how caregivers would have liked to have felt more supported in terms of maintaining their psychological wellbeing, for example by having improved access to respite care for the patient which would allow them to take time away from caring responsibilities. The review also drew attention to a need for signposting to counselling services or carer peer support groups. The 2008 UK End-of-Life-Care Strategy (p107) promotes service delivery which recognises the role of caregivers in the medical setting on account of the unique contribution they bring to health and social care delivery. The recommendations include taking steps to address their individual requirements to support them as co-workers in providing care for the patient. The position of caregivers in a palliative care setting has been explored by several authors (Blum and Sherman, 2010; Penrod et al., 2010 Cavers et al., 2012). In recognition of the essential role played by caregivers, Blum and Sherman (2010) conducted a literature review to explore the benefits and difficulties of being a family caregiver, recognising that they often take on the caregiving role in an uninformed way. The review highlights the challenges that caregivers face in delivering personal and highly specialised care for a family member without the benefit of emotional objectivity and often with minimal or no training. The paper argues for the development of a conceptual framework to help caregivers recognise their unique place in the medical setting and improve their wellbeing by assessing and supporting them and the patient as they transition between caring settings. The objective of the caregiver assessment aimed to support individual caregivers in continuing to provide progressively high levels of care throughout the patient's illness by preventing them from being swamped by feelings of guilt and obligation to provide care. With regard to support for themselves, caregivers especially valued access to respite care, especially at times when the effects of tiredness and strain became overwhelming (Ventura et al., 2014). Those who had help with caring duties from family members also valued this service, though most caregivers saw their own needs as secondary to the patient. Hence, it was difficult for caregivers to ask for help, especially when the needs of the patients fluctuated in ways they

felt unable to anticipate (Morris and Thomas, 2010; Cavers et al., 2012). Because they were not able to predict the patient's needs, caregivers felt unable to prepare for future changes (Penrod et al., 2010; Burns et al., 2010) note that having a single point of contact, as opposed to being issued with leaflets or accessing websites, helped caregivers to feel 'part of' the patient's caring team. This study was undertaken in the initial stages of developing a caregiver assessment tool for use in supporting caregivers in clinical practice. Study findings may have been limited by the bereaved status of the caregivers interviewed, which may have been improved by the inclusion of current carers to draw out the views and perspectives of those currently enmeshed in the lived experience of caring for a patient in palliative care.

2.15 The cost of caregiving

Seminal work in relation to the patient and caregiver experiences reveals that a lack of access to adequate funding in the early stages can impact negatively on their ability to get ready for long term caregiving (Brown and Steltz, 1999). A lack of practical and financial support for caregivers transitioning between home and inpatient hospice care was underlined in an ethnographic study conducted by Hurley et al., (2014). The study aimed to identify points in the patient's illness which challenged patients and caregivers, and which triggered the need for increased input from the hospice interdisciplinary team. The paper took a closer look at how a lack of family support and financial resources triggered the need for an increase in care. A notable finding from this study was that caregivers who had help to care for the patients or had the resources to pay for private care were better able to plan ahead for times when there would be an increase in demand as a result of the patient's worsening condition. Although the study findings appear to be consistent with prior research, this study was conducted in a single hospice in the USA where admission to hospice care is largely determined by financial considerations such as the patient's level of insurance cover. This does limit the findings to caregivers in those countries where similar healthcare funding systems are in place. Not all caregivers experience the same difficulties in relation to the financial cost of caregiving, though a review of current literature by Blum and Sherman (2010) revealed how reliable access to financial resources is seen to mitigate the negative effects of providing care for family members. Two of the articles referred to caregiver's fear of financial

insecurity related to them needing to take time off from work to provide care (Hupcey, 2010; Janze and Henrikson, 2014).

One of the studies (Hupcey, 2010) employed a longitudinal design by documenting the experiences of caregivers providing care for patients diagnosed with a chronic heart condition. Interviews were collected from 26 caregivers over an 18-month period in a bid to develop proposals for supporting caregivers throughout this period of medical instability and uncertainty. The study describes occurrences of where there were financial problems, revealing that these were more extreme in low-income families or those where social and family support was lacking or absent. Financial difficulties were linked most strongly to those who were the sole caregiver. As the only person available to provide care, many were pressed to take unpaid leave of absence from their job while others retired earlier than they had planned. As a result of this, their income was reduced or stopped at a time when there was an illness related increase in expenditure to pay for things like medications, travelling to appointments or travelling to visit the patient. The paper illustrates that changes in the illness of the patients in this study led to an escalation in demands for their caregivers to demonstrate how their needs were just as acute as the patient's though they are manifested in different ways. The caregivers in this study were all wives of patients, recruited from a major healthcare facility in the USA serving patients within a 100-mile radius. The wives recruited were mainly Caucasian which means the findings were somewhat limited, and richer, more meaningful data may have helped to provide a more culturally sensitive perspective of this issue.

2.16 Reflecting on the literature

The literature review evolved from issues raised in the Introduction chapter, which pointed out the effects of a broad range of demographic and health related changes within society and how these have contributed to a rise in the number of adult caregivers in the UK. In light of developments in healthcare, it is reasonable to assume that in future, many adults will be providing care for the growing number of people accessing palliative care services. Overall, this review uncovered several international studies and models which elucidate the intricate nature of providing care for a patient during terminal illness. However, the majority of these studies are positioned within a medical or nursing

perspective which focuses on how the caregivers own physical and psychological well-being are affected by having to negotiate the demands of providing care and how, as individuals, they draw upon different sources to support them. On reflection, the approach taken to explore the experiences of caregivers could be considered to be limited outside of clinical or nursing settings which may fail to reflect the complexity of the caregiving experience at the individual level. Several articles have concentrated on how the specific circumstances of individual caregivers determine how they acquire skills and information to support them in the practical tasks associated with taking care of the patient. It is evident, caregiving is a multifaceted phenomenon, and the caregiver's ability to provide care is only one of several important factors within this experience. With this in mind, the findings from the literature review should be interpreted with caution because the experience of individual caregivers providing care in a particular sociocultural context becomes invisible when interpreted within knowledge produced from the perspective of dominant medical or clinical disciplines. It is important to focus on sensitively capturing the individual experiences of caregivers over time (Grande et al., 2009; Gardiner et al., 2015). In particular, it is important to focus on the experience of the caregiver rather than the patient's illness as the primary focus of interest when exploring their experience over time. This would help to illuminate ways in which they can be supported as a vital part of the UK health and social care system. In June 2018, the Health and Social Care Secretary said the aim of the government was to further the knowledge about how society can strengthen support for caregivers. By addressing the gaps identified in this review, this research aims to expand the knowledge relating to the personal unfolding experiences of caregivers and understand how being a caregiver impacts on individuals who take on the role of caregiver for a family member.

Therefore, I drew on principles of PICO (Booth and Fry-Smith, 2003) wherein the Population was defined as "family caregivers". The intervention was characterised by the "exploration of their experience during the time they interact with palliative care services". Comparing their experiences across time, I aimed for an outcome which would explore where there were incidences of change or stability in their experiences across time. Using these as a guideline, I was able to develop the research questions, aims and objectives seen in Fig 7

Figure 7. Research Questions, Aims and Objectives

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Research Questions

1. How does caring for a family member with palliative care needs change or stay over time?
2. What is the family caregivers' perception and experience of providing care during the patient's illness trajectory?
3. How and in what ways are the caregiver's experience's impacted by their engagement with palliative care support services?

Research Aim

   To explore the unique experiences of individual family caregivers during the time they are accessing palliative care support services.

Research Objectives

1. Understand how being a caregiver impacts on individuals who take on the role of caring for a family member.
2. Explore how and in what ways interacting with palliative care support services impacts on family caregivers.
3. Investigate if and in what ways the caregivers' experience of providing care changes over time.
4. Examine, if and in what way, changes in each individual   caregiver's experience, parallels the illness trajectory of the patient they care for.

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2.17 Chapter summary

This chapter explored the current literature and studies which have shaped the development of my research question aims and objectives. The following chapter will explain in detail the research methodology which provided a framework for this research.

Chapter 3 Methodology

3.1 Introduction

In the previous chapter, I presented a review of current knowledge and literature relating to the experience of being a caregiver for a family member accessing palliative care services over the course of the patient's illness. This chapter outlines the qualitative research approach utilised to address the above-mentioned aims and objectives. An exploration of the relationship between the methodology and the epistemological standpoint of in the study is provided. This provides a rationale for the study design and the chosen method of data collection. Within this, a reflexive approach to recruitment of participants and collecting of data is demonstrated.

In the next section, I present an overview of the study design which provided a background and a context for the discussion chapter.

3.2 Overview of the study design

In this research, I adopted a longitudinal qualitative cross-sectional research design, drawing on the principles of phenomenology to undertake an extensive analysis of the lived experience of nine individual caregivers while they were providing care for a family member receiving palliative care services. The study setting was a twelve-bedded hospice in Yorkshire where participants were recruited from three separate areas of the hospice.

During the recruitment period, I attended weekly meetings of the Day Hospice Carers Group (DHCG) and Breath of Fresh Air Group (BOFA) groups. Attendance at groups afforded me the opportunity to interact informally and build rapport with individual participants. Four participants were recruited from the DHCG, five were recruited from the BOFA group and one was recruited from the inpatient unit. In total, six participants were interviewed three times and three participants were interviewed twice over a period of one year. Twenty-four interviews were conducted in total over a 12-month period.

The method of data collection involved a semi-structured interview approach, with eight of the interviews supplemented by a novel interview technique called Pictor (King and Horrocks, 2010). This method of conducting qualitative interviews is described in greater detail in the methods chapter. With the express permission of individual participants, conversations relating to the research topic area which emerged from individual participant interactions, were

documented in a study research diary, along with my own observations of participant interactions throughout the research period. These accounts also contributed to the findings and discussion chapters.

Data analysis employed an iterative approach which began with my engagement with groups and continued during the thesis writing. Analysis of data involved thematically analysing individual participant accounts within and across cases to illuminate the lived experiences of family caregivers over time. Themes arising from the analysis shed light on how the emerging caregiving role is bound up in the patients' illness trajectory. The caregivers' experience of developing the role is less systematic but fluctuates according to how they each coped and adjusted to taking on the caregiving role. Each caregivers' individual coping and adapting styles were constrained or challenged by their access to regular and reliable sources of support in the form of supportive relationships with the patient and wider social networks as well as reliable and dependable access to palliative care services.

3.3 Epistemology and the research approach

When designing a research project, there are two concepts which come together to make it difficult for researchers to unravel conceptually. These are ontology and epistemology (Crotty, 1998). The epistemological and ontological perspective of the researcher relates broadly to the theory of knowledge, specifically the researcher's assumptions about what is knowable, and how knowledge can be made known (Willig, 2013). Epistemology in the context of a research project makes known the researcher's beliefs about how knowledge can be gained (Guba and Lincoln, 2005). These are important issues because there are a broad range of methodological approaches available to address specific research questions which are grounded in the researcher's own assumptions about the nature of knowledge and what can be known (Willig, 2013). These considerations have particular importance in 'real-life' research like the current study because of the way they affect how the research question is posed, how data is collected and the researcher's choice of analysis and style of reporting the research findings (Crotty, 1999; Denzin and Lincoln, 2013). These matters also influence what the research findings can claim in terms of its contribution to knowledge (Denzin and Lincoln, 2013). By being transparent about their own assumptions, the researcher can provide clarity for readers of

the thesis who may have an interest in human health research but no experience of the phenomena being studied. Transparency on behalf of the researcher also enhances the trustworthiness of the research findings (Crotty, 1998; Denzin and Lincoln, 2013).

The current research was designed to explore a particularly sensitive research topic within a vulnerable population. The aim of data collection was not to explain what this experience is but to select a design which captured the personal and authentic experiences of family caregivers as near to as lived as possible through the collecting and analysing of data and writing of text which illuminated the experience of individuals living through this experience (Moustakas, 1994; Denzin and Lincoln, 2005).

At a rudimentary level, ontology is the study of being and how the researcher attempts to uncover the structure and nature of existence or what it means to exist (Crotty, 1998; Burr, 2003). The two dominant ontological perspectives which receive the most attention in the research literature are objectivism and constructionism.

An objectivist ontological perspective assumes there is an objective reality to experience which is made up of recognisable and measurable 'things' and 'facts' which are both 'real' and 'fixed'. This means they can be 'known' or studied from a detached, objective standpoint. This view of reality is associated with a positivist or quantitative research framework which is concerned with evidence-based information and gathering data for statistical analysis. A quantitative study would aim to gather data by measuring and counting things and excluding extraneous contextual variables from the research which may skew the research findings. The purpose of gathering data for quantitative research is to gather evidence which would enable the researcher to make generalisations about how people are likely to behave under certain conditions. An objectivist ontological focus would not have been the appropriate approach for this study which aimed to understand the experience of being a family caregiver for family member with fluctuating palliative care needs in greater depth. This experience unfolds in the lived world of individuals caregivers. At the same time, it is embedded within the patient's illness and develops over the course of the patient's illness trajectory. Factors which impact on individual caregivers are not immediately observable or quantifiable but are richly

abundant, multi-layered, and highly idiosyncratic, impacting on different caregivers in diverse ways.

A constructionist perspective, however, takes the view that experience does not occur in isolation but is constructed by the experiencer from within their own social, cultural, and historical reality and by their engagement with others in a shared context. The position this study takes is constructivist in that its primary aim is to uncover how individual family caregivers construct meaning during the time they provide care for a patient over the course of chronic illness and palliative care. Within this, the researcher does not seek to uncover 'the truth of' what actually happened, but rather what this experience was like from the perspective of the individual caregiver. The researcher's task is to make sense of their reported perspectives while avoiding claims about what the experience is like more generally.

3.4 Phenomenology

The methodological framework chosen for this study was phenomenology, which is a qualitative human science approach with a strong philosophical basis (van Manen,1990; Spinelli, 2005). The approach offers a hermeneutic human science method which draws on elements of descriptive phenomenology (Plager, 1994). This was particularly useful for providing structure in this phenomenological

longitudinal study which aimed to understand individual experience through the interpretation of textual data.

According to van Manen (1990) human science research is an effort by the researcher to explore the structure of the individual's life world as they live and experience it. His ideas have a particular focus on understanding pedagogy but are transferable to other research contexts (Hardy, 2012). I believe the approach has particular value for understanding the experiences of family caregivers. A detailed account of how this approach was applied in this research is discussed later in this chapter. Phenomenological approaches seek to explore individual lived experience in as natural and un-elaborated a way as possible (Willis, 2001). The approach has much in common with other qualitative approaches and yet it is distinct in its focus on studying the structure of experience as it presents itself to the consciousness of the individual (Crotty, 1996; Willig, 2013).

The approach facilitated an in-depth exploration of the unique and complex journey undertaken by family caregivers as they provided care for a patient with terminal illness over time. This included an examination of how and in what ways each caregiver's experience was impacted by their own engagement with social and palliative care services.

From a phenomenological perspective, we are in a continuous stream of making sense of experience as we encounter it. Spinelli (2005) describes phenomena as 'the appearance of things' as opposed to 'the thing in itself'. As we encounter phenomena within our everyday experience, we are in a process of continual interpretation. The way we interpret and attach meaning to objects or phenomena contributes to the unique view we have of the world. In this sense, the way we interpret and give meaning to the world creates our existence and reality.

Human beings are essentially meaning makers (Willi, 2013) consequently, the way we give meaning to things is influenced by individual factors, for example, our social or cultural situatedness, our physical or psychological status, as well as our place in history. These factors impact on our meaning making and the way we experience the world. Accordingly, people with a different sociocultural history to our own will experience the world differently in ways which correspond to their own meaning making influences.

It must follow, that individual subjective reality is regulated by the lens through which we view the world. Phenomenology, broadly speaking, is concerned with elucidating the content and structure of the individual's reality as it appears to them (Kvale, 1996). The aim of the phenomenological researcher is to explore experience or reality as it appears to the individual, whilst at the same time avoid imposing our own judgments on what the experience is (Moran, 2008). There is no agreed method or theoretical perspective for conducting phenomenological research. Proponents of phenomenology each have different interpretations about the central ideas behind the approach (Moran, 2000). The way phenomenology is applied to research varies according to the strand of the philosophy it is aligned with. Nor are there any clear guidelines for researchers to follow regarding which method or theoretical perspective to follow. Added to this, the linguistically and philosophically complex nature of conducting phenomenological research made this approach challenging for researchers

who find it difficult to get to grips with the diverse interpretations and practices of individual phenomenological thinkers (Ihde,1986). When choosing to explore the lived experience of individuals, the researcher is focussed on offering a holistic understanding of the phenomena.

3.5 Phenomenology as applied to research

The lifeworld perspective is theoretical concept assisting phenomenological exploration of the experience of individuals and how they describe their present reality (van Manen, 1997). The life world of individuals is thought to be pre-reflective, meaning it exists prior to any thoughts about it. Merleau-Ponty (1962) focussed on uncovering the essence of lived experience as it exists now through the lens of the individual's lifeworld, stating that man is in the world, and it is only because he is in the world that he knows himself.

There are common themes within the lifeworld of every individual, and these are said to comprise the existential basis of human experience, pervading the individual lifeworld of all human experience regardless of the individuals' context or situation (Ashworth, 2006; van Manen,1990). The way in which these experiences are described and interpreted by the researcher reflect on the complexity of the individuals' lifeworld. The themes of human experiences are referred to as lifeworld existentials (van Manen, 1990). These are intended to guide the researcher in reflecting by providing a framework for exploring the meaning and structure of individual participants. Lifeworld existentials have been conceptualized in different ways by different phenomenologists (Sundler, Linberg, Nissan and Palmer, 2019). Figure 8 provides a broad definition put forward by Ashworth (2003) to describe the essential structures of the lifeworld of individuals. This description helped to guide the design of this research.

Figure 8 – The essential structure of the lifeworld (Ashworth, 2003)

Essential Structure	Definition
Selfhood	Relates to the individual's identity and their sense of agency within a given situation.
Embodiment	Relates to how a situation impacts upon the individual's body and enables them to interact with the world. Embodiment also includes the individual's psychological as well as physical well-being.
Sociality	Relates to how the individual's relationship with others is impacted by certain situations.
Spatiality	Relates to how the individuals' experience of space or geography is affected.
Temporality	Relates to how the individuals' own concept of time or duration of time is affected.
Project	Relates to how a situation may impact on the individual's ability to perform activities which are important to them.
Discourse	What kind of language or terms the individual uses to speak about and describe their lived experience or situation.

However, when designing and engaging in phenomenological research, it is important to understand the terminology as well as the philosophy as it is applied to analysing the data. I argue that the historical development of phenomenology is worthy of consideration because awareness of how the ideas originated can help researchers when applying phenomenology as a research methodology. In the following section, I will reflect on the philosophical concepts and thinking associated with phenomenology inferring how this approach influenced the design of the research.

3.6 The historical development of phenomenological thinking

Phenomenology was originally developed as a philosophy in the early part of the twentieth century and gained prominence as a research methodology for understanding experience in the early 1980s (Laverty, 2003). The phenomenological approach is principally a method of investigating lived experience whereby the researcher uses interpretation to provide insight into individual participants' accounts of lived experience (Smith, 2009 p.32).

The roots of the phenomenological approach owe much to the work of the English philosopher John Locke (1632-1704) and to the German thinker Immanuel Kant (1724-1804). Both men challenged the idea that our knowledge of the world was achievable through simple observation. They argued that

obtaining knowledge involved a necessary act of interpretation which would allow individuals to make sense of the world around them. Locke's argument can be encapsulated by referring to his concepts of primary and secondary ideas. Primary ideas are ones which exist independently of individual observation of them. This involves things like the shape, texture or speed of something. Secondary ideas arise out of interpretation, and these include, amongst other things, colour, sound, and taste.

Kant took this line of thinking further by positing that it is not possible to directly access the world (which he referred to as noumena) but it is possible to access phenomena. I would have loved to have been a fly on the wall. The distinction between these two refers to the difference between the appearance and reality of things. It is in this conceptual gap that interpretive phenomenology is situated.

Edmund Husserl (1859-1938) is regarded as the founder of phenomenological philosophy which was developed around the time of the fragmentation of psychology as cognition or behaviourism (Ashworth and Cheung, 2006). Husserl's aim was to establish the major concepts of phenomenology as a discipline for understanding human experience. Since that time, phenomenology has developed into two distinctive but interrelated approaches. These are known as transcendental or descriptive phenomenology and Heidegger's existential approach (Ashworth, 2006).

The main differences can be thought of as existing on a spectrum between a descriptive and interpretive paradigm and these positions are often referred to interchangeably as phenomenology and hermeneutic phenomenology. However, there are distinct differences between the two which lie in the philosophical perspectives of the phenomenological philosopher associated with the approach. Todres (2011) provides a synopsis of the different approaches, exploring the way aspects of phenomenology, hermeneutics and existentialism can assist researchers in providing insight into individual experience in health research.

Husserl's ideas lie at the descriptive end of the spectrum, and he used the term 'phenomena' to refer to 'the things themselves' or as they appear to individuals in an un-elaborated a way as possible (Willis, 2001; Spinelli, 2005). A central notion of this idea relates to consciousness, specifically that as humans we are

always conscious of something. So, our thinking is intentional in that it is intentionally directed towards a certain thing. Schultz (1967) however, suggests that human consciousness has no clearly defined boundaries, meaning that human beings are in a constant flow of conscious and unconscious awareness. Husserl, though. considered anything which was presented to the consciousness could be illuminated and understood through the phenomenological process. He referred to this process as encountering 'the things in themselves'. A key tenet within this encounter is the concept of intentionality, which he explains by positing that everyone who is conscious, is conscious of something. This may be some person, place, something awesome situation. It is through this consciousness, according to Husserl, that individuals constitute their world (Sokolowski, 2000).

One way of accessing 'the things in themselves' suggested Husserl was to separate the subjective experience (the noema) from the objective experience (the noesis). By doing so, it is possible to grasp the phenomena in its pre-reflective state. Researchers achieve this by a process of stepping outside of everyday experience to arrive at God's eye view of the phenomena.

Figure 9 depicts the underlying principles of Husserl's idea of intentionality as a correlation of the experiencing of something and how it is experienced. Thus individuals must first go through a process of experiencing something before they arrive at a place where the something has been experienced.

Figure 9 - Noema and Noesis
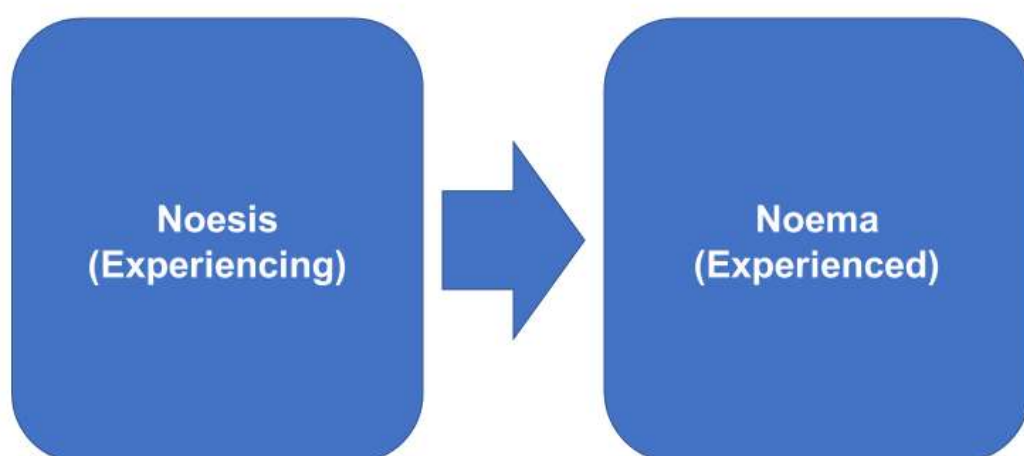
To give context to the intentional correlation portrayed in figure 9, I give the example of a caregiver who speaks of a time when they experienced stress (Noema). They describe their stress as having occurred in a particualr way, for example intermittently or intensively (Noesis). The noesis of the individual typically occurs beyond the level of consciousness (Arvidson, 2013) and cannot be reflected on whilst engaged in the particular experience (van Manen,1990 p.10) Thus, phenomenological reflection is retrospective rather than introspective.

Therefore, when describing a stressful experience, the caregiver refers to a time when they have experienced stress in the past. Even though the experience may appear to be immediate to them whilst recollecting it, the only description available to them is of the noematic experience of stress. We can only describe noema because we can only describe how something happened when we experienced it.

When reflecting upon their experience of stress, caregivers may say they experienced financial strain, physical strain or emotional strain. If I were to probe further about the intensity of the strain, they may use words like severe or describe it on a scale of severity from one to ten. From a phenomenological perspective, the caregiver is describing an experience of strain and they are now reflecting upon this to help them to convey something about this experience of the phenomena of strain. When I try to interpret their experience, however, my interpretation is limited because it remains my own interpretation of their having experienced stress; the actual phenomena of their experience of their stress ultimately eludes me.

From a phenomenological perspective, the researcher can try to get closer to their experience in the moment through empathic identification (Finlay, 2005). However, this would still be the researcher's interpretation of their experience and not the experience itself. If the individual were to describe their experience of anxiety whilst they were feeling anxious, the very act of verbalising their anxiety is likely to change the nature of it, causing it to dissipate or lessen in intensity.

Max van Manen (1990) asserts that all reflection, recollection, or description of experience are transformations of that experience and the issue of double interpretation or double hermeneutic, where the researcher seeks to understand

the meaning of the participants experience of a phenomenon through textual accounts, has been highlighted as an issue for qualitative research (Pietkiewicz and Smith, 2014). It is the task of the phenomenological researcher to be aware of this issue and strive to get as near as is possible to an understanding of individual experience whilst being transparent and aware that their interpretation is one among many possible interpretations of a given phenomenon.

3.7 Phenomenological reduction

Husserl described a process whereby the researcher can transcend their own preconceived ideas or suppositions of the physical world towards a focus on the subjective experience and meanings of experience for participants. His suggestion was that this could be achieved through a process of reflection and suspension of prior knowledge by rigorously questioning any previously taken for granted ideas which had been viewed by them as certainties.

Husserl considered the phenomenological process could elucidate anything 'that presented itself to the consciousness'. He referred to this process as the phenomenological reduction (Landridge, 2007; Moran, 2018). The aim of phenomenological reduction is to allow the researcher access to their own pre-reflective attitude what ways of viewing the world and move closer to the essential features or essence of the phenomena under scrutiny. The role of the researcher in this process is to step outside of the natural attitude (Moran, 2000 and 2018) and subjective opinion to arrive at a place where it is possible to identify the essential features or essence of a phenomena in context (Moustakas, 1994, p.13; Giorgi and Giorgi, 2008). Central to this idea is the notion of bracketing or epoché which is explained by Sokolowski (2008, p.48):

we become onlookers. We contemplate the involvement we had with the world and with the things in it, and we contemplate the world in its human involvement. We are simply no longer participants in the world; we contemplate what it is to be a participant and its manifestations. But the intentionality that we contemplate – the convictions, doubts, suspicions, certainties, and perceptions that we examine and describe – are still our intentions. We have not lost them; we only contemplate them. They remain exactly where they are with the same correlations between intentions and objects still in force. In a very curious way, we suspend them all just as they are, we 'freeze' them in place

From this position, the researcher can describe the phenomena as it is presented to the conscious awareness of the participant prior to any interpretation and in doing so, rediscover their lifeworld (Langridge, 2007; Giorgi and Giorgi, 2008). Merleau-Ponty (1962) speaks of the phenomenological reduction as a device or tool which permits the researcher to discover 'the spontaneous surge of the lifeworld'.

Georgi (2008a) however reminds us that Husserl was essentially a philosopher and cautions us to consider that Husserl's work was written and developed as a philosophical method rather than a psychological research approach to understanding individual experience of the world. Husserl's thinking was criticised by existential phenomenologists such as Heidegger (1889-1976) on the basis of the assertion that it is possible for researcher to step outside of their own lived experience and achieve a 'God's-eye view' of the world. Like Husserl, Heidegger suggested that individual human consciousness is not a static entity but rather it is subject to change across time according to the perspective of the individual in context.

Heidegger was among a group of existential philosophers who focussed on an ontological perspective of existence and the notion of Dasein (man) or being in the world (Todres, 2011). Moran (2000) refers to Dasein as the notion that man is situated in the world which is rich with meaning and it is from this meaningful and multi-layered context that meaning is created. According to Heidegger, there can be no 'universal truth' or essential nature of a given phenomenon. Rather, there are a myriad of possible experiential interpretations of a given experience which are both valid and attainable (Heidegger, 1962). Heidegger's ideas centre around humans as being in a constant process of interpreting the world in which they are situated, though this may not be apparent to them at the time the experience (Ashworth and Chung, 2006).

Heidegger's thinking focussed on human consciousness as a projection from within, stating that humans are open to multiple facets of a given experience. Bringing the notion of phenomenal reduction into question, Heidegger drew attention to the situatedness of individuals who make sense of and interpret their experience within the context of their own linguistic and sociocultural world. This thinking casts doubt on the possibility that it is achievable for researchers

to gain access to phenomena because it is impossible to grasp a given experience outside of the world in which it occurs.

Heidegger's version of phenomenology is associated with the philosophical branch of philosophy know as hermeneutics which is associated with understanding and interpretation (Todres, 2011). Once again, there are no rules or methodological procedures available for researchers to follow. However, there are guidelines available, however there are guidelines available described by Heidegger as discovering 'pathways' towards 'a clearing'. Hermeneutics can be thought of as a process available to researchers for interpreting and understanding events from the individual perspective of another.

Gadamer (1985) is credited with establishing phenomenology as an approach within psychological research. He referred to the hermeneutic cyclical process as the outcome of a fusion of two horizons. This occurs when the horizon of the researcher's understanding gradually moves closer to the meaning of the experience for the participant.

Figure 10 portrays this process applied to the analysis of textual data, enabling the researcher to reflect upon and refine their own understanding of the data by continually questioning and re-evaluating their own grasp of participant accounts. This process of reflective evaluation refines the researcher's own understanding as well as revealing their unconscious prejudices. Gadamer did not claim the hermeneutic circle resulted in a single universal truth. Rather, he states that the process opens the possibility for an account of experience to be reached where each person involved in the hermeneutic dialogue contributes to the creation of fresh understanding.

Figure 10 – The Hermeneutic Circle

New horizon of
understanding
reached

Questioning
prior knowlege

New horizon of
understanding
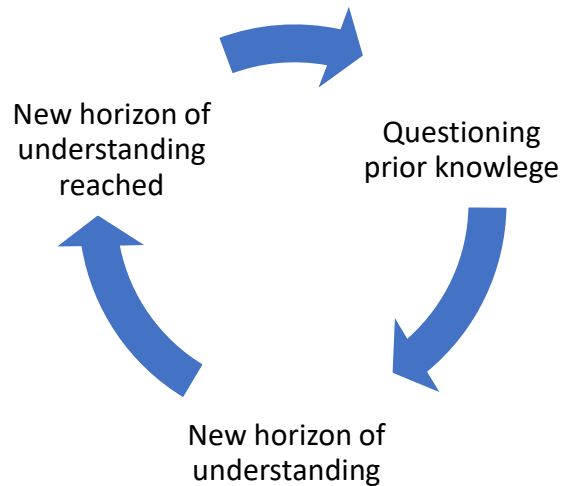
van Manen (2009) asserts that there are two important dimensions to applying the phenomenological method within phenomenology. These are the phenomenological reduction and the vocative dimension.

van Manen considers all reflections, recollections, or descriptions of experience can be seen as transformations of that experience. Being mindful of the issue of double hermeneutics, the researcher strives to get as near as is possible to an understanding of human experience whilst acknowledging that their interpretation is one interpretation amongst many possible understandings of the phenomena (van Manen, 2011). He asserts that phenomenological reduction is achieved by heightening the researcher's awareness to things in the world as they are lived rather than as they are theorised or conceptualised. This is not a distinct technique but rather it is a process of the researcher attending thoughtfully to the meaning and significance of the phenomena which leads them to question the experience (van Manen, 2011). In this process the researcher strives to overcome

'one's subjective or private feelings, preferences or expectations.

This includes theories of scientific ideas which may prevent the researcher from coming to an appreciation of experience as it is lived.

3.8 Reflecting on my own understanding of the phenomena.

My interest in the phenomena originated from my own experience and this impacted on how I oriented myself to the study. I spent many hours observing and listening to the families and friends of caregivers while working in a hospice. This meant I thought about what the experiences were like in a certain

way. I became a caregiver myself for a close friend which gave me a different perspective on how the role is adopted and this also sensitised me in particular ways to the phenomena of caregiving.

Added to this, I had some knowledge of much of the research and policy literature relating to family caregivers using palliative care services. These things combined to shape how I viewed the caregiving experience and the decisions I made while planning the research.

My aim as a researcher was to move beyond these preconceived ideas to be able to grasp the experience as lived. This involved entering a dialogue with the text (see figure 10 - the hermeneutic circle) whereby I questioned and evaluated my own understanding of the participant accounts.

The second dimension referred to earlier is the vocative dimension which relates to the emphasis placed on the role of language in the analysis of text and phenomenological description. However, van Manen (2009) states that a phenomenological study does not attempt to describe the nature of a phenomena but rather it elucidates the structural features of a phenomena that make it visible so as to show the experience in its nature or essence (van Manen, 2011). In pursuit of this aim, van Manen (2011) emphasises the role of language advocating the use of poetic meaning, anecdote and metaphor so as to communicate meaning to the reader. Given the level of involvement required by myself as a researcher, a mechanistic style of analysis would not have been appropriate. For this reason and in keeping with a hermeneutic phenomenological approach, data was analysed thematically incorporating a non-prescriptive coding procedure. Grenz (1996) likened this non-mechanical coding procedure to having a dialogue with the text which recognises the role the researcher plays in grasping hermeneutic meaning.

van Manen (1990) states that hermeneutic phenomenology is a dynamic interplay of six research activities which help the researcher gain a more in depth understanding of the nature of individual human experience. Figure 11 shows how I applied the research activities to the different elements of the research design.

Figure 11 - Research activities and related thesis parts

Research activity	Study design	Description
Turning to a phenomenon which seriously interests us and commits us to the world	Choice of study topic/ developing the research question/ Discussion chapter	Van Manen (1990) states that phenomenological enquiry begins when the researcher identifies an area of human experience which has meaning to them. My interest in how family caregivers' experiences change or stay the same over time and whether or not this is the same or different to the patients experience of illness was the starting point for this research. The ways that their experiences are affected by social and palliative care services developed over the course of the research.
Investigating experience as we live it rather than as we conceptualise it	Literature review / recruiting participants/interview design /data collection.	The researcher's description of lived experience remains just one interpretation of the phenomena. No one interpretation will exhaust another but rather the research aims to investigate the experience as near to as lived as possible. I recognise that my own interpretation may be different from that of another researcher.
Reflecting on the essential themes which characterise the phenomena	Analysis/ Findings and Discussion	What is a true reflection? This is a reflective understanding of those aspects of the experience that are of most significance. These aspects are made known by the researcher who identifies, describes and offers an interpretation of the main themes which differentiate between the appearance of the experience and its essence
Describing the phenomena through the art of writing and rewriting	Reflecting my experiences and thoughts throughout the thesis	It can be difficult for researchers to write about what they are thinking and yet reflecting their thoughts during the course of the research is an important part of phenomenological enquiry. My thoughts and experiences while conducting the research are documented throughout the thesis
Maintaining a strong and oriented relation to the phenomena	Analysis findings and discussion	I strove to remain focussed on the research question and not deviate from the study purpose despite multiple changes in the research approach. My aim in doing this was to develop themes and conclusions relevant to the phenomena which have implications for future research, practice and education.
Balancing the research context by considering the parts and the whole	The research proposal/ research ethics/ study design and context	According to van Manen (1990) it is easy to become side-tracked by phenomenological writing that the researcher loses sight of the overall design of the study and the significance that each part must play in the thesis structure. During the developing of themes , I stood back and reflected on how each theme related to the data as well as the research question and objectives. .

3.9 Longitudinal Qualitative Analysis (LQA)

In keeping with a hermeneutic phenomenological approach which is oriented towards exploring individual experience, this research utilised LQA as a method to explore changes in individual caregivers' experiences over time. McCoy (2017) states that the approach has been criticized by some researchers for its lack of clearly defined philosophical and theoretical foundations and lack of direct guidelines for data collection or analysis (Hermanowicz, 2013). These issues make it difficult for the researcher to stablish rigour within their research (McCoy, 2017). However, the approach does have practical and empirical potential when applied with other qualitative methodologies (Calman, 2013). Indeed, Snelgrove (2014) argues that LQA is an emerging methodology which supports research seeking to explore fluctuations within the perceptions and experiences of individuals over time. The method has applicability when used within health and psychological research as

well as enabling researchers who investigate how social and political interventions impact on individuals as well as their families and wider communities (Thomson and McLeod, 2015). I see the approach as a fitting method for this research which drew on the philosophical and theoretical foundations of hermeneutic phenomenology to explore the lived experience of individual caregivers across time as they engaged with social services and palliative care services whilst caring for a family member. Longitudinal research is gaining popularity within health service research though the method does have challenges which are associated with health care settings (Thomson and Holland 2003; McLeod, Calman, 2013).

During the process of analysing the longitudinal interviews data, I discovered several issues associated with the LQA approach. These related to the collecting and analysing of data, which took considerably longer than I had anticipated. The analytical approach explored the accounts of individual participants first, second and third interviews as stand-alone studies. Delays in gaining ethical approval meant there was a gap of ten months between the first interviews of participant one and participant nine.

During the recruitment phase, I began to attend DHCG AND BOFA where I presented the research to groups of family caregivers and nursing staff at the hospice. Some of the caregivers at these groups later became participants in the research. Building relationships and developing trust during the research is a necessary skill for the longitudinal researcher, though Calman et al. (2013) warned that this may add complexity to the researcher's role where both the participant and researcher can be affected by their interaction over time. Developing relationships with individual participants helped me to build rapport with group members and participants. This helped to engender a sense of ease and comfort for participants who were later interviewed. Snellgrove (2014) advocates a degree of caution for researchers who interact with research participants outside of the research process, warning against a level of unconscious bias which may influence how they plan the data collection and analysis. Within a hermeneutic phenomenological approach, the impact of the researcher's interaction with participants is acknowledged and I took steps to minimize the effect of unconscious bias during the analysis of data.

These steps are reflected upon within this thesis. Reflexivity is an important element of LQA especially when using an interview approach where, according to Mishler (1991) accounts of experience are co-created between the researcher and the researched. Added to this, Farr and Nizza (2019) point out that gathering multiple interviews with the same participant over time can present the LQA research with a challenge when strong bonds of empathy develop between them. This element of the research did require sensitive and careful management on my behalf (Carduff et al., 2014). I drew upon the practice of reflexivity to enhance the quality and trustworthiness of this research (Hammersley and Atkinson, 2007). This involved reflecting on my position of researcher and documenting my part in the construction of interviews to evidence accountability for my decision-making processes throughout all stages of the research (Finlay, 2002). Added to this, decisions made during the research were discussed in supervisory sessions where I was required to account for my choices and give a clear rationale for all decisions made.

A further consideration in using an LQA approach was my own role as a counsellor and bereavement support worker. These roles have sensitised me to the intensity of the carer's experience and given me an awareness of the privileged position researchers hold. I took steps to minimise the possibility that any interaction I have with caregivers did not influence their decision to take part in the research out of a sense of duty or loyalty to the hospice or researcher. For example, I always wore a name badge whilst at the hospice in all areas. This had the university logo and my title as Student Researcher clearly labelled. During presentations, I introduced myself to the different groups and members of staff at the hospice as a researcher for the university, making it clear I was not a hospice member of staff. All Information packs contained the participant information form (appendix) which states clearly that I am a PhD student at Sheffield Hallam University, and I reminded all participants of this before each interview.

3.10 The Pictor technique

Within this research, I planned to use the Pictor technique in certain interviews to help illuminate the participants' experience. Conducting interviews using this technique can assist in revealing the meanings individual attach to their lived

experience by assisting them in visually representing their experience, especially with regard to roles and relationships.

The exploration of relationships and role perceptions is a key element of the current research because of how these impact on individual caregiver experiences of providing care in different settings and contexts. Caring for a spouse with chronic illness in their home is a complex and multifaceted task and caregivers often find it difficult to articulate or reflect upon their experience at such times. There are multiple people and services involved in caring for a spouse with chronic disease and though reflecting on or picturing their experience can assist in the articulation of feelings and thoughts about the wider experience, this can also be difficult because much of what they do is taken for granted, especially when they have been in the caring role for long time. The routinised nature of repeatedly performing certain caring tasks means that spouses may not notice or appreciate small alterations in how they respond or react to changes occurring within their day-to-day experiences.

The Pictor technique (King et al., 2010) has its intellectual origins in personal construct theory (Kelly, 1955) where the process of construing is viewed as fundamentally a cognitive reasoning process. The technique involves inviting participants to construct a chart using arrow shaped post-it notes which are arranged in a way that best represents their interpretation of a situation at a given time.

Pictor originated from a method used in family therapy (Hargreaves, 1979) and has since been used as a research tool by Ross et al. (2005) to examine relationships and identify perceived roles and identities in a variety of health settings (King, 2005, 2010). It has also been utilised to explore how patients and their caregivers living in the community with advanced disease engage with the networks of professional and lay support and care (King et al., 2013).

3.11 Constructing the Pictor chart

Constructing the Pictor chart requires the researcher to give instruction to the participant whilst ensuring they do not influence the chart construction during the interview process. Hardy (2012) claims that an advantage of the technique is its transferability to settings where it may not be possible to achieve complete silence or where the participants focus may be interrupted. In such instances, Pictor makes it easier for participants to re-focus their attention after an

interruption or a pause. The technique can also be used when there is more than one person present at the interview although the current study aimed to capture the experiences of the caregiver only. However, in pragmatic research it is necessary for the researcher to be flexible in order to accommodate outside demands on the caregiver's time and attention.

I intended to conduct a Pictor chart with all participants who opted to construct a chart as part of their interviews. There were issues with using this technique which are discussed in this thesis. The Pictor charts which were conducted were carried out face to face and audio recorded with the participant's written consent. The stages of chart construction are detailed below.

After introducing myself and spending a few minutes becoming acquainted with the participant, I described the Pictor chart construction in as simple terms as possible. The chart is essentially a map depicting relationships between individuals and their relationship to any person, place or thing which represents important aspects of their experience. I explained that the chart is not a test and there was no correct or incorrect way to construct the chart.

A simple example of a Pictor chart was presented to them which outlined my own experience of being a PhD student, where the direction and colour of the arrows were used to indicate degrees of significance, or the particular function of individuals involved in my experience of being a PhD student. This was discussed as an example of what a completed chart might look like.

The participant was encouraged to think about their experience and reflect out loud using their own words. I used the interview topic guide to encourage participants to discuss their experience while constructing their chart while focussing on the participants' own version of the caregiving experience rather the patient's illness. With the participant's permission, recording began when the participant felt confident that they understood the chart construction instructions. During the chart construction, I planned to leave the room or stay in the room according to the preferences of individual participants. All participants who constructed a Pictor chart requested that I stay in the room with them. The recorder was left running until the end of the interview to enable me to capture their words and thought processes during the construction of the chart.

I closely followed the procedure described by King et al., 2010). who used the technique to interview health professionals.

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These are bulleted below.

- The participant is provided with a stack of arrow shaped Post-it notes in three colours and a sheet of blank paper.

- Participants are asked to write their own name in the middle of the blank sheet of paper. No instruction is given about where on the paper any of the arrows might be placed or how different colours might be used.

- The participant is asked to write the initials or names of individuals, groups, or services they are or have been involved with during the most memorable times in their caregiving experience. This is not restricted to individual people but could include any establishment or institution they felt had played a part in shaping their experience. For example, in the pilot study, the participant said that she and the patient had enjoyed watching one hour per day of a box set version of The Hobbit. The timing of this viewing session was a highpoint of their day which she said seemed to act as a dividing line between day and evening time. Within her chart, she named Bilbo Baggins as having played an important part of her experience because his appearance had 'signalled the end of another day'.

- The researcher leaves the room so as to avoid influencing how participants construct their chart.

- Once the chart is completed to the satisfaction of the participant, the chart is used as the basis of the interview. This involves placing the chart in front of the participant and asking them to reflect upon how have placed the arrows and describe how this representation correlated to their experience.

Following the interview, a digital image of the completed chart is taken, the colour and position of the arrow shaped post-it notes on the completed chart were reproduced by drawing around them and the names of individuals or institutions replaced with pseudonyms to protect the anonymity of the participant and others involved. The colour and position of the arrows is then copied clearly and accurately onto a separate piece of paper.

The chart was then photographed and reduced to A4 size, making it easier to refer to the chart alongside the transcript which helps illuminate the text and aid the analysis of data (King and Horrocks, 2010).

In second and subsequent interviews, the copy-chart was used as a template for participants to reflect and discuss changes that may have occurred since the last interview. The participant was asked to indicate changes on the copy chart using fresh post-it notes to represent new services or individuals. These were added to the chart whilst others were deleted or moved to different positions as the participant deems this reflected their experience.

3.12 Summary

Within this chapter I have offered a rationale for my chosen research design by exploring the ideas underpinning phenomenology in some depth, outlining key methodological principles which guided this research. In the following chapter, the method, and the way this is applied in the research is discussed along with ethical issues pertinent to how the research was designed and the process of gaining consent for the study.

Chapter 4 - Method Chapter

4.1 Introduction

In the previous chapter, I discussed the philosophical underpinnings of phenomenology as my chosen method of analysis and how van Manen (1990) hermeneutic science approach guided me in the exploration of individual participant accounts collected at different times. In this chapter, I outline the role of ethical issues in research and how these guided me in applying the methodological framework to the collection and analysis of participant data. The chapter concludes with my reflections on my role in the research process, my engagement with participants and my experience of using a novel approach to data collection.

4.2 Reflexivity

The goal of reflexive methods is to contribute to the analysis of data gathered using empirical methods. It is the task of the phenomenological researcher to get as close to the meaning of a given experience as it is lived and understood by individual participants. According to van Mannen (1990) understanding the 'meaning-making' process of another as communicated through textual data is a complex and multifaceted process. Yet, this process is central to reflexivity as it explains the procedure of engaging with data where the researcher questions question their prior assumptions and knowledge of a given phenomena while engaging in the process of analysing data (Braun and Clarke, 2006).

As a researcher, my unique way of viewing the world may have been shaped by factors such as the sociocultural environment I live in, my education and my own experience of the world. These influences are sometimes easy to distinguish, for example, having been a caregiver and working in palliative care settings has given me a particular understanding of the nature and timing of palliative care service delivery from the perspective of the person providing and delivering care. Other assumptions though are hidden more deeply. For example, it was not until I began to research the topic of caregivers and encounter the work of Ewing et al (2013), that I began to question the ways caregivers' needs are assessed during the time they provide care for a palliative care patient. The process of phenomenological reduction described in section 3.7 of this thesis is a key component of van Manen's method. It was through

this process that I was able to recognize some of my own assumptions and question how they may have influenced the analysis and the emerging findings. To support this process further, throughout the course of the research, I kept a reflective journal which documents my developing ideas throughout the analysis process. According to Clarke (2009) the research diary is an important tool for qualitative researchers which aids in facilitating researcher transparency during the research process. I used the diary to record details of encounters I had with individual participants as well as my own feelings and insights before and after interviews. It therefore seemed appropriate to reflect on my research experience in this thesis at the end of each set of analysed interviews. To do this I revisited my diary entries related to the interviews that had been analysed and also my reflections on the process of analysis.

4.3 Ethical considerations of the study

Ethical matters play an integral part in all research projects, and it is the responsibility of the researcher to demonstrate an adherence to ethical principles and standards in written works (British Psychological Society, 2011). Research with human participants in UK settings are required to adhere to a series of standards and procedures set by the Research Governance Framework for Health and Social Care (2001).

As the lead researcher and project lead for this study, I paid close attention to the physical and psychological wellbeing of participants during all aspects of the planning and design of this research. McCoy (2017) states there are ethical issues which are unique to researchers who adopt a longitudinal approach. These required judicious consideration and management by me from the study outset. All qualitative researchers, especially healthcare researchers, potentially encounter situations where they will hear accounts of human suffering, and these can be uncomfortable for them to listen to. Snelgrove (2014) points out that repeatedly engaging with the same participants and listening to their personal stories permits the researcher into enter into the participants' private and intimate world. It may be that, during this encounter, participants reveal information to the researcher, which is confidential, which they may not have shared with anyone else (Carduff et al., 2014; Hermanowicz, 2015). I was aware of this possibility and remained mindful of the participants' comfort and confidentiality throughout the process of recruitment, data collection, analysis

and leaving the research area. The way I managed these is discussed later in this chapter.

Undertaking research with participants who are caring for people with a short life expectancy, requires the researcher to consider the individual circumstances of participants who are at risk of being impacted by 'reciprocal suffering' affecting them physically, psychologically, socially, and spiritually (Wittenberg-Lyles, et.al., 2011). In the following sections, I will outline how ethical principles were addressed throughout the different elements of the research process.

4.4 Access to participants

In accordance with University policy, before undertaking the research, a full research proposal outlining the aims and objectives methodology and potential ethical issues was submitted to the Sheffield Hallam Research Ethics Committee (REC). The aim of this process is to safeguard the interests of participants and ensure the research meets the agreed standards of integrity, impartiality, and respect for the rights of potential participants. The research proposal received approval from the REC in April 2015.

Researchers intending to conduct research with participants accessing NHS services must abide by stringent NHS research governance measures. The NHS research governance framework exists to uphold ethical standards by ensuring proposed research is of sound scientific quality and is planned and managed well by the researcher (MacPherson, Lattin-Rawstrone, Senior and Barnes, 2005).

The process for gaining approval for individuals accessing NHS care was through the Local Research Governance Consortium (LREC). This procedure was designed for NHS staff seeking to conduct clinical trials with NHS patients. I was therefore initially uncertain about whether approval for this non-medical study would be required by the LREC. In the first instance, I sought advice from the Multicentre Research Ethics Committee (MREC) which scrutinises studies in detail. Calman (2013) points out that there are issues associated with longitudinal research because of the researcher's level of engagement, which necessitates repeated contact with the same participants. She cautions that researchers must sensitively manage their exit from the research process and the closure of relationships with participants who may become accustomed to

having someone to talk to. Hermanowicz (2013) also points out that this is especially difficult within longitudinal studies which seek to explore change or progression within experience over time. Longitudinal researchers often face difficult decisions around data collection and balancing the number of interviews against the risk of attrition (Farr and Nizza, 2013). This was a problem when applying for ethical approval for the research because I was not able to say with certainty how many interviews would be conducted with each participant or at what stage. After my initial approach to MREC, there was an exchange of emails and amended documents before I was advised to begin the process of applying for ethical approval via LREC. The initial application began online via the Integrated Research Application System (IRAS) system in December 2014. The study was approved in August 2016 after a full review (REC reference 16/YH/0201 IRAS project ID 198424).

The long and protracted process of negotiating and gaining approval helped to increase my awareness of the ethical considerations inherent in this and all research studies. It also helped to clarify my thinking regarding the fine details and different elements of the study. These are discussed throughout this thesis. Whilst awaiting LREC approval, I approached the Clinical Governance team at the hospice to enquire about the level of approval they required for researchers to undertake a study. With their permission, I began presenting the research and my ideas to hospice staff only, because at this stage, no contact was allowed to be made with hospice patients or their caregivers. The Clinical Governance team approved the study in May 2016, and I began to attend hospice caregiver groups and present my work to attendees. A synopsis of each group is outlined later in this chapter. At that time REC approval had not been granted and there were limitations attached to the ethical approval granted by the Clinical Governance team. Therefore, no direct contact with patients or caregivers on the inpatient unit was permitted at that stage. Many of the patients on the inpatient unit are still undergoing active treatment or review from NHS services.

Recruitment to healthcare research in palliative care settings can be challenging for researchers. The process requires them to exercise sensitivity, especially when researching caregivers who are providing care for friends or family members facing end of life choices (Addington-Hall, 2002). There are often

delays in gaining approval for research in this area because of issues relating to data protection and research governance regulations. Delays in the process of gaining approval for research projects in palliative care have been noted by a number of authors (Ewing, Rogers, Barclay, McCabe, Martin and Todd, 2016). Other palliative care researchers have reported delays in recruitment arising from 'gatekeeping' behaviour where medical or nursing staff feel torn between supporting research in the area whilst at the same time wishing to protect patients and their families from further anxiety or upset (Ewing et al., 2016). Calman (2013) notes there are particular issues with longitudinal studies in palliative care which rise from collecting data from participants living with various stages of chronic disease. I was mindful of the sensitivity needed when interacting with caregivers and remained eager to avoid causing them stress or anxiety at any stage of the research.

The current longitudinal research aimed to collect data from participants at 'critical points' in their experience. Critical points have been defined as events recognised by individuals, as marking a shift or alteration in their perception of a given experience (Thomson, Holland, Bell, Henderson, McGrellis and Sharpe, 2016). The building of rapport with caregivers played a crucial role in this research which investigates points in each caregiver's experience which were significant to them in terms of how the event shaped and influenced their way of making sense of their experience over time. Participants gradually became comfortable in discussing their experience with me and reporting what they saw as a critical event in their experience. On two occasions, a participant contacted me requesting to be interviewed after such an event, which they felt was important to them in that the event had forced a change in their perceptions and understandings about a crucial aspect of being a caregiver.

4.5 Research context

The setting for this research was a twelve-bedded hospice in Yorkshire which provides holistic care for people affected by terminal and life limiting illness. A range of services are available to both patients and caregivers at the hospice including support for those caregivers providing care in their own home. The participants in this study were recruited from three separate areas of the hospice which, required me to negotiate access to each area separately. The

different procedures for recruiting participants in each area is detailed in the section of this thesis which outlines negotiating access.

4.6 Recruitment

In line with the phenomenological approach the study, I aimed to gather the accounts of individual's who share a particular relationship to the phenomena of being a family caregiver over time (Heidegger,1962). I aimed to balance the number of participants with the amount of data and the time and word count limitations of the research. My priority was to do justice to the participants experience and the idiographic commitments of a phenomenological approach. Because qualitative studies aim for depth and meaning in data collection, the means that determine satisfactory sample sizes are different from those used in qualitative studies (Smith et al., 2009). Within published qualitative and especially phenomenological research studies, there is a focus on detail and richness of individual participant accounts rather than gather multiple accounts of a given experience. It is usual to find phenomenological studies with sample numbers of ten or fewer (Williams et al., 2011). The justification for fewer participants in phenomenological studies is that the study aims to 'honour the richness of the individual's account'. (Smith and Eatough, 2006). Recruitment in this study was aimed at gathering the accounts of people who were comparable in terms of their experience of providing care over time for a family member who is accessing palliative care because of a chronic or terminal illness.

I sought diversity in terms of the participant's age and gender as well as the illness diagnosis of the patient they were caring for. My intention in doing so was to prioritise the experiential accounts of individual caregivers at this time as opposed to focussing on illness related events and occurrences during the patient's illness trajectory. The sampling of participants was guided by 'information power' (Malterud, et al., 2015) where the quality and clarity of dialogue between participant and researcher is prioritised.

4.7 Negotiating access

Participants recruited to research studies are often contacted via referral methods or opportunity sampling which may be through the researchers own contacts or by snowballing (Smith et al., 2009) In the initial phase of the study, I met with the clinical director and two of the senior sisters from the hospice to discuss recruitment to the study. From these discussions, the Day Hospice

Carers Support Group (DHCSG) was identified as a possible area from which to begin recruiting participants to the study. The group is open to caregivers of patients on the inpatient unit and those attending the day hospice. Attendees meet for two and a half hours on alternate Tuesdays where the format of the meeting is varied and often comprises of talks from invited speakers who present on a variety of relevant topics; such as, signposting to local services, and benefits advice. The group provides an opportunity for caregivers to meet with others who are or have provided care for the patient. Here, caregivers can share their experience and concerns with each other, as well as having access to a range of free complementary therapy treatments. Hospice nursing staff attend the group also and are available to offer advice and support to caregivers on a one-to-one basis.

Attendance at the group is fluid and individuals typically attend from from several weeks to many months. Caregivers are offered the opportunity to attend the group when the patient begins accessing hospice services and may continue until the patient stops accessing services. As a result of this, caregivers attend the group at differing stages in their caregiving journey

In accordance with ethical permission granted by the Clinical Governance team at the hospice, I began attending the group regularly. This gave me the opportunity to interact with caregivers and give regular presentations to group attenders, outlining the aims of the research and chatting to them generally. My attendance at the groups helped me to build rapport with attendees and to be available for attendees to ask questions about the research and ask questions before they made a decision to participate. I was also able to foster a sense of being at ease for those who subsequently became participants who were asked to reflect upon their experience in some depth. Recruitment in this area was a process rather than an event and my contact with caregivers spanned several weeks and months before any formal data was collected.

In total, 76 study information packs were given out over a twelve-month period. These packs comprised a participant information sheet (appendix 1), a study reply form (appendix 2) and consent to participate form (appendix 3). Individuals who were interested in taking part were asked to return the expression of interest form (appendix 4) after which an interview was scheduled for a later date, allowing for a cooling off period of no less than 48 hours.

It is acknowledged that there are challenges in recruiting participants affected by ill health to research, especially in palliative care settings (Addington-Hall, 2002, Ewing, 2004). These were discussed earlier in this chapter and there was evidence of gatekeeping (Snowden and Young, 2017) at the hospice, though this was resolved over the course of data collection. This did result in some of the interviews being conducted considerably later than the initial batch. Added to this, the inclusion criteria for participation in the research stipulated that clinical and nursing staff were satisfied that caregivers were psychologically equipped to answer sensitive questions about their experience. At the time of data collection, there were severe staff shortages at the hospice which meant nursing staff were not able to assess the eligibility for every caregiver who expressed an interest in taking part in the research. This resulted in a delay in responding to participants who expressed an interest in taking part in the research and two caregivers, who had returned the expression of interest form, later decided not to take part. In total three participants from the group were recruited to the study.

In August 2016 I met with the steering group after becoming concerned about the low number of people recruited to the study. In response, I was offered to opportunity to attend a new group called Breath of Fresh Air (BOFA) as it was thought I may be able to increase the number of participants in the study. BOFA is a six-week course, delivered by the hospice team and the community specialist respiratory team. The course is for both patients and caregivers struggling with the effects of chronic and life limiting respiratory illness as the result of a range of conditions.

As part of the first week introduction to the course, I presented the research to all caregivers and gave out information packs about the research. Attending the groups enabled me to build rapport and be available for participant questions and to give out information packs to those who expressed an interest in taking part. In total, I attended five of the group cycles and handed out twenty-one information packs. As with recruitment in the DHCSG, individuals who were interested in taking part were asked to take return the expression of interest form (appendix 4) to myself or a member of staff, following which an interview was scheduled for a later date, allowing for a cooling off period of no less than 48 hours. In total, a further five participants were recruited to the study.

Recruiting from the inpatient unit required a full review by NHS LREC because some patients were still receiving active care from NHS services. In these instances, the caregiver's role in providing care for the patient meant they were under the umbrella of NHS care. Following NHS REC approval (Appendix 11) being granted, I met with the senior sister on the inpatient unit, who arranged for me to give a series of presentations to the day and night staff on the inpatient unit. Information packs were left at the nurse's station and three posters were also displayed at prominent points on the inpatient unit where they were visible to nursing staff and visitors to the unit.

When caregivers from the inpatient unit expressed an interest in taking part in the research, nursing staff passed on the caregivers' details to me and I contacted them either in person or by telephone after a cooling off period of 48 hours. As anticipated, recruitment in this area was slow and I made twice weekly contact with nursing staff to ask about potential participants. In a seven-month period a total of two caregivers from the inpatient unit expressed an interest in taking part in the research. One of these later changed their mind. One participant agreed to take part and two interviews were conducted one month apart. After the second interview, the patient died, and in line with the ethics application, no further interviews were conducted.

In total, nine participants were interviewed twice and six were interviewed three times over a period of one year. Figure 16 in Chapter 5 gives an overview of the participants detailing their pseudonym, their relationship to the patient, their age and details of their interviews.

4.8 Inclusion/exclusion criteria

The inclusion/exclusion criteria were designed in order to achieve a balance between closely defining the participants experience whilst allowing sufficient variation so as to reveal differences in their individual experiences of caregiving. The sample size was determined by the number of people available who addressed the aims of the research question, the relevance of accounts to address the study. Malterud et al., (2015) references this as 'information power'. Inclusion criteria

1. The participant is the named caregiver of a patient diagnosed with a chronic or life limiting condition and has taken on

significant caring responsibility for the patient since the onset of illness.

2. The caregiver and patient fall under the 'umbrella' of care being offered by the NHS and the Community Specialist Palliative Care Team and will continue to do so up until the time of the patient's death.

3. Based upon the knowledge of nursing staff, the participant is satisfactorily competent to answer potentially sensitive questions and psychologically equipped to explore their experience in some depth.

4. Participants are over the age of 18.

Exclusion criteria

1. Participants who are providing care for a patient in a residential care   setting or any setting other than the patient's home or the hospice.

2. Participants who have been identified by medical staff as being unsuitable for interview based upon their physical, cognitive or emotional state.

3. Participants, who are unable to read, understand or speak English.

4. Participants who are younger than 18 years old.

4.9 Process of consent

Within the current research, certain safeguards were put into place with regard to informed consent, for example, at the first interview the information sheet (appendix 1) was gone through and participants were reminded of their right to withdrawing their data from the study at any point during the research.

Participants were made aware that if they became upset during the interview, they could request to take a break before continuing or, if they preferred, they could stop the interview altogether.

The limits of researcher confidentiality were outlined in a clear way.

Those that wished to continue were asked to read through the consent form and encouraged to ask questions if they were unsure before being asked for their written consent to take part.

I sought ongoing written and verbal consent at all interviews, and these followed the same format and procedure.

At the end of the interview, participants were debriefed by myself and supplied with a debrief sheet (appendix 5). This included information about who to contact should they become upset or feel the need for support after the interview.

4.10 Data management

Planning the management of research data began with the planning of this project. This involved thinking carefully about how to manage live data, how data would be conserved in the long term and how data would be shared with others. In accordance with the data management plan (appendix 6), interviews gathered at the hospice were audio recorded on an MP3 digital recorder before being transferred onto a secure laptop. Images were recorded as a jpeg on a private digital camera before being transferred to the university's network storage system (Q drive). Some of the interviews were transcribed by a Sheffield Hallam University approved transcriber service before being stored on the University network storage system in both digital and word-processed format. I transcribed most of the interviews myself. All interviews were transcribed in a way which prioritised the safeguarding of participant anonymity (Richards, 2005). In practical terms, this meant all participants were anonymised by using a pseudonym in place of their name in all data, including the final thesis. Direct quotes were extracted from the participant transcripts and many of these were published verbatim within the thesis. Quotes were used and published with the direct consent of the participant. No information which would identify the participant, their family member or the hospice involved in this research was used in this thesis.

Details and demographics of all participants were documented in consent forms. Audio recorded interviews, transcripts, images and field note data were documented logically and clearly according to the content and structure. All hard copies were stored in a locked cabinet in a secure swipe card entry building accessible only to myself and members of the research team. Changes to versions and descriptions of data were documented to ensure clarity and transparency for myself and the supervisory team. This included

information about when, why, and by whom different versions were created, what methods were used, and an explanation of codes used for storage.

All stored data will be destroyed in accordance with the data preservation and storage policy at Sheffield Hallam University. The final report and thesis will be placed in the university repository on a password secure computer where it will be stored and destroyed ten years beyond the submission of the thesis.

4.11 Data collection

Two kinds of data collection informed this research, and these were research field notes and two distinct interview approaches. I will outline the two interview approaches later in this chapter, beginning with a summary of how I used a semi-structured interview method before describing the use of the Pictor technique, a novel interview style described by King, Bravington, Brooks, Hardy, Melvin and Wild (2013)

4.12 Research field notes

Research field notes are a valuable component of qualitative research which encourage the researcher to record notes which can enhance data analysis by providing rich contextual data (Philippi and Lauderdale, 2017).

Field notes are an invaluable tool for qualitative researchers to assist them in maintaining a reflexive attitude to their own evolving ideas and biases (Philippi and Lauderdale, 2017; Hewitt, 2017). I began to collect research field notes early in the research period to document my own learning process. I found they helped to clarify my thinking about the theoretical framework of the study and the nature of knowledge. According to Snelgrove (2014) research notes have an important function within a longitudinal phenomenological approach, as the researcher is tasked with setting aside their own emerging assumptions throughout the process of interacting with participants over time. I recorded my own thoughts and feelings in research notes the time I was interacting with participants which helped me to raise my awareness of my own emerging unconscious assumptions or tentative theoretical interpretations I may have made. McCoy (2017) highlights the issue of the researchers' own assumptions as a unique dilemma for longitudinal researchers, stressing the need for open mindedness and impartiality on behalf of the researcher who conducts recurrent interviews with the same participants.

Research diaries or field notes are frequently used in qualitative research with unique objectives. Documenting the process of research as well as changes throughout the research process facilitates researcher transparency and helps the researcher to develop critical thinking (Clarke, 2009). The research notes helped me to document and reflect on my use of Pictor (King et al., 2013) which is a novel interview tool and one which I had previously used in a pilot study with bereaved caregivers.

4.13 Interviews

Interviews are a major method of data collection, frequently used in qualitative research (DiCicco-Bloom and Crabtree, 2006). There is a wide variation in interview approaches available for researchers to adopt according to their discipline and a research design. Interviews are a pivotal part of the research which provides the researcher with an opportunity to explore the participants experiences in some depth. Van Manen (1990) speaks of qualitative interviewing as a speech activity, with the capacity to facilitate the emergence of meaning through interaction. In a human science approach, the interview is seen as a 'vehicle' to develop a conversational relationship with the participant and broaden the researcher's understanding of what this experience is like for them. van Manen (1990) encourages the researcher to enter into the lifeworld of each participant by adopting an attitude of 'hermeneutic alertness' to the participants' experiential accounts. By immersing themselves in individual participant accounts researchers remain alert for 'living phrases' or anecdotes to obtain a glimpse into the world of the participant and develop a deep understanding of their experience. Serial in-depth interviews were used in this research to investigate change or consistency within caregivers' experiences across time. Murray, Kendall, Carduff, Worth, Harris, Lloyd, Cavers, Grant and Sheikh (2009) highlight how this this approach resonates with the aims of healthcare providers to maintain continuity of contact with service users. Within this approach, I utilised face-to-face interviews with individual participants which, given my level of involvement with participants, I felt was an appropriate style of interviewing compared to more mechanistic style of questioning. A further advantage of a face-to-face approach is that, by asking participants to reflect on their experience at the same time as observing their body language and how they express certain aspects of their experience, I can

move closer to their experience in that moment. Finlay (2005) acknowledges the relational connection that exists between researcher and participant during which the researcher can convey empathy whilst maintaining their own position and identity as researcher during the interview. Throughout the interview, I paid close attention to the participant and conveyed empathy using non-verbal language such as maintaining eye contact, nodding and my own embodied reactions. Finlay describes this attitude as one of 'reflexive embodied empathy' which draws on phenomenological thinking and, I argue, is a fitting approach to interviewing participants who are discussing intensely emotional matters which impact on multiple facets of their lived world.

4.14 Interview context

It is important that qualitative researchers consider the setting and context in which the research interview takes place because these factors impact on the atmosphere of the research interview as well as influencing the quality of engagement between researcher and participant (Ireland and Holloway 1996). All participants were given a choice of place for the research interview depending on where they felt most comfortable. Most participants chose to be interviewed at the hospice which may have been because it is a place, they are familiar with from frequent contact with hospice services. The hospice provided a private room for interview in a, quiet space on hospice premises. These rooms are regularly used to facilitate confidential and sensitive discussions. Two of the interviews were held in the participants' home and in these instances, I worked in accordance with the Sheffield Hallam University lone worker policy.

4.15 Semi-structured interviews

Where the participant expressed a preference for conducting their interview with a semi-structured approach, these were conducted face-to-face using a loose interview topic guide (appendix 7). All interviews were audio recorded with the participant's consent. I began each interview by asking participants about themselves and, as the interview progressed, I broadened the dialogue to include their role as the patient's caregiver. Each participant response was used as a guide for me to encourage them to further reflect on their experience and explore areas of interest by steering the interview in the direction of topics relevant to the research question.

Second and subsequent interviews were conducted following an event identified by participants as critical in that it marked a shift in their perception. Before each successive interview, I reviewed field notes taken after the initial interview and listened to the interview's audio recording.

Hermanowicz (2013) states that the capability to adapt the interview topic guide to meet the requirements of the study differentiates longitudinal qualitative research from quantitative research designs. I used the same semi-structured interview guide (appendix 7) for all participants, first, second and third interviews because an open style of questioning allows the participant to focus on whatever issues are important to them at that point in time. Farr and Nizza (2019) suggest that adjusting the interview schedule in response to earlier accounts inhibit the emergence of new issues which may be significant to the participant. My intention was that the interviews, including the timing of interviews should be driven by the participants perceptions of change in their caregiving experience. I aimed to explore rather than assume change or similarity across time, therefore making inductive comparisons between interviews would have resulted in my imposing my own ideas and assumptions about change in the participants' accounts.

4.16 Leaving the research setting

In total, six participants completed all three interviews, and in final interviews I reminded them that I would not be asking them for further interviews. Three participants completed only two interviews because the patients had died and in accordance with the ethical boundaries set down by LREC, no further interviews were conducted with these participants. Some boundary issues did arise during the data collection period when one of the participants invited me to attend his wife's funeral. I sought advice from my supervisory team and the hospice clinical governance group on this matter in case there was a protocol for such occurrences. I was told by the hospice team that it was not good practice to attend patients' funerals and I decided not to attend. However, I did offer my condolences to the participant via post. Approximately six months after her last interview, one participant contacted me via email to let me know that she was doing well and feeling positive. She also wished me well in the write-up of this thesis and requested a lay copy of the thesis upon completion.

Because of my continued attendance at groups, it did not feel as if the participant-researcher relationship was being ended abruptly. Three of the participants continued to attend the groups so there was some consistency in contact until I left the hospice to allow another researcher to start their research study.

On my last day at the hospice, the staff and some of the group attendees held a goodbye celebration with afternoon tea on my behalf. Seven of the participants came to say goodbye. Three of them thanked me for offering them the opportunity to take part in the research and share their views and experiences. In each case, it felt like the researcher-participant relationship was coming to an end on the participants' own terms.

4.17 Analysis of data

I selected a longitudinal qualitative analysis (LQA) approach to analysing the data. This drew on the principles of phenomenology (Braun and Clarke, 2006) to analyse the accounts of nine caregivers and make known how they perceived and made sense of their experience of providing care for a family member with chronic and life limiting illness. The aims of the research were to understand more about change or stability in the experiences of caregivers engaging with palliative care services while providing care for a family member over time. The literature review highlighted previous studies which focus on the kinds of things that may impact on their experience and how this may or may not change over time. The research analysed and presented data from individual participants, first, second and third interviews as a stand-alone study. These were organised into a thematic coding plate for each first, second and third interview. Using the participants' own understandings of incidences which they considered important, I explored these incidences in terms of their similarity or dissimilarity to the patients' illness trajectory or to their interactions with palliative care services. In the next section, I will outline the process of selecting a method of data analysis, justify the timing of interviews and give a rationale for my choice of data presentation.

4.18 Longitudinal Qualitative Analysis (LQA)

The term LQA is a general phrase which describes a design used by researchers to investigate experience across different points in time. The approach has gained attention for its applicability to research in a variety of healthcare settings including its compatibility for use across a range of research designs (Calman, 2013; Snelgrove, 2014; McCoy, 2017). A particular strength of LQA is that it enables the researcher to move backwards and forwards across experiential accounts gathered at different times to make known the temporal features of the participants' experience and shed light on fluctuations in their perspectives at different times. According to Carduff (2014) well designed LQA has the capacity to shed light on even subtle changes in the perspectives of individuals over time.

This was a benefit to this study which aimed to explore clear or nuanced changes in caregivers' experiences and explore how these are similar or different to changes in the patients' illness. An approach for comparing individual experience, whether this be within multiple groups or across multiple points in time, was particularly appealing for this study. I aimed to explore if, and in what ways, the caregivers' experiences resonated with metaphors used in current literature which are assumed to reflect the journey of being a caregiver for a patient with palliative care needs (Morris and Thomas, 2001; Shulman Green, 2004; Marsella 2009; Shearkhani, 2016). These representations are frequently used in palliative care and other healthcare settings to illustrate how the caregivers' experience corresponds to the patients' illness trajectory.

There are particular benefits to the LQA approach for researchers who have an interest in exploring the experiences of individuals affected directly or indirectly by progressive illness and disease (Meleis, 2000; Murray et al., 2009; Calman, 2013; Kendall et al., 2015; Carduff et al., 2014; Spiers, 2015).

A review of longitudinal phenomenological studies by Farr and Nizza (2019), stresses the increase in the use of LQA studies which is committed to an idiographic level of understanding experience as lived in terms of its temporal flow. McCoy (2019) highlights a particular difficulty with longitudinal research, suggesting a way to explore changing experience would be to revise conventional assumptions of time as a linear process in favour of a more subjective view of time. This approach would question commonly accepted

views of time as occurring in a linear way. Smith, (2007) states that good LQA research should demonstrate change over time by showing how the same theme may manifests itself in the accounts of different participants and different ways. His cross-case analysis explores women's identity development during the transition to motherhood using the thematic structure to evidence similarities and differences in participant accounts by focusing on the account of one participant, Claire, at the beginning of each new theme before comparing and contrasting the experiences of other participants to that of Claire's. Gathering single accounts of individual caregivers would not have enabled me to explore how each participant's experience of living with chronic illness impacted on them over time. Certain authors have pointed out the advantages of using temporal research designs instead of 'snapshot' techniques which restrict an adequate understanding of the participants experiences to a single point in time (Snelgrove et al., 2014). Providing care for a family member is rarely a single event, more frequently, providing care that takes place over weeks, months and in some cases years. During this time, there may be many changes which affect how caregivers perceive and adapt to being a caregiver. I argue that understanding more about how and why caregivers' perceptions might change or stay the same has important implications for future research and practice in this area.

LQA does require interpretation on behalf of the researcher and phenomenology was utilised in this research because of its interpretive (hermeneutic) epistemology and its commitment to an idiographic level of analysis (McCoy, 2017). This approach investigates change and stability within individual accounts of experience by interpreting individual accounts of participants who have a particular relationship to the phenomena. I consider a phenomenological approach to be sensitive enough to explore the subjective experience of participants providing care across time whilst still maintaining the study's scientific rigour (Seymour, 1998).

4.19 Thematic analysis

Data was analysed thematically using an approach described by Braun and Clarke (2006). This was chosen because of its focus on identifying, describing, analysing and reporting of idiographic patterns of meaning across participant accounts. Thematic analysis can equally be applied to data sets to capture

incidences of difference and similarity (McCoy, 2019). Braun and Clarke assert that this reflexive approach is compatible with phenomenology, social constructionism, and other critical approaches to qualitative research.

An advantage of this approach for this research is the ability to utilise the method across a range of epistemologies. This element of theoretical flexibility enabled me to adapt the approach to meet the aims and objectives of the study and provide rich and detailed accounts of unfolding experience within a complex dataset. Braun and Clarke (2006) emphasise the need for researchers to be positioned at the centre of the research process and to demonstrate reflexivity throughout the process of analysing data (Braun and Clarke, 2006). This level of transparency on behalf of the researcher improves the trustworthiness of the research by the researcher making known their thought processes and reasoning throughout the analysis of data. This was evidenced in this research by my keeping detailed records of how and when I assigned themes to the data including how and when themes changed during the analysis. These records were used as a basis of discussions at supervision sessions where I was called upon to justify my decision-making process when adjusting the thematic structure.

4.20 Recurrent cross-sectional approach

There is a lack of guidance within qualitative literature regarding the best way to capture and convey experience over time. The review presented by Farr and Nizza (2019) outlines two different approaches which have been used to present the findings and analysis. The first approach is referred to as themes spanning time where data is analysed and presented as a set of themes describing a particular aspect of all participants' experiences over multiple time points. An example of this was conducted by Shaw (2016), who interviewed participants moving into a retirement village at three separate time points to investigate the experiences of older adults' as they move into extra care housing.

The second approach is described as themes tied to time points where themes which are relevant to individual participants at a given point in time correspond to other adjacent time points. Smith (1999) used a theme-tied-to-time-points approach in his exploration of the identity of women as they transition to motherhood.

In both these studies, themes are presented by using one participant's account to exemplify a particular aspect of their experience. At the same time, the experiences of other participants are amalgamated into the narrative to compare and contrast their individual experiences of a particular theme. By comparing the different accounts of participants, using quotes to evidence progression across time, the study conveys the participants unfolding idiographic experience of a phenomena.

An article by Grossoehme and Lipstein (2016) compares and contrasts two different approaches to analysing longitudinal studies of individuals interacting with healthcare systems. These are described as are a recurrent cross-sectional approach in which data from different points in time are analysed as a single study. Individual participant quotes are used to reveal how and where participants perceptions of the phenomena change or stay the same over time. Whilst none of these approaches are mutually exclusive, I felt a recurrent cross-sectional analytical approach was the most appropriate for the current study for the following reasons.

- The aim of this research was focussed on elucidating differences and similarities in the perceptions and experiences of individual participants across time as they engaged with palliative care services as part of their role in caring for a family member with chronic or life limiting illness.

- This assisted in bringing data collected at multiple points together as a series of studies which, though they are independent, are also the essential parts of overall interpretation of experience, McCoy, (2017).

- This approach is thought to be especially valuable in studies where participants are recruited from a highly transient group or where mortality may impact on data collection (Grossoehme and Lipstein, 2016).

- The approach allowed me to analyse interview data, when completed at different time points, as a stand-alone study. Data from subsequent time points were then analysed in respect of its similarity or difference to the preceding timepoint enabling the researcher to focus on explicating change or consistency across

time. I had initially considered this to be an advantage of this approach. However, there were delays in recruitment which meant there was a gap of ten months between conducting the initial interviews of the first and last participant. This did lead to a delay in writing the findings and analysis chapter.

4.21 Template Analysis (TA)

The interviews produced a large amount of data which required careful handing. In analysing the data, I drew on TA (King and Horrocks, 2010) which evolved as generic approach for use within a variety of thematic analysis approaches. The approach can be used to analyse any kind of textual data from many but not all methodological and epistemological positions. The approach can also be used in research that takes a similar realist position to mainstream quantitative psychology, in seeking to 'discover' the underlying causes of human phenomena. In contrast it can also be used within a 'contextual constructivist' position (Madill et al., 2000), which assumes there are multiple interpretations to be made of any phenomenon, and that these depend upon the position of the researcher and the specific social context of the research. The approach was developed by Professor Nigel King at the University of Huddersfield (King and Horrocks, 2010) and has since been used widely in real-world settings (Wyatt and Sylvester, 2015), including healthcare research (McCluskey, Brooks, King and Burton, 2011; Brooks and Youngson, 2013). It has proved especially useful in research where multiple participant perspectives across different settings are considered (Brooks and King, 2012). The iterative approach to analysis is particularly useful for developing those themes which relate most specifically to the research question in greater depth without losing sight of the participants experience which may seem less directly relevant, but which nevertheless plays an important role in contextualising their experience.

The term 'template analysis' refers to a particular way of thematically analysing qualitative data. This may be data from interview transcripts; however, it could also be a different kind of textual data, including diary entries, text from electronic interviews or open-ended question responses on a written questionnaire. The approach involves developing a coding 'template', which summarises themes identified by the researcher(s) as important in a data set and organises them in a meaningful and useful way. Hierarchical coding is

emphasised, using broad themes which include successively narrower, more specific themes or sub-themes.

A distinct feature of this approach is permissibility of *a priori* themes, which are themes or topics tentatively defined by the researcher in advance. These may be based on theoretical or pragmatic interests which relate to the study. King and Brooks (2017) discuss a priori themes as a continuum between 'hard' a priori themes being clear in their definition and objective and 'soft' a priori themes which may correspond to the research aims or objectives. According to King and Horrocks (2010), the key advantage to using a priori themes is that they can help to speed up the initial coding phase of analysis. Given the amount of data produced in this research, this was a distinct advantage. However, there are drawbacks to using a priori themes for example, researchers may ignore data which does not relate to a priori themes because they are focussing on data which does correspond to them. There is also a risk that researchers may fail to notice if an a priori theme is not resonating with the collected data or if it does not prove to be an effective way of characterising it (King and Horrocks, 2010). To prevent these issues, I kept in mind the tentative nature of any a priori themes and redefined or removed them when they did not serve a purpose in the analysis. I cautiously identified soft a priori themes from focusing broadly on the ways caregivers' experiences have been conceptualised in previous literature. However, to lessen the possibility of a priori themes steering the analysis in a particular direction, I ensured that they were defined loosely and related to incidences where caregivers alluded to change or stability within their experience.

4.22 How TA was applied to data

Central to the TA approach is the creation of a hierarchical coding template, which is typically constructed in stages beginning with an initial template from a subset of data. transcripts and using a priori themes where appropriate. The initial template was created by identifying chunks of text in the transcript which appeared to be helpful in furthering my understanding of the phenomena. The initial template is then applied to the remaining transcripts by modifying, adding or changing the thematic structure of the initial template in an iterative fashion to develop new themes or restructure others as applicable (King, 2012). A worked through example of how I developed the initial template this can be found later

in this chapter. Within the template, themes are displayed in a hierarchical fashion though the hierarchical pattern of themes does not necessarily indicate levels of importance. Rather, organising the data in this way allows the researcher to show different levels of meaning within the experience of participant's The process of applying the template to newly emerging data means the template is modified multiple times until a final interpretation of all participants' experiences are arrived at. This, it seems, is the researcher's interpretation of the data.

Throughout the development of the template, I kept an audit trail of the stages of analysis, documenting in my research diary how themes were identified and how my thinking progressed. The researcher's decision trail reveals the process of revelation (Rapport, 2004) and is an important component of trustworthiness (Whitehead, 2004)

In keeping with the phenomenological tradition of focussing on meaning, I drew upon participants narratives of their lived experience to explore the phenomena of caring over time. This was done by hand coding each participant transcript in an iterative process of insightful discovery, described by van Manen (1990) as a 'free act of seeing'. Eventually, I was able to grasp a thematic understanding of how the experience of being a caregiver evolved and changed over time. In order to bring to light individual caregivers' experiences, I drew on a cross-case analysis using the idiographic accounts of each participant to draw attention to those themes were most pertinent to individual caregivers at certain points in time. By doing this I was able to focus on where key themes in the coding template applied to these participants at given points in the data collection period.

According to King and Brooks (2017) there is a risk within this process that assigning thematic codes to individual participant accounts can lead to an over-generalisation of their lived experience at the cost of a deeper and more holistic understanding. However, the template does not represent a generalised view of overall experience but metaphorically speaking, the themes and subthemes are 'like knots in the webs of experience' (King, 2012) around which individual experience is lived and experienced. Thus, the thematic template can be understood as a meaningful whole reflecting how the participants in this study made sense of their experience.

Fig 12 outlines the process of thematic coding and how participant interviews transcripts were used to construct a template which reflected the experience of caregivers' longitudinal experience. Top-level themes (Indicated by the blue u-shaped arrows) are used to inform but not determine 'soft' a priori themes for the analysis of all first, second and third data sets. The temporal dimensions of caregivers' experiences were made known by scrutinising salient times from each set of interviews (the parts) and examining whether and how patterns of themes changed or stay the same between successive timepoints.

The meaning of change and stability is explored in Chapters 5 and 6 of the thesis. King and Brooks (2017) note a lack of longitudinal studies using TA where experience over time is explored using successive templates to demonstrate how and in what ways an experience changes over time.

Fig. 12 The process of thematic coding.

4.23 Assigning themes

Many of the themes assigned at a during the process of analysis included the experiential accounts of more than one participant. The important point about assigning themes is that that they interpret experience in a way that balances expression of individual experience with capturing the essence of the phenomena.

In keeping with the phenomenological tradition of focussing on individual experience, the aim of this study was to go further than the exploration of hierarchical patterns within or across the template themes which may lead to over-generalising participant accounts at the cost of a more holistic understanding of caregivers' experiences (King and Brooks, 2017).

To reveal the expression of individual experience, participant quotes were used to make known how individual participants' experiences changed or stayed the same and how this had been impacted by their interactions with palliative care services. The element of flexibility within this approach is especially useful for the LQA researcher who seeks to investigate and make known where in the data where there is change, fluctuation or stability in participant accounts (King et al., 2013).

In using TA, I sought an iterative approach to data analysis which would allow me to organise and restructure the thematic outline of data in accordance with newly emerging findings or themes. The element of flexibility within the TA approach is particularly appealing to researchers conducting pragmatic research in real world healthcare settings. Data was audited by having a record of each version as well as keeping a research diary documenting my decision-making process throughout the developing of the template.

Copies of the emerging template were discussed with supervisors who critically examined it at different stages. Throughout the process of writing the findings, analysis, and discussion chapter, I circulated copies to selected peers for their review and feedback

4.24 Stages of developing the initial template

The recorded interviews from all first interviews were transcribed verbatim using a transcription service. Analysis of the transcripts began as soon as possible after each interview had been transcribed. I selected a subset of participant transcripts based on the richness of their experience and diversity from each other in terms of their individual characteristics, the patient's illness types and the amount of time the participant had been in the caregiving role. Some of the transcripts were difficult to read because of repeated words and non-words such as 'ums' and 'errs'. I found this distracting and for this reason, I listened to the recorded interviews while reading each interview in a line-by-line approach. This approach supported meaning making to a deeper level than reading the interviews alone. It also helped me to immerse myself in each participant's account and become more acquainted with the fundamental nature of their individual experience.

During this time, I engaged with research and field notes to allow me to identify where certain phrases, expressions or passages of text appeared to reveal something fundamental about the essence of the phenomenon.

Selected units of text relating most closely to the meaning making of each participant were colour coded in the script. These were cut out and organised into the thematic categories which related most closely to the research question and furthered my understanding of the phenomena. At this initial stage there was considerable crossover of categories and I found it helpful to write a summary of each theme in my research diary to clarify my own thinking. However, I did not want to define the themes too strictly at this very early stage of the analysis. Fig 13 shows the structure of the template after developing the first of a subset of interview transcripts

Fig 13. Stage one - developing thematic categories from the account of one participant.
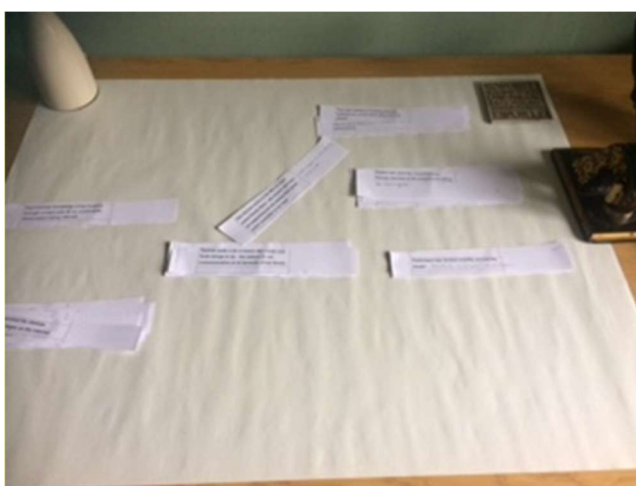
This longitudinal study generated a significant amount of data, and I spent a considerable amount of time developing thematic categories. Although these were interesting, I later recognised that they were not helpful in terms of furthering my own understanding of the phenomena. King and Brooks (2017) remind researchers that the purpose of constructing the template is to assist in exploring individual participants' experiences. I remained focussed on exploring areas most pertinent to each participant as it related to the research aims and objectives.

Following multiple discussion sessions with colleagues, some of the themes were redefined or discarded. Similarly, I had tentatively selected a priori themes

prior to analysing data. However, I remained open to discarding these if and when they were not relevant to the research.

I cautiously selected the top-level themes from the account of the first participant as 'soft' a priori themes to inform stage two of the template development.

Fig 14 Stage two developing the template further.
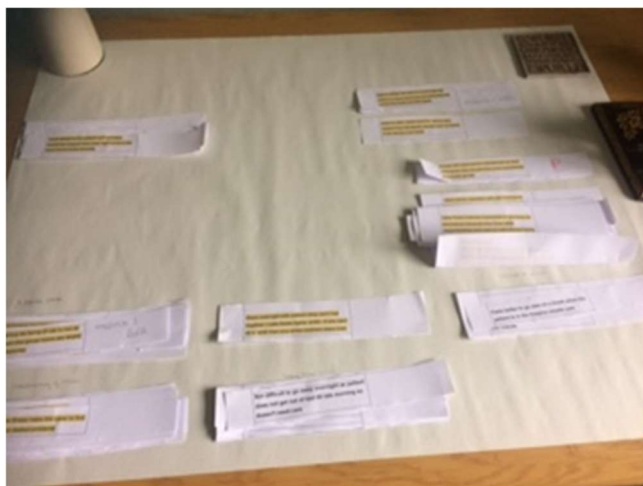
One of the challenges this presented was remaining true to the phenomenological tradition of recognising the researcher cannot entirely remove themselves from their position in the research or knowledge gained from researching the topic.

Having acknowledged that some emerging themes may or may not correspond closely to the themes in the initial template, the challenge was to avoid being influenced by these themes when scrutinising the subsequent data sets lest they influence and restrict how I construct stage two and successive template versions. While utilising top-level themes of the initial template as a priori themes, I disregarded sub-level themes elaborating on the main themes in detail. Where specific themes emerged from the data that correspond to top-level themes, for example, where caregivers discussed their perceptions of being in transition, I remained open to exploring the different ways they discussed this. I was cautious in not making their experience fit with themes in the previous template. I read carefully through each transcript and used the 'copy' and 'paste' function to attach relevant participant quotes in the data to the relevant section of the template. The 'comment' function was used to label each quote with the line number in the transcript so it would be easy to find it in the

future. I also kept a copy without quotes to look back on and used the 'track changes' function to record the reasons for developing the emerging template. Throughout the process of developing this initial template there were instances where I stood back from the data to re-acquaint myself with the research question and re-evaluate how the themes contributed to the overall phenomenon. King (2004) recommends reviewing and adapting the template in this way to allow the researcher to consider the data at varying levels of specificity and detail.

Fig 15 shows the structure of the template after having added the data of all three participant transcripts to the template. Having coded all three transcripts, an initial version of the template was developed which shows how the hierarchical grouping together of similar themes reflected broader themes within the data set (Fig 8)

Fig.15. Initial template from the accounts of three participants

Theme 1 Effect on caregivers' own wellbeing

Theme 2 A sense of self

Theme 3 Adapting in non observable ways.

    3.1 Changing the environment

    3.2 Help seeking behaviour

    3.2 Something is different

Theme 4 The drive and desire for a normal life

Theme 5 Becoming an inexperienced expert

Theme 6 Ways of understanding illness changes

    6.1 Illness has a predictable framework

    6.3 Change defined by an increase in the frequency of hospital visits

    6.3.1 Treatment changes

    6.4 Increase in demands on caregiver

Theme 7 Critical moments

Theme 8 Managing relationships

    8.1 Carer/ patient

    8.2 Family members

    8.3 Medical and professional staff

This initial template was applied in an iterative fashion to the remaining transcripts by revising and merging thematic categories together and inserting or deleting them when they were no longer useful in revealing the experiences of the participants. When all participant accounts had been applied to the emerging template, a final version emerged revealing the interpretation of caregivers' experiences of the phenomena as it unfolded in real time. This is explored in more detail in the findings chapter

King and Brooks (2017) draw attention to qualitative studies where TA has been used to compare data sets. For example, the analytical process used by Wyatt and Silvester (2015) to explore the experiences of black and minority ethnic (BME) managers was used to compare them to those of white senior managers However, so far, studies using TA to compare experiential accounts collected at different points in time have presented data of unfolding experience within a single whole template. The current longitudinal study goes further by coding and indexing different data sets collected a different time points. Patterns of themes within the data sets are used to reveal incidences of change and stability in the participants' experience over time.

4.25 Ethical governance

The research setting for the study was a hospice in West Yorkshire where holistic care is provided for patients and caregivers who are or have been affected by terminal and life limiting illness.

The process of recruiting participants from the hospice began in 2015 when I was asked to send a copy of the research proposal to the Clinical Services Manager and the Medical Director at the hospice. After meeting with the Hospice Governing Team (HGT), permission to recruit participants to the DHCG was granted and I began attending the group who met fortnightly. At the request of the HGT, nurses in the Day Hospice would play a gatekeeping role between myself and any potential participants. In practice this meant the nurses would act as an intermediary between myself and participants to ensure that, based on their knowledge of the patient's family, all who participate in the research are mentally robust enough to speak in depth about their experience of caring for a family member. Gatekeepers therefore could permit or deny permission for researchers to access to potential research participants. Whilst attending the

DHCG I gave numerous presentations outlining the research to group attendees. I also met regularly with day hospice staff and sent monthly updates to the HGT to inform them of the progress of the study. After recruiting for six months, just two participants were recruited to the study despite considerable early interest being shown. It was suggested by the hospice governance team that I widen the scope of recruitment to include attendees of the BOFA group. I began attending these groups in 2016 where again, I presented the research to group attendees as well as hospice staff and community physiotherapists. A further five participants were recruited from these groups.

The HGT stipulated that recruitment of participants from the inpatient unit should not begin until approval from NHS Rec was in place. This approval was granted in November 2016. I initially met with the senior sister on the inpatient unit and it was agreed that I would give a series of presentations to day and night staff who would be acting as gatekeepers. Steff did seem to be very enthusiastic about the research and asked lots of questions. I felt I had addressed their concerns though some expressed misgivings and spoke of feeling torn between wanting to lend their support to the study and protecting family members from avoidable anxiety.

It was agreed that study information packs would be left at the nurse's station on the inpatient unit. Family members who expressed an interest in taking part in the research would be screened by staff. Those who were considered psychologically strong enough to participate would leave their details with staff who would forward them to myself. Two participants were contacted and sent a study information pack and one agreed to participate.

 I had anticipated that recruitment to the study would be slow, and it is possible that the practice of gatekeeping contributed to delays in recruitment. This is discussed in the limitations section of this thesis.

4.26 Establishing quality

The quality and validity (or trustworthiness) of qualitative research is evidenced using a different set of concepts to those applied to qualitative research. Quantitative research seeks to produce findings that are generalizable across contexts or reliable and valid across time. However, there are no strict rules or universally agreed guidelines that are applied to evidence qualitative research

outputs are of a high standard. King and Horrocks (2004) point out that there are a set of guiding principles, which can assist researchers in fulfilling their professional and ethical obligation to ensure high quality in research outputs by offering insight and understanding into the phenomena being studied. Yet, there is much debate around what criteria can be used to determine that this is achieved.

The objective of qualitative research in terms of establishing quality and validity is to demonstrate good scholarship and pass the 'so what?' test (Sendelowski, 1997). Yet, quality is a many-sided concept that differs according to the context and aims of the qualitative research study (NICE guidelines, 2012). Broadly speaking, guidelines must take into consideration the significance of the research question and the rigour of methods applied. The aptness of the researcher's interpretations and the clarity of their writing are further features which will assist reviewers and other researchers in the critical appraisal of the study findings (O'Brien et al., 2019).

From a range of proposed guidelines for ensuring quality in qualitative research, I chose to utilise an adapted version of the consolidated criteria for reporting qualitative research (COREQ) (Tong, 2007). The checklist (see appendix 8) was developed from an extensive search of qualitative journals and reference lists from major medical journals. Items selected for their usefulness in helping researchers achieve clarity when reporting on the study process, design, analysis, findings and reflexivity are grouped into three separate domains.

4.27 Domain 1 takes the unique position of the researcher into account and makes clear how their own experience may influence their observations and analysis of findings.

Later in this thesis, I reflect on my use of Pictor as an interview technique and how my own position as researcher impacted on how the technique was used. I acknowledge that the same technique has been used by other researchers and achieved a different result. I am also I aware of the limitations of phenomenological research over and above how the method is applied. These are associated with the aim of conducting phenomenological research and giving voice to individual experience as opposed to offering causal explanations (van Manen, 1990). Through my exploration and developing of essential themes, I also acknowledge that these findings are specific to the context of this

research. Therefore, I do not claim that they are applicable to findings beyond the research setting. Moreover, I acknowledge that my own interpretation of the participants' experience is one interpretation. This means that a different researcher may interpret the same data and arrive at a completely different interpretation of the participants' experience.

4.28 Domain 2 addresses the design of the study and prompts the researcher to demonstrate how they adhered to the philosophical underpinnings of the research approach consistently through the planning and design of the study.

Within this research, I endeavoured to ensure that the research methods I selected are in line with phenomenological philosophy and the Human Science Research method proposed by van Manen (1990, 197a). I have explained and documented the research methods in some detail and have attempted to employ these in all aspects of this research. Through my use of Template Analysis, I have demonstrated transparency through detailing the process of this research and discussing this in detail with supervisors and colleagues. (Whitehead, 2004). By demonstrating reflexivity throughout the thesis I have exhibited trustworthiness, which is an important element within qualitative research approaches.

4.29 Domain 3 calls upon the researcher to demonstrate where they have been systematic in documenting and recording stages of analysis and interpretation of data. This can prove challenging in phenomenological research where the aim is to highlight complexity and ambiguity across individuals in given contexts and settings (Dahlberg et al., 2008).

There are some common mistakes made by longitudinal qualitative researchers when managing large amounts of data. These include highlighting everything in the data thought to be of interest without considering how it is relevant to the overall research topic (Willig, 2013). The study generated twenty-four interviews, meaning there was a significant amount of data to analyse. I initially fell into the trap of selecting excerpts of text and developing themes which did not directly address the research question. This was a time-consuming process and multiple themes were later discarded. This is documented in my research diary. There were also diversions in the focus of the research driven by changes in supervisory teams and it became apparent, at a crucial stage in the analysis,

that there had been some miscommunication between me and the original supervisory team. On reflection, this experience had both advantages and disadvantages.

I lost focus many times during the process of analysing data as I became torn between being steered towards focussing on clinical and nursing outcomes while striving to maintain an applied psychology focus to the data. Eventually, I was guided back to clarity by returning again and again to the data, where the voices of the participants guided me to the findings. I have demonstrated transparency by recording and documenting my decision trail when adapting different versions of the template and justified my reasons for doing so. I did not rely on my own judgement regarding analysing data, but I regularly circulated copies of different versions to selected peers, including a discussion of my decision-making processes.

Reflexivity is an important element of qualitative analysis, where accounts of experience are co-created between the researcher and the researched (Mishler, 1986). The process of reflecting on their part in the construction provides an opportunity for researchers to evidence their own accountability for decisions made in the planning and conducting of qualitative research (Finlay, 2002). People come to the PhD process in a variety of ways. Often, though by no means always, they develop an interest in the topic area or a group of people who interest them and who they would like to explore further. My interest in caregivers began when working with patients and caregivers in a local hospice. This experience sensitised me in particular ways to the idiosyncratic way their experiences unfold. Yet, my view of this experience is from a particular perspective, being influenced by working as well as studying the topic of caregivers in palliative care at degree and master's level. I have also been a caregiver for a close friend and have experienced the death of two close family members who were accessing palliative care services at the time of their death. These experiences alerted me to the stresses and burdens associated with caregiving which shaped how I view the topic area as well as the decisions I made while planning the research

4.30 Reflecting on my engagement with participants

All researchers hold a privileged position in the research scenario and there are strict ethical guidelines available to help them manage the potential power imbalance that can occur between the researcher and the researched (Mitchell and Irvine, 2008). There is a growing body of research which explores the concept of power within the research participant encounter (Bashir, 2019). The dominant assumption within the literature, however, assumes that the researcher holds power over the participant because of their level of expertise (Downey et al., 2007; Mitchell and Irvine, 2008). Bashir (2019) suggests that in a bid to address potential inequalities of power and to protect participants deemed to be vulnerable, the researcher may make choices that render them more vulnerable to that of the participant. My aim was to minimise the power imbalance as much as possible and to ensure that participants did not feel under any pressure to take part in the research out of a desire to please me. I was also aware that they may have been under the impression that taking part in the research was compulsory or it formed part of their overall care whilst at the hospice. These issues were addressed in the participant information sheet (appendix 1) and in the section of this thesis which details how I ensured informed consent (appendix 3).

Throughout the period of data collection, I became a regular attender at hospice groups where I interacted with group attendees over a period of months. Being in regular contact with the participants meant that I developed relationships with individual participants who shared their feelings and experiences with me. This element of trust building is a necessary skill for the longitudinal researcher, though it has also been seen to blur the boundaries of their role where the researcher and participant may be affected by their extended period of contact (Calman, 2013). Recruitment to the study involved working with a hospice member to ensure only those participants who were physically and psychologically capable of being interviewed about their experience were approached to take part in the research. Looking back to my reflective diary, I noted before some of the interviews how nervous I felt about the change in role from friend and group member outside of the research interview to researcher in the room. This may have influenced how I interacted with participants during the interview.

I found that, over time, I began to identify with the feelings expressed by some of the participants and I developed a growing sense of empathy with them. I drew on this experience in the research process and found it helped me to empathically interact with participants. Empathic interaction is a style of engagement which is congruent with feminist perspectives and focusses on gathering first-hand accounts of individuals enmeshed within an illness experience from a non-medically dominant perspective (Smith, 1999; Bashir, 2019). I noted in my research diary that I found a tension between responding to the participant and remaining focussed on the research question. Given my experience as a bereavement support worker, there were occasions when I found it difficult to abandon the role of researcher and focus on offering comfort to participants especially when they became upset. I drew on skills developed in specific roles in my career and many of these skills overlap with the kinds of abilities needed to be a good researcher. I have found the process of reflexivity helped me to overcome some of my anxiety as a researcher as I learned how to apply those things that worked well in my research practice.

Finlay (2005) discusses the role of empathy in relation to research participants and the importance of communicating to individuals that they are being heard and valued for their experience and contribution. Person-centred counselling practice encompasses many ways that counsellors are able to convey a sense of being heard and valued to the participant using a range of verbal and non-verbal skills alongside techniques such as openly reflecting on the participant's account and clarifying certain parts of the story. This is a way of conveying to the participant that their account of experience is both unique and of value in terms of its contribution to the project. Whilst it is important for researchers to develop skills which enable them to focus on gathering and exploring information, these must be balanced with an awareness and understanding of the participants psychological well-being. In this instance, I drew on my person-centred counselling training to communicate the core values of respect, empathy and unconditional positive regard (Mearns and Thorne, 2007) as participants shared personal and potentially distressing information with me. Subjectively, working in this way enhanced my research practice in that I was able to gain interesting data in some depth. However, as I reviewed the transcripts later, it became apparent that my knowledge of the participant and

their circumstances influenced the way I asked certain questions. An example of this was during one participant's interview, when discussing changes, I ask whether her husband, the patient, has been in respite. This prompted the participant to focus on this particular aspect of change in the patient's condition and her experience of the event. On reflection, a better question to ask would have been whether there have been any changes since the last interview that have affected her.

On balance, I felt that building relationships was an appropriate course of action for the current study which offered several unintended advantages. This approach can enhance the participants experience (Murray, 2009; Calman, 2013) and participants may be more comfortable in sharing experiences about sensitive issues with someone they know. Indeed, they may not share certain elements of their experience within the context of a single research interview or a strictly 'research-participant' encounter. There were occasions when participants were keen to share inside and outside of the research interview. For example, without being prompted, one participant began to keep a journal of their experience to bring to the interview. This added an extra layer of depth to their lived situation. Another participant telephoned me in between interviews to share thoughts with me about gaps in services which they found difficult to discuss with clinicians. Both participants commented that having the opportunity to raise these issues left them feeling satisfied that they had used their experience to make a valued contribution to ongoing research with caregivers.

4.31 Reflecting on using the Pictor technique

Part of the design for the current study involved the use of the Pictor technique, which has been used in a variety of studies to represent episodes of collaborative working with different groups of specialist and general nurses in health and social care settings. (King et al., 2013; King, Brooks and Bravington 2014; King, Bravington, Brooks, Melvin and Wilde, 2017). It has also been used to explore the learning styles of medical students in clinical settings (Berkhout, Helmich, Teunissen, Vleuten and Jaarsm, 2017). Hardy, King and Firth (2012) used Pictor to increase understanding of the experiences of lay populations by focussing on the experiences of patient and caregiver dyads accessing multiple health care services.

I had hoped using this technique would assist the participants in telling their story in a novel and relaxed way. When recruiting participants to this study, I initially offered a choice of using a Pictor chart to tell their story as an alternative to a more traditional interview style of speaking with the researcher one-to-one. All participants recruited in the first six months of data collection expressed a preference to be interviewed using semi-structured talking interviews. Halfway through the data collection period, no participants had opted for a Pictor style interview. Following discussions with my director of studies, it was agreed that I would continue to recruit only those participants who wished to be interviewed using the Pictor technique for a further five months. In total four participants agreed to a Pictor interview though only one participant agreed to be interviewed three times using this technique. Although the approach has been very successful with other researchers; in this study it was not found to be helpful and there may be several reasons for that.

It is possible that my relationship with participants, which covered a period of months in some cases, was a factor. While Hardy et al., (2012) noted that using Pictor to interview patients and their caregivers, added depth to the interview, the participants in this study appeared to be distracted by the process of constructing the chart and over the course of the interview engaged with the chart construction less and less. For example, two of the participants requested that I help them construct the chart by writing the names of different individuals on the post it notes and, under their instruction, place them at a given position on the chart.

Hardy et al., (2012) found using Pictor to be an emotive technique for the participants in her study. This contrasted with participants in this study who appeared to treat the process of constructing the chart as an exercise to support their accounts of experience. During Harold's second interview for example, he described how one of his daughters had become more involved in Christine's care since his last interview. Looking to the chart, he asked me to place the arrows at a specific point, when I asked him if I had placed them correctly in terms of their proximity to other individuals within the chart, his answer was that it was fine. In this instance I wondered if the chart really depicted Harold's experience or my understanding of his experience. I did not pursue this any further with him because his general demeanour indicated that

he was not engaged with the chart construction and any further involvement on my part may have been leading. There was a significant difference in the way the technique was applied by Hardy et al., (2012). During Hardy's study, the researcher left the room or sat in silence whilst participants constructed their chart. In this research, during chart construction, I asked the participants if they wished to be left alone and all four participants requested that I stay in the room. Two participants explicitly asked for my assistance in the chart construction.

During the interview, though some of the participants openly reflected on their experience, many did not appear to be engaged with the chart but maintained eye contact with me whilst reflecting out loud, without looking at the chart. In Andrea's first interview, the chart was positioned on a table in front of her and as she spoke, she turned her body away from the table, so the chart was positioned by her side. During the interview, she spoke about her relationship with her three brothers and the different role they played in supporting her in providing care. When I asked her if she would like to represent that scenario on the chart using the arrows, she looked to the side where the chart was positioned and commented that she had forgot. At the end of the interview I asked how she felt about constructing the chart and she said she wasn't bothered either way. In her next interview, the chart was on the table ready for her to engage with or not. By that time, I was aware through my interaction with Andrea in between interviews, that her mother's condition had deteriorated significantly. In this case, I did not feel it was appropriate to request that she used the chart to speak about her experience. In summary, my relationship with the participants was a significant factor in how the technique was applied. In the study by Hardy et al., (2012), the researcher's position as a district nurse meant participants had never met the researcher prior to the research interview. It is possible that participants are more comfortable about being given instructions by someone they perceive to be a staff member than from a researcher with whom they have a less formal relationship.

Bravington and King (2019) noted that participants varied in how quickly they adapted to making use of the Pictor technique approach and advise caution in instances where the researcher constructs the chart on behalf of the participant lest they influence the interview agenda. One of the ways this can be overcome

is for the researcher to give participants specific instruction about the chart construction. For example, by encouraging them to focus on a specific episode of their experience rather than a broad overview. On reflection, the technique as it was used in this research, may have been improved by using a different researcher to conduct the Pictor charts, though this was not possible as resources did not allow for another researcher on the project. Moreover, it is not certain that participants would have reflected on their experience in the same amount of depth with a different researcher.

Perhaps there are advantages to having minimal or no contact with participants before and between interviews. However, a research design where the researcher engages with participants over the data collection period was appropriate for this study.

In this chapter, I have detailed the process of gaining ethical approval for this research and explained how the method described within the methodology chapter was applied in the process of this research. The philosophical underpinnings detailed in the Methodology chapter are evidenced in the analysis of data. Finally, as a way of improving the trustworthiness of the research, I have explored the concept of rigour and the quality of the research using a recognised framework.

Chapter 5 Results of interviews 1, 2 and 3

5.1 Introduction

The aims of the study were to explore the experiences of nine caregivers for patients who were accessing palliative care services for an illness diagnosed as terminal or life limiting. My interest in the area arose from a desire to understand whether, and in what way's the experience of being a caregiver is similar or different to the patient's experience of illness. The literature review drew attention to aspects relating to current knowledge in the area of caregivers and their journey of providing care over time. In the previous chapter, I gave a rationale for my choice of phenomenology as an appropriate research method for this study because of its explicit focus on understanding a given experience from the unique perspective of individual participants.

This chapter begins with an overview of the nine participants recruited from three different areas in a hospice in Yorkshire. This is followed by a profile of the individual participants in which I share my observations as recorded in research field notes throughout the data collection period. Lastly, I present the interview findings from the thematic analysis of the participant's first second, and in the case of six participants, their third interviews. The themes emerged from the accounts of individual participants and use their own words as a way of adding context and depth to the analysis Editorial elision used by the author involved deleting repeated sounds, vowels or consonants within a phrase. This was done to help the reader focus on key points and is indicated within the text by three dots (…) (Smith, 2007)

5.2 Procedure

Although the main focus of the research is to explore the experience of caring for a family member with terminal or life limiting illness, other people or organisations have been considered where it helps to illuminate the caregivers' experiences of engaging with services. Such services are NHS, social services and specialist palliative care services. Figure 16 provides an overview of the people who participated in the research including the relationship to the patient, their age and the context of their interviews.

Figure 16 - Overview of the participants

Pseudonym	Relationship	Age	Interview 1	Interview 2	Interview 3
Diane	Wife	63	Home	Day Hospice	Day Hospice
John	Husband	71	Day Hospice	Day Hospice	Day Hospice
Steven	Husband	67	Day Hospice	Day Hospice	Day Hospice
Maureen	Wife	59	Day Hospice	Day Hospice	Home
Tina	Wife	40	Day Hospice	Day Hospice	RIP
Stan	Husband	78	Day Hospice	Day Hospice	RIP
Harold	Husband	70	Day Hospice	Day Hospice	Day Hospice
Andrea	Daughter	41	Day Hospice	Day Hospice	RIP
Alison	Wife	60	Day Hospice	Day Hospice	Day Hospice

5.3 Profile of participants

Details of the participant's circumstances are intended to assist the reader's understanding by providing context and detail for each caregiver. The next section provides a profile of individual participants as well as my own observations noted in research field notes throughout my continued engagement with them over the data collection period.

All participants were interviewed on their own (not in the presence of the patient) and all summaries represent their own perspectives of the experience. It is acknowledged that, on occasions, the participant's understanding of the illness diagnosis does not tally with general medical logic or procedures.

Participant 1 Diane

Diane is 63 years old and is married to Geoff. She and Geoff are both retired and have two daughters and one granddaughter. Diane was keen to take part in the research and to talk about her feelings about having been Geoff's caregiver for 'such a long time'. The interview took place in their home while Geoff was at the day hospice. The couple live together in a small rural hamlet where they were part of a close-knit community. Six years ago, Diane said she had noticed

that Geoff was finding it increasingly difficult to walk. However, she kept her observations to herself for about a year until one of her daughters noticed that 'something was wrong with how he walks' at which point they went to the surgery to 'sort it out'.

Her understanding of Geoff's illness was that it was like motor neurone disease in how it affects the sufferer. Geoff has been unable to walk for the past three years, has minimal control of his right hand and no control of his left. They were recently told that Geoff's vocal cords will soon stop working and have been gathering a bank of over 600 recorded phrases in Geoff's own voice. These recordings will be built into an electronic speaking device, allowing him to communicate verbally using his mouth and right hand. Diane said the news that Geoff would lose his voice came as a significant blow and the process of preparing for a time when he could no longer speak, was particularly upsetting for them both.

Participant 2 John

John is 71 years old and married to Ellen. The couple are retired and have two sons, one of whom lives in Australia and the other in Sussex. The couple had worked together for an American oil company where they travelled throughout the world. He described Ellen as having been a wonderfully capable woman who had achieved good results in challenging circumstances. He spoke of his working life which had involved working in regions at a time of civil war, comparing this experience his experience of witnessing Ellen's illness, he said 'these are the biggest emotions I've ever gone through, even worse than the civil wars'

John reflect ed backwards on how Ellen's decline in in health had been an early sign of an undiagnosed heart condition. He did not view this decline as the beginning of his role as her caregiver because he had thought her problems were the result of old age and 'burning the candle at both ends'. However, an emergency operation for an unrelated condition seemed to mark a turning point for Ellen as well as John because there followed a catalogue of illness related events which had led to his caring for her, 'more than I was doing anything else'.

Participant 3 Steven

Steven is 67 years old and a retired drama teacher. He is married to Mandy, who is also a retired teacher and they met when Mandy joined Steven's school over thirty years ago. Steven has two sons and three grandsons from a previous marriage. He told me that Mandy had been unwell for some time but had suddenly got much worse a few months earlier where she was hospitalised. He said this episode had alarmed him, especially as Mandy had not recovered her previous health status since that time. He spoke of how Mandy's illness affected her on a daily basis however, he did not mention how it affected him other than to laughingly say he had taken responsibility for all household chores including cooking and cleaning. He went on to say this shift in responsibilities led to him feeling exhausted and he had recently lost a significant amount of weight. He did not see this new development as part of his role as Mandy's caregiver because, though he realised she was ill, he hoped she would recover her fitness and their lives would return to as it had been before her illness. Later in the interview, he mentioned how friends and family had noticed the way Mandy's fluctuating health had affected him psychologically, resulting in his becoming withdrawn and less sociable. He admitted there had been a change in how he behaved around people, saying when they visited, he went and sat in another room where he could be quiet. His initial attendance at the BOFA group had marked a significant shift in Steven's outlook. Here, he met other people who were feeling as he did, saying there was 'something in the atmosphere' which made him feel like there was something to be optimistic about.

Participant 4 Maureen

Maureen is 59 years old and married to Alan. Maureen has one son who, along with her sister, is helping her to care for Alan who had been retired due to illness for several years. Maureen retired early from her job on the grounds of her own ill health which she said she 'managed'. She reflected on how Alan had looked after her during illness in the past and so she viewed taking care of him as part of her role as his spouse. Maureen was not able to recall the exact date or dates of Alan's health deterioration because she hadn't been counting, she said. She could however recall the sequence and how events had unfolded. Maureen's story of Alan's decline began with the death of a much-loved cat. She had noticed that Alan's health was deteriorating around the time of the cat's

death but said any attempt to convince Alan to see a doctor had failed. The cat had cancer and had to be euthanized, which left Maureen feeling distraught. When Alan tried to comfort her, she told him she of her fear that he would be the next thing she lost. His visit to the GP led to a diagnosis of emphysema which responded to treatment, and although his quality of life was affected, he was stabilised on medication for three years. At some point Alan was offered surgery to improve his condition and was told this would improve his quality of life further. Immediately after his surgery, his condition improved dramatically but because of what Maureen had been told was a surgical mistake, he required further emergency surgery and though his condition has since varied, he has remained very ill since that time. Margaret said Alan had undergone a change of personality after his latest surgery and she found the most difficult part of providing care for him was keeping him motivated and helping him with his depression.

Participant 5 Tina

Tina is married to Theresa and they live in a rural community outside the main city centre. Tina met Theresa at work some years earlier and the couple moved to the area after being married and buying their house. When Theresa became ill, Tina had taken leave from her senior role in the Civil Service to look after her. Tina considered the most difficult aspect of caring for Theresa was that, as her illness progressed, she had become more confused and unrecognisable as the person Tina had once known. A feather of Theresa's cognitive decline was that she developed a deep mistrust of people, including Tina. As a respected member of the Civil Service, Tina said being viewed with mistrust and having her personal integrity called into question by the woman she loved was upsetting and she spoke of grappling with feelings of sadness, anger and loss.

Participant 6 Stan

Stan is 78 years old and has been married to Monica for 58 years. They have a son and a daughter as well as four grandchildren. During his working life, Stan worked in industry while Monica stayed at home until the children left home after which she did voluntary work. He told me Monica had been ill for the past four years, but she had gradually got worse, and he wasn't sure but thought it was their GP who had referred her to the specialist community palliative care team. She was given oxygen at home and referred to the BOFA group by the

team. Stan said he had been involved in caring for Monica since his retirement. He couches her declining health in terms of how it marked 'the end of our cruising days' because on their latest cruise, she had been hospitalised mid-cruise in Canada. The couple were not permitted to travel anymore but he said he enjoyed being part of a rotary club. He said he was no longer able to plan ahead because Monica's condition is fragile and unpredictable. The couple have had to cancel their arrangements on several occasions in the recent past because of her health. They do not have caregivers coming to the home because Stan said he felt able to manage her care himself. Though, they had a son and a daughter who lived nearby, both Stan and Monica preferred to protect them from the effects of Monica's illness unless necessary. He found the most challenging part of caring for Monica was managing her medication. This was because, it seemed that the medication had a cause as well as an effect which had made it hard for him to know which of her symptoms arose from her illness and which were a side effect of the medication. He said he was aware that her condition was deteriorating but had not had an opportunity to discuss what to expect at the end of her life with anyone so far.

Participant 7 Harold

Harold is 70 years old and married to Christine who has Huntingdon's disease. The couple live in near to the hospice and have two daughters who support Harold in looking after Christine. Harold told me that Christine's father died from the condition, and he had been aware that Christine carried the gene Huntingdon's gene when they first married. As a way of preparing themselves for the future and learning as much as they could about the condition, the family had been involved with the Huntingdon's society for the last 20 years where Harold himself was branch secretary and treasurer.

Harold explained that not everyone who carries the gene for Huntington's will develop the symptoms but said there is a test available for carriers to screen themselves which will tell them if they are likely to become a sufferer later in life. Harold talked of how Christine had not begun to show outward signs of the disease until some years earlier when she recognised the symptoms in herself. He found it difficult to accept that Christine had the illness at that time saying, 'I couldn't see it despite seeing it in thousands of other's'. Of the two daughters, one had recently undergone genetic screening and discovered she was not a

carrier of the gene however the other daughter chose not to take the test because she preferred not to know.

Harold referred to himself as Christine's full-time caregiver and saw his part in this role as organising for her needs to be taken care of. This was done by a full-time private carer who was known to the family and came every day to wash, feed and bather Christine. He said this level of care was very expensive and he applied for funding to cover the cost from NHS Continuing Care. He became very animated when talking about the dispute he was in with this organisation who disputed which of Christine's needs were related to her health and which were social needs. He was still in the process of appealing claims made two years earlier but considered he was fortunate to be able to pay for Christine's care until the dispute was settled.

Participant 8 Andrea

Andrea is 41-year-old and lives with her husband and a five-year-old boy she refers to as 'her boy'. She explained that the child is her eldest brother's son and she, with her husband have legal guardianship of him because of a substance misuse issue within the family. Andrea said she had offered to take care of her brother's child to avoid him entering the care system. She began attending the BOFA group with Betty, her mother who lived at home on her own. Betty was visited by family members every day, but Andrea said she was her mum's primary caregiver meaning that if any other members of the family were worried about Betty when they visited, they would automatically call her. She said one of the most difficult aspects of caring for Betty was fitting in caring with her job as a carer in a local nursing home. Andrea told me that caring for Betty had also impacted on her relationship with her husband and their five-year-old and she found the various roles difficult to balance. Andrea found it very upsetting to leave her mother on her own whenever she visited and said she felt uneasy when Betty was not being attended by herself or another family member. Andrea was finding there was a financial impact to being Betty's caregiver because she did not drive, and bus fares were quite expensive. She said her mum insisted on paying her £30 per week, which is what Betty received in benefits to pay for someone to provide her care, though Andrea felt bad about taking money from her mum.

She found delivering personal care like toileting and intimate washing to her mum difficult and embarrassing. She said she had never expected to take on this role for her mother but preferred to do it herself because she knew Betty would not allow home-carers to wash her. Andrea admitted that it felt uncomfortable for her to admit that she found this and other aspects of caring for her mum difficult because she washed and bathed people in her job in the nursing home.

Betty had been assessed by social services and a care package was in place, but the amount of care put in place fluctuated according to Betty's health status. So, if she improved and became more mobile, then Betty told the home-carers not to come because her daughter would provide her care. This frustrated Andrea because Betty tended to make this decision based on how she felt on that day, but she did not consult with Andrea to check if she was able to accommodate this change in caring arrangements.

Participant 9 Alison

Alison is 60 years old and married to Paul. She was a very active woman, involved in the local community and the Women's institute. The couple had moved to the area the previous year to be near Alison's daughter when Alison retired from her job as a legal secretary. Paul had retired a few years earlier when it became harder to do his job because of his illness. Alison said she chose to continue working after Paul retired because Paul didn't need her to be around at that stage. She told me they had moved to the area so she could help her daughter with childcare.

As Paul's condition deteriorated, both agreed that Alison should maintain a social life, despite Paul not being able to accompany her. To minimise the impact of Paul's illness, caregivers from a private care company were employed to take care of him when Alison stayed away from home. She said she had begun to feel mixed emotions about leaving him while she went away because she was aware that he relied on her for such a lot. These feelings were mixed with being mindful of her own need for self-care.

She said she been researching her husband's illness online and this had given her an understanding of what stage in his illness he was at. This process of making sense of his illness progression in this stage-based way appeared to help her to accept his level of deterioration.

She said it upset her to see how isolated Paul had become since he was not able to communicate. He was no longer able to walk or leave the house and his speech was very slow and limited. Alison missed spending time with Paul watching movies or reading together, and she admitted that she felt alone when they were together at home.

5.4 Introduction to interview findings

The method chapter of the thesis has outlined the stages of the LQA approach taken in this study. In line with this approach, the idiographic accounts of nine participants interviewed over a 12-month period were analysed according to the principles of thematic analysis (Braun and Clarke, 2006). Having provided a profile of the participants, in the next section I present the interview findings arising from the thematic analysis of their first interviews. The process of analysing data gave rise to three themes and two subthemes which are now presented and discussed. The themes emerged from the accounts of individual participants using the participants' own words to add depth to their experiential accounts.

5.5 Thematic analysis of first interviews

Theme 1 Caring role emerges from illness trajectory

       1.1 Attitudes to being a caregiver

Theme 2 Depictions of the caring role

       2.1 Coping and adapting

Theme 3 Interacting with professional care services

Theme 1 Caring role emerges from illness trajectory

In each first interview, I began by asking participants to tell me, in their own words how they came to be a carer for the patient. I was aware that, in using the term carer, I may have been assuming about how they each saw their role. However, each participant had read the participant information sheet (PIS) before returning so I felt it was safe to assume that they were comfortable or at least familiar with being referred to as the patient's carer. My reason for using this open style of questioning was that I wanted each participant to discuss the

emergence of their role in the context of their own circumstances and in a way which made most sense to them.

There was some variation in each participant account, some of which may have been because they varied in how long they had been in the caring role. So, some were relatively new to caring whilst others had been providing care for longer periods. Of interest was that in most cases, the patient's illness progression was used as a background against which their stories unfolded and set the scene for the development of their role. I begin this theme by introducing. John, who told of a series of downhill steps, given shape by a different health crisis taking John nearer to being consumed by Ellen's needs.

> *She got a couple of bad bouts ...that was really the tipping point of me realising that I was going to become a full-time caregiver. I was only beginning to realise my role was changing. ... what really tipped the balance was, a perforated ulcer. For, for a year she was ill but recovering, and then … he had some TIAs...she got oedema again…by 2012 I was caring for her more than I was doing anything else. Each time it was a step down. (John interview 1)*

Tina's account echoed John's experience in terms of how illness had influenced the emergence of her caring role. When asked how she began to be Theresa's caregiver, she said there had been an increase in the number of medical specialists involved in Theresa's care at which point, her working life was impacted.

> *...in April this year she woke up in the morning and she said oh I've got a bad headache. She said I can't read… I took her to the hospital, and she'd seen a whole gaggle of specialists and had more tests than you can shake a stick at. Three brain scans and a rheumatologist, a vascular consultant, …-and a neuropsychologist. So, I took time off work from that minute. (Tina interview 1)*

Harold told of how he had been aware that Christine was carrying the gene for Huntington's disease when they married. This meant the couple had lived with

the knowledge that she would potentially develop disease symptoms at some point in their life together. This knowledge had influenced their family life also and the couple with their children became actively involved in the Huntington's society. Harold told of the randomness of the disease and how it was difficult to predict the onset of symptoms in different sufferers. I found it interesting that, although he exhaustive knowledge of the action of the disease and at a physical and genetic level, his account of becoming Christine's carer was told in terms of recalling psychological changes in Christine when she first developed symptoms of the disease.

> *There's no set pattern … my wife, like her father, didn't show symptoms until she was in her late 50s. I could not see it in Christine at all. She said …it's starting, I said how do you know? I can't see. She said I can feel it in my face, I can feel the twitching in my face. I said well I can't see it. Once she knew she, she was going to develop it, she was much more positive I think, though she was going through a period of mood swings which was the start of the Huntington's and everything else. (Harold interview 1)*

Like Harold and Christine, Alison and Paul had been aware of Paul's illness many years before he began to need care from his wife. Alison revealed that she had not initially seen herself as Paul's carer, perhaps because it was a term she used to describe paid carers from the caring agency. During her interview, she said she had begun to realise that her role had now grown to the point where she cared for his needs whenever paid carers were not there. I noted in my diary after the interview that Alison often gazed out of a window slightly to her right during the interview and I wondered if this knowledge had come to her in a moment of reflective insight. After her interview, I wondered if I had crossed a line from researcher to counsellor by my exploration of how she used the term.

> *Well, he was first diagnosed about 15 years ago with Parkinson's, um, and to start with he was, he was OK. I think probably the last two years, two, maybe three years, he started to get worse. And I think the last, I would*

say, probably a year he's got a lot worse. So, he now can't walk very well and speak and swallow and all those sorts of things. So, he does need quite a bit of, of looking after. About three years ago when he needed a little bit more support. We have a company that we use. They come in the morning and in the afternoon and they do the bare minimum really. I'd started to do more things for him…And leading up to now, … I do pretty much everything for him. (*Alison interview 1*)

Maureen's said she did not see did not see herself as Alan's caregiver because she considered caring for him to be part of being his wife. I noted in my research diary that Maureen had been caring for Alan's changing mental and physical health needs for many years and I wondered if the length of time and lack of recognisable landmarks or turning points in his illness has led her to frame this experience as one uninterrupted process unfolding against the backdrop of their relationship.

I've done it for a long time, but without ever thinking oh well I'm caring for him because I just think it's what a wife would do. I don't think about it, I just get on with it. (Maureen interview 1)

Theme 1.1 Attitudes to being a caregiver

This research question sought to explore stability or change in the perceptions and experiences of caregivers over time. Through my interactions with carers, it appeared that individual perceptions were associated with their expectations and how they thought or felt about becoming a carer. It can be difficult for people to speak openly about their thoughts and feelings especially on the topic of caring for a friend or family member. It appeared that some had strong views while others were more accepting about taking on the role of carer. Maureen's account, for example, suggested she saw caring for Alan was a natural extension of her role as wife rather than a change in her status or function within their relationship.

I'm still his wife though I've just said I'm his carer now and I've never actually thought about it that I'm his carer… I don't ever say to anyone...

That's the first time I've ever thought of it, to be honest. You know… I make sure he's alright in every respect. I've done that for a long time, without ever thinking oh well I'm caring for him. I just think it's what a wife would do. If you love somebody, I think you do go the extra mile. (Maureen interview 1)

In John's interview, he spoke about feeling conflicted about becoming a carer for a woman who had been his wife and business partner. When I asked if he could tell me more about this, he spoke of how Ellen had been before her illness compared to now. I got the sense John felt cheated by Ellen's illness and was now deprived of the woman he knew. I noted in my diary, that although, accepting of his role John seemed resentful of this change and misled into a new way of being which had curtailed his freedom. This was confirmed later in an email from John where he spoke of feeling penalised by the lack of stimulation in looking after Ellen.

She was becoming increasingly introspective …whereas she'd always been a tremendous social animal. I was still wanting to cling to being outgoing…so there was frustration at that. And that's the situation I'm in now you see … I call myself, the slaviour, because you're both a slave and a saviour at the same time, aren't you? (John interview 1)

I spent some time chatting to Tina before, after and in between her interviews. My research diary shows how I write frequently about times when I saw her, recording even brief interactions we had in some detail. Of all participants, Tina's psychological wellbeing concerned me the most and I found myself seeking her out if I hadn't seen her on the inpatient unit when I went to the hospice. Tina spoke about how she became hypervigilant in monitoring and researching the internet to understand the signs and symptoms of Theresa's brain tumour. It appeared this helped her to recognise change and deterioration in illness. Her accounts suggest she had abandoned herself to becoming Theresa's carer when hearing that her tumour was inoperable. Her account indicates that this choice was made in an uninformed way.

So, I've kind of been supporting her all that time , not really expecting her to be still here, um, and in, in a way unfortunately she's still here,

because it's nine months later and I'm still off work, um, and it's been very difficult, I made a rod for my own back because I ended up stuck … in the side room… not doing anything apart from running around after Theresa. (Tina interview 1)

Tina's response contrasts with that of Harold who also had extensive knowledge of Christine's illness. It appeared that having adequate practical and financial resources to provide for Christine's care positively impacted his psychological health and enabled him to continue living as near normal life with Christine for as long as possible.

I don't begrudge the money because I want Christine at home, I'm fortunate in the sense that I have, I have a good pension and I've substantial savings and …we also get Disability Living Allowance, full rate for her from Department of Work and Pensions. ...we get full rates for both elements for so I'm lucky in that respect. I can afford to pay for a caregiver to come in and get Christine washed and showered, toileted and dressed… she has been coming in four times a week, but it's now getting to five or six times a week. and occasionally… at least once a month she'll stop overnight so that I get a full night's sleep. I always get Christine up and we have breakfast before she comes just like we always have. (Harold interview 1)

Alison and Harold's account highlight the cost and benefits of having sufficient financial resources in place while caring for a patient with palliative care needs. Her account emphasizes this and underscores the importance of saying physically and psychologically well while caring for a relative.

They charge quite a lot. We have to pay for this. It costs … I think it's about £16 or £17 an hour. I need to have a break occasionally, so if I stay overnight, they [the caring company] come. It means I can go away knowing that he's being properly looked after. Otherwise. I would probably go around the bend. (Alison interview 1)

Theme 2 Depictions of the caring role

Caring represented many different forms and participants described the different things they did which were understood by themselves as acts of caregiving. Maureen, for example, spoke of how prior to becoming ill, Alan had stepped into the role of caregiver for her. She said this had placed her under additional pressure to manage her own long-term condition and stay well while caring for Alan. She said she had feared not being able to take on the more physically demanding tasks of caring or of tasks which had been previously assumed by Alan.

> *I've got lots of things, fibromyalgia, arthritis, and they're testing me for MS. ...I need to be fit for Alan, so I've started doing my yoga again. I think I might have put myself under a bit of stress. It's me who's got to lift everything …it's me who's got to organise all the packing and everything and it's me who's got to do, and he hates it. And that is a difficult thing and I just have to. He used to do it, he did all the heavy stuff, and he can't do that now, so that's role, role reversal in that respect. (Maureen interview 1)*

John spoke about the enforced lack of stimulation involved in being a caregiver. Though accepting of duties, his account suggests that he had no alternative but to become immersed in what he perceived to be a female dominated world.

> *Lack of stimulus that my role in looking after Ellen penalises me with. As you understand I led a stimulating and sometimes challenging lifestyle, even in retirement. I find that my life has become one of routine and lack of masculine stimulus. I now inhabit a world populated almost exclusively with women where the most stimulation comes from a good drying day or a well baked cake! I do sometimes resent the loss of male interaction and, while I have learned to keep house and cook etc. it is not a path I would have chosen. (John interview 1)*

Tina described how she became a mediator between Theresa and the world as Theresa became less able to identify and communicate her own needs.

> *She can do nothing for herself. She can't even give herself a drink, so you have to give her a drink in a beaker. She can't physically hold the*

> *cup. So, she'll go, 'I want that, I want that' …Often I know what it is she's*
> *looking for, but you get to the right item and then she knows what she*
> *wants. If I ask her what she wants for breakfast, she's no idea what she*
> *wants. You've to kind of 'do you fancy that, hmm, do you fancy that?'*
> *(Tina interview 1)*

As the only daughter in a large family, Andrea was chiefly responsible for Betty's care. Although other family members were available to share caring tasks, she said her unique role was to ensure round the clock home care for Betty.

> *I'd ask my brothers …. but with them being men my mum doesn't ask*
> *them to do the things that she'll ask me to do. She doesn't like asking*
> *them to empty the commode. She doesn't like asking them to make the*
> *bed, because they can't make it right, I'd never ask him to like take the*
> *responsibility of anything female wise … my mum's granddaughter…she*
> *comes in and does the bathing. I finish my evening shift at half past*
> *eight and …my husband has to pick me up from work, drop me off at my*
> *mum's, I sleep over, he picks me up the next day. (Andrea interview 1)*

Steven described how he took on the role of caregiver in an uninformed way. Recalling his first session at the BOFA group, he said he was asked to fill out a questionnaire for caregivers. He reflected how at the time of completing the questionnaire, he had been too engrossed in the day-to-day tasks of caring to notice the amount of work involved in caring for Mandy until he had begun to feel the pressure and strain of the workload.

> *It was week after week after week… getting up every morning early to*
> *make her breakfast before the nurses come. We have a community nurse,*
> *district nurse, carers, and we've a little box outside the door to let*
> *themselves in. …I'd be awake anyway so I may as well get up, you know,*
> *and let them in. You tend to forget what you're doing until there's certain*
> *stress that you yourself are suffering you know. (Steven interview 1)*

Theme 2.1 Coping and adapting

Participants adapted their caring styles to cope with fluctuations in the patient's illness in various ways. Most had been enabled to do this by drawn strength from other people by reaching out to friends and family. This theme speaks to

how caregivers utilize available resources to cope with and adapt to different aspects of being a carer. Steven's account for example, highlights the benefits of utilising peer support. He spoke in his interview about feeling as if he was at the outer limits of his ability to cope with the unremitting nature of caring for Mandy without a break Following his interview, I noted that his body language had changed, and tears came into his eyes when he described the sense of relief, connection and hope when meeting other attendees of the BOFA group.

> *I was nearly at my wits end… purely looking after Mandy… and God knows what. I mean occasionally a little thought would cross my mind oh we haven't been out for ages, knowing that we couldn't possibly go out with her in the state that she was in. It just happened, you know, night after night after night we were stuck in. I think before the Breath of Fresh Air, I was nearly at my wits end. Simply and purely looking after Mandy … The Breath of Fresh Air changed things round. I ended up crying at the end of the first session simply and purely because they were encouraging. So that first session… you know was just optimistic. And I ended by the end of it feeling a great relief. Nothing has happened. No exercises, nothing. Just the atmosphere and everything, you know. (Steven interview 1)*

Similarly, Harold's coping strategy involved identifying sources of nonprofessional, nonclinical support from people within his own community. He described some of the challenges of providing care and outlined the soothing effect he experienced when of meeting regularly with fiends from the bridge club which helped him to cope with fluctuations in Christine's personality as the result of her illness.

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> *Christine doesn't go out now, she finds it difficult. She's going through mood swings, and this is part of the symptom process, she'll lose her temper very quickly and then get depressed. I play bridge on a Wednesday afternoon; I find that helpful and relaxing. I play in a team, so that's, that's another means of support. (Harold interview 1)*

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Feelings of being constrained by the caregiving role were a common aspect of many participant accounts. Tina spoke on many occasions about feelings of falling into a vacuum and another time, she said she feared she would disappear in the routine world of hospice life.

She occasionally helped out in the hospice garden, but this had been hampered when Theresa constantly called out her name. She spoke of not being able to find anything meaningful to do and had begun to doubt her own existence. Feeling confined by these circumstances and the physical surroundings of the hospice, said she had two days a week where she looked forward to leaving the hospice premises and going to the pub with her dad.

> *I ended up stuck here…. I'm finding it increasingly difficult to just be hanging around … she could be like this for months. I'm here all the time. I go home on a Tuesday and a Friday. I go home and I go out with my dad to the pub and I get drunk. I don't exist anymore. (Tina interview 1)*

Maureen was supported by members of her family who provided care for Maureen and Alan. They have also supported Alan during times when Maureen was ill and needed care. Her first interview was postponed when she got the opportunity to go on holiday with her family and she spoke of feeling renewed and refreshed by not having to respond to the Alan's ceaseless illness needs.

> *I went on holiday with my sister and the children, and I came back a new person, we'd only gone for a week, and it's because there were no phones, I didn't have to keep running upstairs for him and going getting him things. (Maureen interview 1)*

Diane had been Geoff's carer for the past five years during which time she had attended the DHCG. She was an active part of hospice life being a member of the choir as well as being involved in multiple fundraising events. She said she enjoyed being busy but had been finding it a challenge to balance the demands of caring and running the family business. She told of joining a local group where she would engage in different activities with women in her area.

That's what I find the hardest, to go up at night-time to try and do it, I can't do it, I'm too tired. I fall asleep. I try and fit it in during the day. I can't find that hour or two to shut off, because it's stops, start, stop, start again. Anyway… I've joined the WI, tonight someone's going to do a thing on kimonos and the stories about them and how they wear them …And they do vodka tasking and gin tasting and chocolate tasting and all sorts of different things (Diane interview 1)

It seemed Diane liked to be involved in activities outside of the house where she could engage with people unrelated to the caring scenario. After the interview, I wrote in my research diary that there had been a noticeable change in her demeanour when she spoke of how sharing her experience of being a caregiver with others had influenced local support networks.

A couple of weeks ago I had a letter, because my friend who I've just started to get to know a bit better, she sent me this letter, she's just been co-opted on to the committee. To say they're doing a pastoral thing for people who need a bit of support, a bit of a shoulder to cry on. And I thought that was lovely because…. I've got a feeling she's done it with me in mind because my story I prompted her. (Diane interview 1)

Alison spoke of the isolation of being a caregiver despite her and Paul having a large circle of friends. Paul became more withdrawn as his Parkinson's disease progressed and Alison said it was important for her to have interests outside of their home. She attempted to make Paul feel a part of the village community he had once played an active role in by chatting to him about what she had done and seen while out.

I'll talk to him sometimes and say, you know, what's happened, you know, during the day if I've been out, if I've been somewhere, just so even though he can't participate I think he finds it quite interesting. Yes, I mean he will occasionally come, not so much now, but he would have come, sometimes with me. I think it's quite nice for him because obviously he doesn't get out very often. Which is why it's quite nice for me to, to go out … I've got friends. I belong to the WI and I'm on the

committee. It gives me other interests and I meet people. …otherwise, I'd just sit at home all the time. (Alison interview 1)

Theme 3 Interacting with professional care services

Caregiver' s spoke about the patient's illness and interacting with services as two different but equally important aspects of the same experience or journey. Further analysis revealed that interacting with services was integral to the participants experience and for this reason, interacting with services was treated as an integral theme. All participants were or had been caring for their family member at home whilst accessing services at the hospice. This theme emphasizes the differences and similarities in the way participants experienced and worked with professional services.

Diane told me there were multiple services and individuals involved in supporting Geoff and it was important to her that she establish an easy to access supportive network of professionals to support for him. Her In her first interview, she presented me with a calendar on which, she had recorded every person involved in supporting Geoff up to that point in his illness. Though the services were in place to support Geoff, it was apparent that Diane benefitted from them also and she spoke of how important it was for her to have easy and quick access to the right individual at the right time. It seemed the calendar functioned as Diane's directory of people she could contact for Geoff's multiple and fluctuating needs.

> *So, it starts off with the consultant neurologist, so it was Geoff, me and the consultants or lack of but that was nightmare. Then it was the charity, the GP played a big part. Community matron, she said if we need her… it's perhaps once every blue moon. They always refer you to somebody else anyway. Now these are one offs, and these are all the people that have been involved all the way through… we had lots of others but each time we got one, we had to keep repeating everything we'd said. We stopped visiting the consultants, I've cancelled them because it takes too long and Geoff is knackered before we get there and when we get there it's five or 10 minutes to tell them what I could tell them on a sheet of paper. So, continuity was and important thing. …there are so many*

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different people for different things. Eventually we got one…she says I'll come see to him this time but if you need me…she's been my key point, but it's taken me three years to get one. Incontinence nurse, social worker crisis intervention team, what did they do? I can't remember what they did, or did they do anything? I can't remember …but they were obviously on the radar. Care plan nurse, put these down as one-offs moving and handling (sighs) – oh supply nurse she might have to come again. She comes to do a bit of training…wheelchair services, equipment loan services …community transport oh and another agency but it comes under the Parkinson, they are funding it. Parkinson's are funding them and Home Instead it's been split… the nurse couldn't do both sessions, so they do one (Diane interview 1)

Tina's also referred to the numerous services involved in service delivery, and she contrasted her experience of accessing professional hospital services with those offered by the hospice. Tina held a senior position in a large organization and said she felt fortunate because this had given her the confidence to engage with and question the professional practice of one organisation. She told of a time when she had acted as Theresa's advocate on one especially emotionally charged occasion.

She'd seen a whole gaggle of specialists, three brain scans and a rheumatologist, a vascular consultant and a neuropsychologist. He rang the scanning team and had a conversation with them and said you'll be hours. So, I had to go home, and I said I'll be back, in about an hour. Before I got back, she rang me and said I've got cancer in my brain, they've told me. Yeah, they told her on her own. So, they sat her in a corridor outside a ward on her own. Anyway, we sat around for hours, and hours and hours and I ended up getting annoyed with them and said what are you doing with her, are you going to admit her or are you going to leave her sat in the bloody corridor? …clearly, we're all a bit upset. Anyway, they found her a side room. I said what are you going to do with her tonight? They said, well nothing. I said, well what's the point of her staying here on her own then? She's just been told this information. She doesn't really want to be here alone in a hospital overnight. I took her

back the next day and they did the scan and referred her to Leeds… he said forget all you've been told before, that's never had anything to do with why you've got memory problems, it's because of this; he said we can't cure it, it's only palliative care that you're going to get. So, they gave her six weeks of chemo radiation. (Tina interview 1)

Immediately prior to the research interview, Tina had been told that Theresa's condition was now considered clinically stable, and the medical team were planning to discharge her to the community team for home care. During the interview, Tina shared her fears and misgivings about this decision which had been made without involving her in any of the care plan meetings.

I thought oh my God, I cannot take her home in this condition because when she's shouting and screaming for pain relief and I'm ringing the district nurse and they're an hour-and-a-half away, because they're over the other side of God knows where and they've got to come all the way over …it'll be me…I can't do it. (Tina interview 1)

The importance of establishing relationships with individuals in professional services was also highlighted by Margaret. It was clear that she and Alan had developed a good working relationship with the community palliative care team, and this increased their confidence when negotiating Alan's specific care needs. At one point in the interview, Margaret became angry and upset when she recalled the outcome of Alan's assessment into hospice care. It appeared she and Alan were told that his illness status lay between two diagnostic qualifying criteria. This meant he was considered ill enough for hospice care services but not ill enough to qualify for respite care. Like Tina, Margaret had not been invited to meetings where Alan's care delivery was discussed nor were the couple allowed a voice in the assessment process. She told me how the outcome of the assessment would impact on her as Alan's caregiver.

Alan has very good relationships with the physiotherapist and his special-specialist nurses, he wasn't doing very well at the rehab. So, they came out to see him and she sorted him out with different sorts of exercises

that do the same thing. Anyway, he saw the doctor and I remember walking in, and I saw his face …and I just knew then that he'd get us sorted out. Well, he admitted him that day. But again, the nurses helped, he listens to them. And now he's doing the proper amounts of exercise, so that's reassuring. I'm very grateful she did because I've got my husband back. He's funny and he doesn't moan. But there's nothing for me to have respite, there's nothing for me. Last year I came back a new person… Now, last year he was well enough to look after himself; this year he's worried, so I won't go. But that means I'm not going to get any respite either. (Maureen interview 1)

I was especially interested in how and when the caregivers' needs are assessed. Harold spoke as someone who had been through the process of having a carers' needs assessment by local authority services. He expressed his exasperation at this process which he said was protracted and contained multiple layers of bureaucracy which caregivers had to negotiate their way through.
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I've applied for NHS Continuing Care, which means that the NHS should be paying for all her nursing care and what they call social care… if she hadn't got Huntington's disease she'd be looking after herself…like washing, dressing, and eating, etc… She cannot do it herself. I argued that I'm basically a fulltime, 24-hour caregiver … if I walked out, she'd have to go into either a home or a hospital and that would cost the NHS more. Social services start off with the checklist where they do an assessment of needs and then if you've got a certain number of scores on this checklist …it then can go forward to this decision support thing and then you're assessed by the Continuing Care nurse and the social worker again, but with stiffer criteria… then it goes forward to the Clinical Care Group and then when you get the result. it took them two months after the thing went forward to make the decision. (Harold interview 1)

Alison's account of being assessed for funding mirrored Harold's and reflected on how the process of assessment is focussed on evaluating the patient's illness, with little consideration being given to the caregiver's ability to take on the role of caring.

> *Social services care people came out and did an assessment on Paul.*
> *They decided back then that he probably didn't… he just needed help*
> *when I wasn't there. And they, and they said if the situation changes,*
> *come back to us and we'll come out again and, and reassess him, which*
> *we did. …if I wasn't around it's going to cost them an awful lot more than*
> *me looking after him most of the time. (Alison interview 1)*

5.6 Researcher's reflections on the thematic account of first interviews

Before their interview, many participants said they were enthusiastic to take part in the researcher and commented on being keen to contribute to ongoing research which aimed to improve services for future caregivers All participants agreed to be interviewed with the knowledge that they may be asked to speak about some emotionally charged elements of their experience. I was appreciative of each participant's generosity and openness in the sharing of these experiences, and I was keen not to abuse their trust by mistakenly saying or doing the something to upset them.

I approached all first interviews with some nervousness because, although I had experience of supporting caregivers in hospice stings, I was aware that my role as a researcher was different. For example, as a bereavement support worker, I was there to ease the suffering of people caring for patients in the hospice or local community by providing them with emotional and practical support. As a researcher, my remit was to collect data and organise it in such a way as to increase academic knowledge of a particular phenomena or aspect of their experience

The interviews brought forth moments of realisation for some participants. I got the sense they were unused to talking about themselves without referring to the patient or their illness. For example, Maureen said she had conflicting feelings about acknowledging her role as Alan's caregiver saying that she herself had a

long-term health condition which Alan had supported her with before his own illness had deteriorated. It may have been that the interchangeability of the carer patient role that characterised hers and Alan's relationship made it difficult for her to identify as the one caring or the one cared for. Following her first interview, she commented on a shift in her perception, saying she believed her and Alan to be each other's caregivers.

Diane, Harold, Andrea and Alison chose to complete a Pictor chart as part of their first interview. Diane approached the chart as a task – choosing to write down her depiction in rough before depicting her account using the chart and post-it notes. Other participants showed an element of having prepared for their interview. Alison and Yvonne both arrived for their first interview with written accounts of their experience which served as a chronology of events. Of interest was that they engaged minimally with the Pictor chart, preferring to communicate their experiences verbally using their prepared accounts. Harold gave a detailed description of his experience, becoming animated at certain points in his interview. However, the chart appeared to be an addendum to the interview for him rather than an aid for him to reflect on his experience. Alison initially used the chart to depict her experience but after a short period of time, she sat back and did not look at it again. In this sense, the Pictor may have been a novel appendage to the interview, but it did not appear to act as a reflective tool for these participant's

In keeping with an LQA approach, a second interview was conducted with all nine participants. The aim of a second interview was to investigate each participants' perceptions of change between interviews and explore how and in what ways critical points in the experience of caregivers, influences their perceptions and appreciations of change and how these give shape to their experience of being a caregiver. The timing of second interviews is an fundamental aspect of the methodology used and is discussed in more detail in method chapter.

 Data from all participant's second interviews, were analysed according to the principles of thematic analysis (Braun and Clarke, 2006). These generated four themes which shed light on where there was change or stability in their experience. These are discussed and summarised in the following section.

5.7 Introduction to the thematic account of second interviews

Second interviews were conducted following an event which had been earlier identified by the participants as having had significantly shifted their own perceptions of being a caregiver.

In between their first and second interview, I had interacted with all participants and in some instances, I had spoken informally with the patient. After Diane's second interview she invited me to meet Geoff who was currently staying in the hospice for respite care. I made no notes about these interactions as they were outside the remit of this study. However, I noted in my research diary that, I felt a sense of privilege as if I was being "invited in" to their private world. An unintended benefit of this was that it appeared in instances where I had interacted with the patient as well as themselves, these participants spoke more spontaneously about their experiences.

All nine participants spoke again about when and in what way their role as a caregiver was developing and changing. In second interviews however, the patient's illness provided a backdrop for them to discuss their own evolving experience. Integral to many of the accounts were accounts relating to how they managed caring for the patient at home as well as when they were in the hospice. This included incidences where they changed and adapted during the time thy were interacting with palliative care services. These are discussed within the thematic account to provide the reader with an insight into how the participants' experiences were unfolding.

Two of the participants, Harold and Alison, chose to construct a second Pictor chart within their interview. Alison interacted slightly more with her second chart than her first and she was animated during the chart construction, talking in some detail while using the chart's shape, colour and position of the arrow shaped post-its in the chart to convey her dissatisfaction with Paul's medical team. I was surprised then when, at the end of her interview, Alison requested that she be allowed to 'just talk' at her next interview. I agreed and asked out of interest why this was. She said that, despite appearing to be engrossed in the process of chart construction, she had felt a sense of detachment from the reality of the experience whilst portraying her experience in this way. She said it felt as if she was conveying someone else's story and not counting her own.

Harold, who appeared to have lost a significant amount of weight since his first interview, did engage with the chart, though he seemed to be having difficulty focussing and seemed less engaged with it than in his first interview. When I asked him how he felt about constructing the chart for the second time, he remarked that he always felt better for speaking about his experiences. He said he had no feelings about using the chart stating that he had understood construction of the chart to be a part of the interview process.

Consistent with an LQA approach taken in this study, six participants took part in a third interview. The names of all participants and the number of interviews are detailed in figure 16. Despite issues with study attrition, the analysis of third interviews did add richness and depth to the analysis, generating four experiential themes. The themes emerged from a phenomenological analysis of participant interviews, and these added a layer of meaning to their unfolding experience of experiential change over time.   In keeping with an LQA approach, a second interview was conducted with all participants to investigate if and where there have been any changes which help us to understand more about their unfolding experience. The timing of second interviews is discussed in more detail in the Methodology chapter

5.8 Thematic analysis of second interviews

Theme 1 The fluctuating role of individual caregivers

Theme 2 Monitoring and making sense

Theme 3 Making and maintaining connections

Theme 4 Interacting with clinical services

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Theme 1 The fluctuating role of individual caregivers

Analysis of Initial interviews revealed how each participant had developed an appreciation of their role as changing in relation to the patient's changing illness. In this sense, their accounts were unique in that the patients were suffering with different illness trajectories. However, although their understandings were told with reference to illness changes, underlying their

accounts were stories which revealed how changes impacted on them in unique and practical ways. It appeared that these were the changes which marked a shift in their appreciation of how their world was changing. For some, such incidences forced a sudden realisation about their role as caregiver whilst, for others, changes tended to be more gradual or dawning. To give an example of this, John spoke of his desire to return to work after retirement and how he planned to balance his work with being Ellen's caregiver. However, following the first interview, John contacted me by email to share his recurring feelings of resentment at what he saw as an enforced lack of choice and stimulation in his life. His second interview was conducted after he called to say there had been some positive news about Ellen's condition which made him view his role as caregiver in a different light. I found John terminology usage very interesting, especially the way he portrays his present respite from the caring load. He interprets his role as caregiver by comparing it to on who has been released from the bonds of slavery with its connotations of being controlled or owned by another. At the same time, he now takes on the identity of one who redeems or delivers the enslaver from their suffering.

> *…the load's definitely lifting a bit at the moment. I've been itching to get back into business. We can find ourselves going backwards… …but as things stand at the moment … the sword of Damocles has been removed. I did resent it …I'd managed to control it and it would go away and then it would build up again. Now I'm, I'm feeling more expressive of myself and hopeful that the slaviour aspect won't reoccur because I'll get the stimulus that I do need…outside just being a caregiver. (John interview 2)*

At the time of her Tina's second interview, she was adjusting to the news that Theresa was assessed by the multidisciplinary team for discharge under the care of the community palliative care team. The news that Theresa's condition was considered clinically stable by professionals involved in caring for her, invoked fear in Tina. It is interesting to observe that, in her first interview, Tina had spoken of her feelings of being confined within the safe shelter of the hospice environment. The news of Theresa's discharge however had provoked

feelings of exposure to a level of care and her discharge which seemed like too big a step for her to manage. Tina's experience of having cared for Theresa at home had given her a glimpse into the world of a 24 hour family caregiver. She was aware that Theresa's condition had deteriorated considerable since that time and said her greatest fear now was that she would not be able to cope with adjusting and expanding her role to meet Theresa's fluctuating care needs at home.

> *I'm terrified of her coming home…because I just don't know how I'm going to cope. It's just all the responsibility is going to be on me. People will be tripping in and out but ultimately, I'm responsible for making sure what happens in the middle of all that? They don't do 24-hour care in the community…. I just want it to end, but then I don't …I don't want her to die. But it feels like purgatory. It really does. (Tina interview 2)*

Christine's recent deterioration had resulted in an increase in the amount of care she required. In Harold's first interview, he highlighted the importance of establishing resources and funding for Christine's care. I had seem Harold several times at the DHCG and I noticed he had begun to look tired. He spoke to me one night about his concerns that Christine had been unwell for over a week and later asked me to set up his second interview saying Christine's her condition had since deteriorated further and he needed to organise an increase in the amount of care she received. He described the step up in care Christine would require. I found it interesting to note that most participants were inclined to speak in terms of what they did in response to fluctuating care needs. Harold described how he took into consideration the limits of his competencies as well as his health requirements when organising an increase in Christine's care.

> *She's finding it more and more difficult. We are going to have to get more help in. It's the nights that are the biggest problem because she has disturbed nights. It's only probably to take her to the toilet and then bed her down again but I don't' get a full night sleep. I have to pay somebody to sit in overnight while I go in the spare bedroom and get a good night sleep… it'll come to that next. I will care for her at home as long as I*

possibly can. Fortunately [carer] comes in to get Christine up in the
morning and shower her … she'll come in extra and at weekends as well.
(Harold interview 2)

Steven for example spoke of being unable to appreciate the full impact of being
Mandy's caregiver until sometime into this role. He described his frame of mind
when filling out a questionnaire for caregivers at the hospice.

We had a list of questions: how has this affected your life?.., you know,
and various things. Very slightly, slightly, severely, whatever, and I filled
it in all wrong. I was either being too noble or thought I could manage
better than I have been doing. (Steven interview 1)

It seemed Steven had not been appreciated the full bearing of being a caregiver
until his own health had begun to deteriorate and he was at the outer limits of
his coping ability. His second interview was three months after his first where he
spoke of how he was beginning to understand the full effect that caring would
have on his life. His experience highlight's the instinctive way some caregivers
adapt to taking on the role of caregiver

In actual fact it's affected me a great deal. So, week after week after
week you tend to forget what you're doing. Whereas the thing I filled
in…anybody reading it would think you were leading a normal life, you
know, which certainly I haven't been doing. I was nearly at my wits end.
(Steven interview 2)

Steven's words highlight the intuitive way some caregivers adapt to the role of
caregiver. It seemed he was not able to appreciate the full impact of his
caregiving role until his own health began to deteriorate and he was at the outer
limits of his coping ability.

Theme 2 Monitoring and making sense

For some participants, part of adjusting to the patient's illness involved being
hypervigilant to the slightest change in the patient's condition. Even when the
patient's illness symptoms were stable, many spoke of how they scrutinized

subtle and nuanced changes in the patient's demeanour. This process appeared to be part of recognizing illness progression which relieved some of the uncertainty and unpredictability of living close to chronic illness. Tina exemplified this theme in how she drew on a range of information sources for a clearer comprehension of the volatile and unpredictable course of Theresa's illness trajectory. I asked her to tell me more about her researching because I wondered if it was driven by a need for information, comfort or a sense of control and preparedness. She told me that most of the time, her feelings vacillated between hope, fear and guilt.

> *It's a bit of a rollercoaster because you see something that you know is going to happen or you see that as progression. There's a lot of information on the internet. I tend to look at the American Brain Tumour Association and Medicine.net. And I read medical articles as well …and the symptoms that she's got are the things I look out for. Sometimes you think she's on a path and other days she seems to step off it … it's not easy to assess people's abilities or end of life timeframe. I noticed her foot was going this morning…she was quite fishy eyed …she was quite vacant two days ago… staring through the TV. And then she keeps asking what time it is. …there's something called sundowner's syndrome which is people asking what time it is all the time and that's on the tumour progression line as well…that must be kind of what that is then. I just want it to end, but then I don't because I feel really bad for saying that. (Tina interview 2)*

Alison also indicated a need to understand more about the progression of Paul's illness. She said she was able to gather most of her information by observing him closely and applying a common-sense approach to understanding his illness progression and likely cause of death. It appeared that she needed to understand Paul's illness in a way that made sense to her because she had been left feeling confused after multiple conversations with different medical professionals.

> *So we haven't had a great experience with the consultants. I think there's various stages of Parkinson's and he's in probably the last, stage five I think it is now. I've noticed when he's taking his medication, it doesn't*

always have much of an effect, it doesn't make a lot of difference. He gets infections…bacteria …it's all a bit vague and I'm not sure how the body functions. He's had this infection for months. They keep giving him antibiotics, but it never really gets rid of it. It's the saliva I think, it keeps going down the wrong hole. And you can die from it…it doesn't actually kill you, but you can die from it. (Alison interview 2)

A tendency to seek out further information was evident in Diane's account. She said she studied Geoff closely, noting the pattern of change in him, she said it helped her to make inferences about how the illness was affecting him bodily.

It plateaus...his left side is the weakest side ..when he sits he tends to be keeling over to the left but on the odd occasion …its usually an indication …an infection or something, there's something different happening all of a sudden you get the leaning to the right ad that's my indicator of there's something wrong. He seems to be dipping more frequently now. (Diane interview 2)

Monica was being cared for by Stan who said he had not had much input from medical staff. I asked if he had spoken to anyone about Monica's illness in detail. It seemed he had not found a suitable time or place to speak to staff and in the absence of information, he drew his own conclusions about her illness trajectory. It was clear that he did not find it easy to discuss the end of Monica's life and I wondered if he had been avoiding a conversation where the subject might come up. Stan lad linked Monica's symptoms to the side effects of her medication rather than her illness and I got the impression he feel swamped with managing the pace and amount of change in her condition.

No. Nobody mentioned it, I've kept thinking but I've never got a chance to talk to anybody on their own about that. I just presume the breathing will get worse and it seems that eventually it gets and then that's, that's it… At the moment we're not doing hospitals...We've done those in the past lots of times. They can never find anything that they can cure. I don't know if it's the tablets that make her confused of whether it's the medication...she also has a tremor in her right hand now which is getting worse. It's been a

different thing ever few months…you get one thing done and then another
thing comes with it (Stan interview 2)

Andrea was the only participant to monitor illness progression in terms of time rather than how illness was manifesting itself in Betty's body. This may have been because Betty's condition had recently improved to the extent that Andrea had returned home to her own family. I noticed that since she was no longer living in Betty's home, she was monitoring her symptoms less compulsively.

She has good days and bad days. But when…it's a bad one, it seems to
last longer (Andrea interview 2)

Theme 3 Making and maintaining connections
Within individual participant accounts were stories highlighting the importance their interactions with others and how these supported them whilst in the caregiving role. For most this meant working relationships with friend and family though relationships on all levels were evaluated in terms of the role played in supporting them.

I refer to Steven, who spoke at length of the support he'd received through his interactions with attendees and staff at the BOFA. group. Patients and their caregivers were referred to the course by the Community Physiotherapy Team. Attendees came together weekly for the seven-week course of support, education, and information to help them develop strategies for effectively managing and living with chronic lung

Steven was visibly moved when he recalled how group members decided to maintain contact with one another when the course had finished. He told me about how he enjoyed sharing his experience, strength and hope with others who were going through similar life experiences to the ones he faced as Mandy's caregiver. These meaningful connections based on empathy and identification appeared to ease his isolation and leas to deeply meaningful connections for Steven.

We built this support group, and we meet at lunch every six or eight weeks. You know. Just have a chat bit of fun it's all part of the release mechanism. (Steven interview 2)

In her first interview, Diane spoke in some detail of her plan to redesigning her home as a more accessible space for Geoff whilst also making it a being a welcome space to enjoy with visiting friends and family members.
. .

It was a dining room…but then the dining room is now Geoff's bedroom. There's a television in it and there's music …it's like a living room. We use that a lot when friends come. (Diane interview 1)

From our conversations at the DHCG, I knew Geoff's illness was deteriorating rapidly and by the time of her second interview his illness had deteriorated considerably, and he had been admitted to the hospice on two occasions for a review of his medication. Diane said while Geoff was in the hospice, she had taken the opportunity to break from her regular caring duties. During this time, she had enjoyed and time away from their home to catch up with friends outside of the caring scenario.

Talking of Geoff's return home, she reflected on the temporary nature of this break from the labour of caregiving and contrasts the two world she inhabits.

he just needs to be back half a day and what has gone before is completely gone...you're straight into mode again of work, care mode, you know, it just, it's like that It's like when you go on a holiday, isn't it, and you come back, first day at work… you're straight back into it and that's gone, yeah, until the next time… it's just a constant toileting, bedding, feeding, I do everything so I just want to meet up with friends and play. Go and have a coffee… when Geoff's there I can't do it. Last Saturday I met up with my friends and we went to the new pub (Diane interview. 2)

Alison also mentioned the importance of meeting and interconnecting with people outside the caregiving scenario saying she took advantage of short periods of time to connect with established network of friends outside the caring scenario. An example of this was when she told of how much she appreciated meeting with friends on the days when Paul was at the day hospice. The two women's accounts reveal how drawing on established relationships for support had played a central role in maintaining their own health and wellbeing.

> *and I've made a couple of really good friends so …I really enjoy it …*
> *It's not long but it does give me a little bit of time. It frees me up if I want*
> *to go do something, so I go and have a coffee with a friend. (Alison*
> *interview 2)*

Tina's contrasting experience confirms the invaluable part friendships play in the lives of caregivers. Because she was staying at the hospice with Theresa, her opportunities to take a break from caring were limited. I noted that in her first interview, she spoke of seeking opportunities to interact with people in her immediate environment. It seemed these strategies had helped her to feel grounded and find meaning at a time when she felt empty and disassociated from herself and the world, she inhabited which was dominated by illness and death.

> *I end up helping the nurses or I'd go in the kitchen and load the*
> *dishwasher or, I've been helping the gardener, because the doctor asked*
> *me last week, are you finding anything meaningful to do, I said I feel like I*
> *don't exist anymore. (Tina interview 1)*

In her second interview, Tina's told of how she had been able to reconnect with some of her established relationships. This appeared to give her a sense of normality and had the effect of buffering some of the dread and anxiety she experienced while waiting for Theresa's life to end.

> *I'm just there to look after somebody else and there's no end to it. I feel*
> *really bad for saying that. I don't want Theresa to die but it feels like*
> *purgatory. It really does. I was at home on Tuesday night. I went to try*

and find my niece a teapot for Christmas. And then I went home, made my dad some egg and chips…and then we walked down to the pub…drank lots of beer. (Tina interview 2)

Theme 4 Interacting with clinical services

Part of the caregiver's role was to co-operate with various clinical services and healthcare providers to negotiate an appropriate care package for the patient. Many of the participants' spoke with me inside and outside of their interviews about their experiences of interacting with different service providers. The importance of having clear lines of communication with service providers as well as being included in the decision-making process when professionals meet to discuss the patient's care plan was raised by many Appropriate care was framed as care which incorporated support for patients' needs as well as taking account of the caregiver's own circumstances and ability to care for them. Generally, it appeared that those participant's whose experience had gone without unexpected difficulties did not touch upon this issue. For others though, the process of working with services was less smooth, presenting them with unanticipated challenges. In her first interview, Alison for example reflected on when she had attended Paul's clinical assessment and how they were both impacted by an apparent lack of communication between two separate medical teams. This resulted in considerable stress for Alison who had to take Paul to three different hospital appointments before he was assessed by a team who could diagnose and treat his symptoms.

The first consultant …referred us to Sheffield for Paul to have this implant and when we got there, he said we didn't qualify because he didn't shake. The last one said she wasn't going to change his medication. They do this deep brain implant for people with Parkinson's so, this doctor wanted him to go and be assessed…which was a bit of a trauma. It's so frustrating…they said I'm really sorry you need to go back to your GP for a referral. So, then we were referred to the third consultant. So, I guess that is where they explain everything. (Alison interview 2)

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Following the third consultation, Alison said she was still unclear about the way forward in terms of understanding Paul's treatment options. I noted in my research diary after the interview that Alison had spoken with what appeared to be a sense of resignation about her struggle to negotiate her way through a complex care system.

Maureen's experience had mirrored that of Alison's when she recalled feelings of powerlessness at being excluded from discussions about Alan's care plan at the hospice. She spoke to me at some length about her medical history and her specific health needs. She said she was frustrated that her ability to care for Alan had not been factored into his advanced planning. This left her to question the future and doubt her ability to manage his illness at the same time as her own condition.

> *He's quite ill, you know, his condition's terminal. But because he tries, well we both do to keep on top of things, there's nothing until he's a lot further down the line. There's no respite. There's a gap and there's nothing that says, oh hang on a minute Alan, you can come and stay. I don't feel as if I can leave him. I need help. My condition isn't getting any better. Yeah there's a big gap and they'll be more people than us. (Maureen interview 2)*

Maureen felt her choices were limited by what she called a 'gap in services' meaning some important aspects of specialist palliative care services were unavailable to her and Alan.

Tina was visibly upset during her second interview and spoke of feeling excluded from Theresa's care planning. She recalled how two weeks prior, a decision had been made by the hospice multidisciplinary team to discharge Theresa into community palliative care services. The decision had wide ranging implications for Tina's own psychological health and especially her capacity to cope with caring for Theresa at home. In her interview, she spoke of feeling uncertain about her future as Theresa's caregiver and relayed a conversation with the district nursing team who had identified practical barriers to caring for Theresa at home.

I spoke to the district nurse, I explained that they're considering a discharge plan at the hospice. I said but I'm really nervous about that. She said well we can look after people with syringe drivers, but the problem is …she has to be hoisted …to do the suppositories and the toileting and all the rest of it. But the carers usually come for one or two hours at a time. But that means that the district nurse would have to come and administer the drugs. And then they'd have to be there while she's hoisted. It would be tying the two things together. The other concern the district nurse raised…her most significant concern would be where we live…its quite inaccessible if it snows or the weathers' really bad. And if Theresa needs a syringe driver changing and it's been snowing, we will not get to your house because it's difficult to access (Tina interview 2)

Theresa died shortly after this interview and no further interviews were conducted.

5.9 Introduction to the thematic account of third interviews

All third interviews emerged from the phenomenological analysis of participant's third interviews. The timing of interviews is discussed in the Methodology chapter. The interviews enabled the exploration of changes since last interviews which help us to understand their unfolding experience better.

5.10 Thematic analysis of third interviews

Theme 1 Looking back and looking forward in time

Theme 2 A network of relationships

Theme 3 Ways that caregivers manage changes over time

Theme 4 Continuity of care

Theme 1 Looking backwards and forward in time

All participants who took part in a third interview were aware that this would be their last. This may explain why, many who participated appeared to be reflecting on their experience of change while being a caregiver. John, for example spent time reflecting on how he had been impacted by this experience

had blurred the boundaries of time, concealing his future in a way that affected how he viewed the world and his changed relationship with Ellen. Referring to how Ellen's illness had led to an enforced shift in the balance of power in their relationship, John's use of a military metaphor suggests he felt diminished by his change of role

> *I was a good second in command [now] I reluctantly wear the role of commander in chief. And this is the fear for the future, what happens when half of my team are side-lined? I've been getting involved with this new business venture - also the trusteeship thing. And they're outgoing and making me feel part of the world again. I've got other things going on. I've had a small black phase in the last three weeks. I mean here we are now; she's diagnosed as terminally ill and yet in my mind I can see another five years of gradual deterioration ahead of us and that's where my blackness has come from to some extent. It's a mixture of anger and disappointment and frustration. I suppose, thinking how am I going to cope over the next five years and what am I going to do after that? (John interview 3)*

Diane also spoke about time and how she now viewed time as a resource which was in short supply. It seemed as if her time was being consumed by the sheer amount of practical caring tasks. This left her little time to be fully present and attentive to his need for interaction. She spoke of her sense of inadequacy when she saw other people communicating with him in a way that felt beyond her physically and emotionally.

> *I feel totally inadequate that I haven't got 24 hours to sit and listen to him. If I was coming in to sit, I'd be happy as anything to do it but I can not, I mean I haven't got the time. Because people can come, friends can come and our daughter and she's great. But she's only coming for half an hour. So, she can sit patiently while Graham tries to tell her something. But when I'm trying to do things it's never a one minute or five minutes, it's about quarter of an hour. So, then it's chipped into what I'm trying to do, so it's stop start, stop start. (Diane interview 3)*

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Alison talked of spending time in a new role she had taken up within her local community. She stressed how important it was for her to find meaning and purpose outside of her role as caregiver and how she had balanced her time and energy between two important roles.

> *I think if I was to be there all the time with him, I'd probably end up you know getting very depressed and then maybe not be able to cope. I'm still active still doing my bit. Did I tell you I was on the committee? So that hasn't had to change. I mean it's only once a month so really it doesn't impact that much and its quite nice sort of for me to get away and you know get out of the house... (Alison interview 3)*

Steven was a participant who concerned me the most and challenged my ability to stay in the role of researcher and not lapse into counselling him. So marked was his distress at certain times, I found myself looking out for him on the days he came to the hospice with Mandy. He spoke openly about how caring for Mandy had sapped his energy reserves but said speaking to others had helped him realise how weary he had become. I asked him after his interview one day what he planned to while Mandy was at the day hospice. He told me excitedly that he had looked forward to this time to himself because it afforded him an opportunity to re-establish a sense of normality in his world which for him meant relaxing with food and a newspaper.

> *Occasionally I'd just feel drained as a caregiver, but everything here is superb…. I get that break you know where I can go back home and get a newspaper and sit and read and have a sandwich and time to just relax…it's normality you know. (Steven interview 3)*

Theme 2 A network of relationships
The importance of making and maintaining connections featured largely in all conversations and second interviews of participants. This suggests it is an important feature of the caregiving experience. Steven's account stresses the importance of maintaining relationships when he spoke of how he had

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considered himself to be a gregarious person who enjoyed the company of others, especially his family. He spoke of how this had changed over the course of Mandy's illness to the point where his caregiving role was the most prominent feature of his world. Because of this, he became less able to spend time with people who played an important role in his life. I made a note in my research diary whenever he spoke of his persistent and growing feelings of isolation. On one occasion, he sought me out at the hospice and spoke of he saw this sense of loneliness as a temporary or short-term loss though he felt resentful at this narrowing of his world.

> *So, my grandsons. …it's no fun for the kids to just come and sit by her bedside. I do miss my relations and my three boys …but the thing is, there is no way we can see them. We used pop-up or they used to call. to see us and naturally that's eased off, so we've lost that social contact as regards people coming to see us, they can't come over now. (Steven interview 3)*

Diane reflected on how her network of friendships had diminished over time because it became more difficult to maintain relationships as Geoff's illness continued. When first interviewed, Diane spoke of enjoying time alone in her garden where she 'watched the world go by'. In her second interview, she said her home was also an important social space to share with friends and family. Her third interview was conducted while Geoff was an inpatient at the hospice. She spoke of how she saw this as an opportunity to travel further away from her home to visit friends where she was able to share her experience with others. It appeared this enabled her to gain a light-hearted perspective of her situation.

> *Anyway, I went to a party on Saturday. There were five of us …Claire, who lost her husband and then the other person lost her husband very suddenly. And then there's a woman who's had lots of cancer but she's still alive. And then a woman who lost her husband with a brain tumour two years ago. Then one woman lost her husband prematurely. So, between us we had a really good time (laughs) It's black humour but it*

was amazing what they were saying … it was a good laugh. (Diane
interview 3)

During this interview, Diane said she found it hard to come to terms with
changes in Geoff's demeanour and especially how these changes had impacted
on their relationship.

> *He doesn't respond to me as a wife, there's a bit of tenderness there on*
> *the very rare times. I don't know if he's capable or not. I said, you're not*
> *the person that I married, and I find it really hard. I said I know you're*
> *going to change; you're bound to because of what's going on but it's*
> *really hard because you're not the person that you were. It's a*
> *personality change… he'll smile when our daughter comes and our*
> *grandchild. His little eyes will twinkle. But after that it's back to yes and*
> *no for me. So, it's really difficult for me to accept. (Diane interview 3)*

Others reported feeling sad because of how illness had resulted in changes
within intimate spousal relationships. All of the spouses in this research had
been with their partner for over fifteen years. It appeared that changes within
the dynamics of their relationships were especially difficult to adjust to. John
and Ellen were spouses and business partners for many years. He used the
terms wife and business partner interchangeably when speaking about Ellen
inside and outside of interviews.

His words suggest a struggle to recognise Ellen as a fragile woman even as he
adjusted to accommodate the way he communicated with her so as not to
challenge her or cause her distress.

> *If we go back several years, we discussed everything. We communicated*
> *and now I tend to do more things without discussing them with her. I've*
> *become less free with my ideas and thoughts because I don't want to*
> *burden her, I guess. My mind works a lot and in the past I would just blurt*
> *it out and say 'what do you think of this? shall we do that?' because a lot*
> *of the time she's asleep and if I try to talk to her you can see she's*
> *nodding off. If she's awake, I'll say 'I'll be back in half an hour, is that*

okay?' But if she's asleep I'm stuck there. How can this woman who strode the world with me fall ill like this? I find it hard to come to terms with this frail lady being my wife. (John interview 3)

More than any other participant, Harold appeared to plan his caregiving and maximise opportunities to ensure his own physical and mental health were protected. This involved maintaining relationships with different groups of friends who supported him in distinct ways. In his first interview, for example, he spoke of regular planned leisure time with friends at the bridge and bowling club.

I play bridge on a Wednesday afternoon with a group of friends from the bowling club. The same group of friends from the bowling club… we bowl in the summer months; I play in a team so that's another means of support. (Harold interview 1)

By the second interview, there had been marked deterioration in Christine's functioning condition. This meant Harold spent more time at home with and, at this time, drew on support from family and other groups of friends who came to visit him and Christine at home.

There is more interaction with her friends and family and what have you. Her friends are very good because they've seen her deteriorate over the years. They only stay for lunch and go back in the afternoon, but it helps, it's the change of company I think as much as anything that helps. Because if there's only the two of us seven days a week, it's boring isn't it? (Harold interview 2)

Harold's account highlights the important role of relationships for caregivers as well as the patient they care for. On several occasions, Harold as well as other participants referred to the how important consistency of care was. I noticed that Harold planned every aspect of his and Christine's care in fine detail. On days they attended the hospice, he arranged for a parking space to be made available with his name on it. He struck me as a man who wasn't comfortable with leaving anything to chance. He appeared especially thrown therefore when

there was an influx of new referrals to the day hospice service and Christine was asked to take a break from her weekly slot so others could be given a chance to attend.

> *She was very disappointed when they said you've got to have a break and somebody else has got to have a turn. She had a week's respite which she enjoyed thoroughly and she's coming in again in November for another week. I had my normal holiday in Wales with the gang. (Harold interview 3)*

It was this incident which prompted Harold's decision to be interviewed for the final time. In the interview, he stressed how the hospice had been among one of several important resources for him. Because Christine had been attending the hospice for some time, Harold had made friends with many members of staff. It seemed their trips to the hospice formed an important part of their daily and weekly routine.

Being able to take breaks for caring was valued by many of the participants and Alison said on multiple occasions that she felt her mental health would be at risk if she had not been able to take a break. In her third interview, she talked about how her and Paul's shared world began to shrink when Paul became more isolated and detached from their friends and family. Throughout her interviews, Alison outlines the changes in her and Paul's social world and said she was saddened by a friend's response to changes in Paul's appearance and functioning ability. She spoke candidly of how the side-effects of Paul's medication had begun to affect relationships near to home and of her continuing process of adjusting to sustain valued relationships.

> *With the Parkinson's medication there can be a sexual obsessiveness. He said something to my younger daughter about nine months ago and she just wasn't happy about it understandably. So, they won't come over anymore. So that's hard it's hard for me. I go over there, and I see them, and nothing's changed there. It's just their relationship or her relationship, it's difficult so that hasn't helped. If he comes here on a Monday, she'll come over with the kids. You know we have coffee and*

lunch which is lovely, but she won't come if he's there. She did say to
me, 'Mum he spends a lot of time in his room so I can come over'. I said
'I wouldn't because you just never know when he may decide he wants
to get up and come down'. She did say that she knows that's what
caused it, but she just can't get it out of her head and I totally see that.
(Alison interview 3)

Theme 3 Ways that caregivers manage changes over time

Caring was most obviously manifested in the things the caregivers did and how they adapted their caring style to accommodate the patient's illness. Participants were faced with different challenges at certain times. These were linked to changes in the patient's illness as well as their individual circumstances. Maureen, for example, said spoke of needing to manage her own long-term condition to ensure she would remain capable of caring for Alan throughout his illness. Though part of being a caregiver for Andrea was being able to manage different family members according to individual skills and abilities. Steven spoke of how he had learned to monitor his own health needs, having previously not fully appreciated the impact of the caring role in the early days of Mandy's illness. John said he had been able to utilise available resources to manage change over time though he found it a challenge to interact with people outside of his usual male oriented social group.

I project an image of capability; the caring makes me feel part of a
woman's world. I've left a load of washing in this morning because good
drying days are not to missed at this time of the year. The people that
visit are Ellen's girlfriends, so I've learned to talk to them about their
children and their chilblains and whatever. It's not me naturally. I was
brought up in very much a man's world, you know, international
construction is a world where women generally don't penetrate at all. So,
I've had to learn this other side and I don't particularly like it. I don't show
the symptoms, but I do have things that are happening to me because of
her illness. (John interview 3)

Being Ellen's caregiver meant that John adopted the persona of someone more competent that he felt himself to be whilst occupying a world which was strange and new to him.

Aware of the progressive nature of Huntington's disease, Harold had made every attempt to anticipate how Christine's illness would change and how this would affect her needs. Throughout the course of the data collection, Harold was engaged in an ongoing dispute to ensure long term funding for Christine's changing needs. He spoke of how it was important to both he and Christine that her wish to die at home was carried out.

> *I've got the help in a morning. I have a cleaner that comes in and I manage to do the rest myself, but it won't always be - we're going to have to get more help in. It's the nights that are the biggest problem, because she has disturbed nights. I'm doing that, you see. So, I think we're going to have to pay somebody to sit in overnight while I go in the spare bedroom and get a good night's sleep. It'll come to that next, yeah as long as we can stay at home. That's my major concern, yeah. She wants to be at home as long as possible,* she prefers to be at home. (Harold interview 3)

Fundamental to Harold's account was his recognition that Christine's needs would increase in complexity over time. This said he anticipated this would require greater input from himself as well as an increase in the amount of paid care. While Harold was engaged in a struggle to secure extra funding, Steven began to take on different roles and responsibilities in the home. In his third interview, he looked tired and said a lack of lack of sleep and the burden of being exclusively responsible for what were once shared household tasks had compounded his feelings of being overwhelmed.

> *Things like putting washing through putting the dishwasher on… I rarely did that when she was well. We did things together really and suddenly I've got it all and this is where I find it to be a bit of a strain. (Steven interview 3)*

Again, consistency and the importance of establishing routine was mentioned by Diane, whose role as Geoff's caregiver appeared to have merged with the paid carers. Diane named her daily tasks and said the sheer amount of things to do left her feeling exhausted and unable to care for all of Geoff's needs especially towards the end of the day/

> *To start with the boring things, I sort the cat out, make a fire, get all Geoff's PEG foods ready and set his clothes out. It's all just toing and froing. It's stop start, then I get it ready for the carer to come. I always get Geoff fed his first lot of medication because he has to have it an hour before food. Then the carer comes at 7:45 so I get all those things ready for when she comes. When she arrives, I help her briefly and I make his bed because it allows her more time with Geoff and I'll set myself one task that really needs doing. I've started to give him his last medication at 8 o'clock then at 10 he starts wanting to talk with his card and I've just had it by then. (Diane interview 3)*

Alison said she found it difficult for to get an idea of Paul's fluctuating care needs. Like other participants Alison planned to increase the number of paid carers to enable her to take regular breaks from caring. In her second interview, she shared her observations about his deteriorating condition and how this was consuming increasing amounts of her time. In her final interview, she reflects on how his fluctuating illness made it difficult for her plan her time.

> *The thing is because he struggles so much now in the morning and it takes him a good couple of hours to get ready, to get up. I don't know how much longer we are going to be able to do it to be honest. Gateway to Care came out and did the assessment and they said about eight or nine months ago he wasn't so bad then. He was able to sit in and room and talk to them which he couldn't do now. At the moment, we have caregivers come in if I'm going away. Otherwise, I just look after him, he still has some ability and some days he has better days than others. I mean for example yesterday he was quite good and then yesterday he had a bad day. (Alison interview 3)*

Theme 4 The meaning of good quality care

An important theme throughout participant interviews was the different experiences of providing and organising car for the patient. Once again, consistency and reliability were raised as essential to good quality care when using outside services. Diane, for example had established positive working relationships with the regular carer who came to their home to provide care for Geoff. She mentions dependability and clear line of communication as being an important part of their relationship because entrusting Geoff's care to another person was not something, she found easy.

If you need carers, which we do because I can't do it 24/7 you need to have help. And you only get it paid for if you haven't got any money or if you're under a certain amount. You can go through the council, and they can supply it, but they'll still charge. That's why you pay a lot of money for these companies to do it. If those carers are on holiday you've got to find someone else to come in. I told them not to send [agency carer] but they did. Then at teatime, there was supposed to be another one, but she couldn't come because she was ill. So, we got one who was training…I had to double up with these two people. I'm going to raise it with them and say when our normal carer is away, let's have that one please because I know I can trust her, and I know she's safe. Yesterday the regular carer went to London which caused an upheaval because we have her four times a day. So, it meant we had to have three different carers yesterday because they hadn't got one that could do it. The first one wasn't used to a convene. He has the convene on to make it easier for the carers. One of them dealt with him when he was much more mobile and able but yesterday, he wasn't so she felt inadequate and got very upset. Continuing Care have paid for Geoff's care but it's being reviewed, they could take it off us. The letter states that they'll check whether he's stabilised or whether he's gone downhill or got better. I would say he's plateauing, but each day is different… It's unpredictable there's a lot of changes. I mean they know there's a lot of changes, they could say well we'll fund you for two hours a day, not the full four hours a day. (Diane interview 3

Diane had requested that her third interview was conducted as Geoff was about to be assessed for further funding having been awarded full funding for his care for the previous three months.

Maureen also raised issues of funding care, pointing to gaps in services where Alan had been assessed for support based on his current condition rather than his overall circumstances. Maureen felt Alan's assessment for care did not take into account her capability to care for him at home. Alan's funding for outside care had not been granted and Maureen contacted me to give me this news and request that her final interview take place in their home. The couple told me of their decision to employ a family member to take care of them both full time.

> If she's happy to give up her job. We will have to pay her, but we have to pay anybody but at least I know we're both getting the best care You know there's nothing for us, when they are at life's end there's a gap… a really big gap actually where nothing is available. Because he's not ill enough, he's still managing to wash himself though he needs help with bathing. I help him but it doesn't do my back any good. I've got some Tramadol, but I don't like the way they make me feel so I try to use the TENS machine as much as possible but when I can't manage with that then it's Tramadol. Normally I have injections twice a year but that's just not happening because the waiting list is so long. I mean we are fortunate because we both had good jobs, we both saved otherwise we would have been absolutely shattered now. So, we have the means to be able to pay somebody to come and stay overnight. (Maureen interview 3)

When I arrived at their home, Alan answered the door as Maureen was in being cared for by her sister in a downstairs room. He explained that Maureen and Alan had chosen to fund their joint care using savings to pay Maureen's sister to care for them at home.

Harold had concerns about his own health and was keen to ensure that Christine would continue to receive funding for appropriate care in her own home regardless of his ability to care for her. After having received a decision about Christine's funding for care, he requested that he have his final interview.

He spoke about the care that Christine was currently receiving, again the issue of trust and continuity of care was raised as significant.

> *The carer that comes in to get Christine up in the morning and shower her and apply her creams and what have you. She has several clients who she cares for. She'll get them dressed and get them in the shower or bath. Yes, she's very good because somebody with Huntington's, they need continuity of care.*
> *They made a decision on the latest assessment which we're going to appeal. The problem isn't severe enough, but my argument is that Christine has a complex neuro degenerative disease, if she hadn't got that disease, she'd be able to cope and do things for herself. She wouldn't need getting dressed and being washed and showered by someone else, she wouldn't need to be fed because she could hold a spoon or a knife and fork. There is an assessment process. It's called a decision support tool where there are certain categories, and you are graded according to the severity of illness. She was first assessed in March 2016 and went through the full assessment process, got her results and they offered us eight weeks respite at £156 per week. They call it funded nursing care which would not have paid for a nurse for a week. If she went into a nursing home, it would have cost £1500 a week. The trouble is there are no strict rules, it's all guidelines. There is a national framework and there are national guidelines and it's their interpretation of those guidelines. (Harold interview 3)*

Expressing his feelings about the assessment process, Harold outlined some of the issues he thought made the process unfair.

Alison had been taking care of Paul to varying degrees for over fifteen years but increasingly more so since moving to a new area three years earlier. Wider family members had been assisting Alison with Paul's care, but there had been recent illness related complications and family were no longer able to offer him support. This meant Alison was Paul's sole carer with occasional help from a private care company. When he began to need more specialised levels of care, Alison was advised to request a local authority assessment. After assessing

Paul for care at home the second time, Alison was instructed to contact the organisation when she felt she was unable to cope with his care.

> *Gateway to Care came out and did the assessment. What they said was he wasn't so bad. He was able to sit in his room and talk to them which he couldn't do now. I think they felt when they came out to do his assessment that at that stage, he was all right, not alright but able to still cope. And she left us a contact number and said when you get to the stage where you feel you can't cope any more you need more help then contact us. (Alison interview 3)*

5.11 Chapter summary

This chapter began by providing an overview of nine participants recruited from three different areas in a hospice in Yorkshire. Having presented a profile of the participants and a thematic analysis of three sets of interviews conducted at crucial points in the caregiving experience, these have been discussed in terms of longitudinal change or continuity in the participants' experience. In the following chapter I present an overview of the longitudinal perspective of each participant as a way of demonstrating where longitudinal development is apparent within their accounts. Following this, the accounts of individual participants is used to illustrate how longitudinal change and adaptation impacts on different participants at different times with different effects.

Chapter 6 - The longitudinal perspective: an overview

6.1 Introduction

It became apparent when reviewing the literature that most studies in this area adopt a cross-sectional approach which provides the researcher with a snapshot of experience to reflect on. This research aimed to provide a deeper understanding of how the caregiver's role develops by undertaking interviews with caregivers at different time points in their journey. The intention was to undertake three interviews at points in the caregiver's experience which they identified as being crucial in terms of how it shaped their experience. From these interviews, the participants' unfolding experiences were brought to light through the themes, revealing a picture of longitudinal experiential change. The previous chapter demonstrated how certain themes were apparent in the accounts of individual participants at different times, revealing the uniqueness of the phenomena. In figure 17 themes and sub-themes relating to aspects of the same topic are placed in the same line to demonstrate where there is developmental continuity in the themes, and, by default, where there are differences. This made it clear that there was a considerable amount of reflection on behalf of the participants relating to taking on the role of caregiver. In first interviews, it seemed that the patient's illness had shaped the way the role of caregiver emerged. Interactions with professional care services highlighted the importance of having clear lines of communication with medical staff and within this theme, accounts of interactions with social services revealed some of the difficulties experienced by caregivers when navigating their way through layers of bureaucracy.

Attitudes to taking on the role of caregiver emerged in interview one. This is perhaps unsurprising as caregivers spoke in early interviews of their initial adjustment to the role and how they felt about it. It appeared some had conflicting feelings about taking on the role while others did not recognise themselves as caregivers but considered their actions as providing care for a family member during their illness. Once the reality of their role as caregiver had been established, caregivers spoke less about how they felt and more about how they coped and made necessary adjustments as the caring role emerged.

Figure 17 - The underlying themes relating to longitudinal development of individual caregiver experiences

Interview 1	Interview 2	Interview 3	Underlying Theme
Caring role emerges from illness trajectory	The fluctuating role of individual caregivers	Looking back and looking forward in time	Caring role developing longitudinally
Attitudes to being a caregiver			Initial adjustment to caring role
Depictions of the caring role	Adapting to new levels of caring		Continued adjustments to caring role over time
Coping and adapting	Monitoring and making sense	Ways that caregivers manage changes over time	Developments in coping longitudinally
	Making and maintaining connections	A network of relationships	Importance of relationships
Interacting with professional care services	Services	Continuity of care	Changes related to professional care services

It appeared that the caregiving role did not grow systematically, as the illness progressed for the participants. By the second set of interviews, it emerged that development of the role fluctuated according to multiple factors. Not all these related to the patient's illness though the data in first interviews suggest caregivers were hypervigilant in their monitoring of the patient's symptoms. Some participants had tried to make sense of their experience by gathering information and closely monitoring changes in the patient's illness. The account of one participant, Steven, is used to reveal how caregivers adapt to new levels of caring, though they may not notice the effect that providing care is having on them until their own health fails. The need for adapting and adjusting was not limited to adapting to the patient's illness but to wider influences embedded within the psychosocial world of individual participants.

Concerns about being able to manage the demands of caregiving in the future was evident in second and third interviews and it was apparent that social factors relating to participants on an individual level played an important role in how they coped and adapted to change over time. One aspect of this was related to the participant's own connection to a network of supportive

relationships. Typically, these were friends and family but for some, their relationships with privately paid and professional medical and nursing services played an essential role in how participants adjusted and managed the developing role of caregiver.

In the following section, I will draw on the data and participant's accounts to exemplify where there was change and stability in each caregiver's experience and how this revealed the longitudinal development of their experiences.

6.2 Change and stability in longitudinal experience

The availability and access to personal funds was seen to influence the experience of some of the participants. Though not a strong feature of the longitudinal thematic account at any one time, having access to adequate funding made it possible for some participants to take regular breaks from the demands of the role. For some, this provided them with an opportunity to interact with others outside of the caring environment. Those who were able to take time away from caregiving duties were more likely to tell of the positive aspects of taking on the caregiving role. Harold's experience exemplified this aspect of the longitudinal experience and he spoke of how he felt fortunate that he was able to afford to pay for Christine to have a private carer who came to their home every day. This meant he was able to have breakfast with Christine in the morning and meet with friends to play bridge once a week. When his own health began to fail, Harold said again how lucky he and Christine were that they had the same carer who was willing to adjust the amount of time she spent with Christine and provide more care for her at time when Harold was unwell.

In their third interviews, the participants tended to reflect on their experience and think about the future. Harold told of how he and Christine had come to regard the private carer as a family member. The couple had many long-standing friends who continued to visit them regularly throughout Christine's illness, adjusting the length of their visits according to Christine's condition. Having this degree of flexibility meant Harold was able to maintain his husband-and-wife relationship with Christine as well as meeting regularly with friends outside of the caring scenario. Being able to retain an element of normality appeared to support Harold in his adjusting to the caring role across time.

In all his interviews, Harold spoke of an ongoing dispute with NHS Continuing Care who had assessed Christine for funding to pay for her care. It appeared

the disagreement centred around the classification of her needs as social or nursing related. In his second interview, he said he was concerned for his own health and had recently undergone medical tests. His own health needs not been taken into consideration when assessing him as part of the process of a carer's needs assessment. Expressing his frustration, he said in his final interview that the appeal process for funding Christine's care was 'in limbo'. His major concern with securing funding was that, in the event of his death, Christine would have sufficient funding in place to enable her to be cared for at home until her death. In this sense, Harold was making plans for his daughters to be enabled to adapt to Christine's fluctuating care needs in the future. Fluctuation in relationship networks was evident in second interviews and continued to be a major element of longitudinal experience throughout accounts. Many experienced shifts in relationship dynamics which called for a different kind of adjustment for participants as the uncertainty of their situation changed how they lived together and thought about each other. Some of the caregivers had access to practical and emotional support from friends and family members who played a key role in assisting them to manage and respond to fluctuations in the patients' illness. A major determinant of the ability of caregivers to continue in their caring roles over time was how they interacted with medical and nursing professionals. Having reliable access to help from professionals played a key role in the caregivers' ability to cope and adapt over time.

Steven said in the initial stages of Elizabeth's illness, he had adapted to the role of caregiver by taking on a greater share of previously shared responsibilities in the home. This left him feeling exhausted and his already fragile health began to deteriorate further. As Elizabeth's condition worsened, Steven drew on help from family members as well as professional care services who visited daily to support him in managing Elizabeth's condition. Steven, who described himself as a sociable person, saw the arrival of well-meaning individuals to his home as an intrusion. His perceptions of the community nurse's involvement were, however, positive. He saw this intervention as an opportunity for him to take a step back from his role in providing care. Over time, it became apparent that his role in caring was not shrinking but increasing and said he had less, and less time stay in touch with friends outside of the caring environment. As his sense

of isolation increased, Steven spoke of a critical point when he and Elizabeth had been invited to attend the hospice together. This marked a dramatic change in his outlook and his ability to cope because it presented an opportunity for Elizabeth to access medical and nursing help without impacting on his own health. He described this first visit to the hospital as wonderful and became emotional when he said he had felt a renewed sese of hope and an opportunity to renew his contact with his grandchildren and wider social circle.

The theme of adapting to the role of caring was less apparent in Tina's account. This may have been because her wife was an inpatient at the time of her interview and though Tina was spending much of her time at Theresa's bedside, as Theresa's condition deteriorated, nursing staff were available to respond to her changing needs. The importance of relationships was a dominant theme within Tina's account, and she said there had been a breakdown in her relationship with Theresa's family. She spoke of this as a permanent breakdown and stressed other networks of support she had accessed. Having given up work to provide round the clock care for Theresa, she said she missed he the daily interaction with her work colleagues and the intellectual stimulation of her busy job. Tina had been staying at the hospice for a few weeks when she was interviewed. Spending time with hospice staff had enabled her to build relationships with staff and she spoke of how she considered her relationships with hospice staff to be an important source of practical and emotional support. Continuity of care from professional services was raised in second interviews as the participants continued to cope and adapt to managing changes in the patients' illness. In Tina's first interview, this theme related to when there was a lack of continuity in Theresa's care. Having different diagnostic teams involved in Theresa's care management meant that she had to manage care delivery when they were giving conflicting advice, as well as multiple illness diagnoses. Tina, along with Diane and John spoke of researching the illness and this appeared to help them understand and make sense of the illness progression. It emerged that being aware of the illness signs and symptoms helped to minimise some of their uncertainty about their own future. On two occasions, Tina took control of Theresa's care management by challenging advice offered by medical staff and approaching a different team of medical experts for a second opinion. She spoke with anger, of feeling excluded from interactions

with professional car services when a decision was made in her absence to manage Theresa's care in the community.

Her fear of not being able to adapt and cope with Theresa's illness in the community followed an experience where Theresa had been in acute pain and demanded an increase in her pain relief medication. Being at home out of hours with no access to Theresa's medication, Tina had to placate the distressed Theresa for hours until community support arrived. Because of this, she was not prepared to care for Theresa at home and place herself at risk of unreliable access to home care services. Having no family members to support her in caring at home, Tina's sense of isolation intensified when she tried to defend her decision to not care for Theresa at home to Theresa's family.

Diane's first interview highlighted the importance of having reliable access to professional services. It had taken a long time to establish consistent and reliable connections with people and services who could help her to adapt and cope with Geoff's deteriorating illness. The accounts of Diane and Tina draw attention to the impact of interacting with multiple service providers. Diane said she spent much of her time repeating details of Geoff's symptoms to different medical and nursing groups in the early part of his illness. Over time, a regular team of carers was established, and Diane worked in partnership with them to provide Geoff's care at home. Diane enlisted outside help with Geoff's care by employing carers from a private care company. In her initial interview, she said this enabled her to take regular breaks to relax at home while she worked in her garden. Over time, Geoff's illness became more complex, and by her third interview she said when private carers came to their home to care for Geoff, she would work with them by giving instructions on how best to care for him. Diane said she was unable to secure regular or personalised care for Geoff because the care company was not able to guarantee the same carer would visit every time. As a result of spending more time with the formal carers, Diane had less opportunity to take breaks from caring and her relationships with Geoff and other family members suffered. Around this time, her own physical and psychological wellbeing began to deteriorate.

There were similarities in the accounts of Steven and Maureen's with respect to how her health was impacted when she adapted her role to meet Alan's increasing illness needs. However, Maureen did not see this increase in

responsibility, saying she was responding to his changing needs as part of her role in Alan's care and perceived this as an extension of her role as his wife. When adjusting to helping Alan with bathing and moving around the house, Maureen experienced a flare up of her own long-term condition. Despite this, she continued to prioritise Alan's needs above her own. When she asked for an assessment of her needs by the local council, Maureen was told she and Alan would be responsible for funding of any care Alan required. Like Tina, Maureen felt her voice had not been heard in the assessment process and believed that without considering her ability to care for him, neither her nor his needs had been fully and adequately assessed. Her third interview was conducted in their home where she and Alan managed their joint care with the help of a family member who had given up her job to care for them both full time. Maureen said when her own health suddenly deteriorated, she applied for respite care for Alan so she could take a break from caring. She was upset by what she saw as a lack of continuity in caring services when she was told Alan was not eligible to use the hospice respite service because he had chosen not to attend the day hospice.

Both Maureen and Stan, however, said they felt supported in their providing care by the community palliative care teams and the relationships formed with individuals within the service were especially valued. Continuity was a dominant theme which permeated both of Stan's interviews. Monica's health had remained stable for a considerable amount of time when, eleven weeks after his first interview, he contacted me requesting a second interview following a marked deterioration in Monica's cognitive function. At this stage he was still being supported by community services and had acquired new skills to adapted to changes in Monica's health. Monica died one week later so no further interviews were conducted.

Those who had been able to maintain a strong network of supportive relationships considered themselves fortunate because they had been helped in practical ways to cope with their caregiving roles. John and Ellen, for example, had moved to the area to be near to family who were able to provide daily help with Ellen's care. John said he valued the practical and emotional help he and Ellen received help from his family support network. However, he described how he had begun to feel increasingly more penalised by Ellen's emotional

dependency on him, though his research told him this was a sign that her illness was deteriorating. Ellen was unable to tolerate John leaving the house for long without becoming worried and agitated. Not wishing to cause her distress, this aspect of her illness nevertheless limited his ability to maintain relationships with friends outside of the caring scenario. In his second interview, he shared some recent good news which suggested a possible improvement in Ellen's health. This gave him confidence that he would be able to pursue more meaningful interests outside of caregiving in the home. Ellen's level of dependency on John, however, was unchanged by this improvement in her condition and in his final interview, John's low mood had deteriorated to the point where he said he could no longer see a future for himself outside that of being a caregiver.

Emotional adjustment also impacted on Andrea, who spoke about the complexity of her family relationship dynamics. As the only daughter out of six children, Andrea had sole responsibility for washing and bathing her mother Betty. This was because other members of the family were not capable of providing reliable care for her. Even when formal carers came to Betty's home, she refused their help because she preferred Andrea to wash and bath her. Andrea had very little interaction with services visiting Betty but viewed them, along with other family members, as a resource to be used to fill in gaps when she was not able to be available to provide care for her mother. In her second interview, Andrea was upset that Betty had told formal carers not to come again after she said she felt better. This meant Andrea would have to adjust her caregiving role by spending more time providing her care for Betty. This had a financial impact on Andrea as well as her husband and son when she had to reduce her working hours to spend more time providing care. Betty had offered to pay Andrea for her care and she said in her second interview, that although she was uncomfortable, she had begun to accept £15 a week to help with her lost wages.

When describing the gradual way, she had taken on the role of Paul's caregiver, Alison talked about how the couple moved to the area early in Paul's illness. At this stage Paul was still mobile, and together, the couple immersed themselves into the local community. After a while, Paul's condition deteriorated, and he was referred to three different consultants before he was

able to access treatment for his condition. In her first interview, Alison described the lack of continuity in care and of having multiple teams involved in Paul's care. Her experience resonated with that of Diane and Tina and all three women said their partners had decided they did not wish to attend further hospital appointments. It appeared that the patient's symptoms were the most reliable source of information for them in terms of knowing if the illness had or had not progressed.

Like John, Steven and Tina, Alison had experienced a growing sense of isolation which escalated when they provided care in the home. When Paul began to spend more of his time at home, Alison employed a private care company to take care of him during the day so she could leave the house to meet friends in the local community. She described the care provided by the private care company as minimal but considered taking a break from providing care was essential for the maintenance of her own psychological health. In her first interview, she said Paul had been assessed for local authority care early in his illness. The assessment was aimed to ensure his needs, as well as the needs of his family, were addressed. It appeared that because Alison was managing Paul's illness well, the couple were not eligible to apply for additional help and she was told to ask for a re-assessment when she felt she was no longer able to cope. In her third interview she said there had recently been a rift in family relationships. It appeared that Alison's daughters supported her in maintaining her own physical and psychological health but had recently stopped visiting the couple's home. They also stopped providing Paul with practical face-to-face care. It transpired that there were side effects to Paul's medication which lead to impulsivity. One of her daughters had been distressed by communication she received from Paul and refused to visit the house with Alison's grandchildren in the future. Though Alison understood her daughter's position, she said she preferred to visit her grandchildren at home because it gave her a good reason to be out of the house.

6.3 Chapter summary

The previous chapter brought to light the idiosyncratic nature of the caregiving experience through the thematic analysis of interviews taken at three different points in time. By comparing patterns of change and stability within the thematic categories, the unfolding experience of individual caregivers was revealed. The

overview of the participants' longitudinal perspective reveals that although the participants' perspectives were shaped by changes in the patient's illness, patterns of developmental continuity within the themes suggest a more random process of change than would be seen in most disease trajectories. Having and maintaining a supportive network of relationships was an important component of the longitudinal experience of the participants in this research. It appeared that where good quality collaborative relationships were formed with palliative care services and where care from services was reliable and consistent, caregivers felt better able to adapt and cope with managing the changing health needs of the patient.

In the following chapter, I will present an examination of the study findings in terms of how they address current gaps which were identified in the literature review. This will contribute to existing knowledge relating to which factors of the caregivers' longitudinal experience are associated with the patients' illness as well as which factors are impacted by their engagement with palliative care services.

Chapter 7 Discussion

7.1 Introduction

The aim of this study was to explore whether and in what ways the experiences of family caregivers are similar or different to the patient receiving palliative care for a chronic or life limiting illness. To address this, the following questions were asked at the beginning of the study.

- How does providing care for a family member with palliative care needs change or stay the same over time?
- What is the family caregiver's perception and experience of providing care during the patients' illness trajectory?
- How and in what ways are caregivers' experiences impacted by their engagement with palliative care support services?

The study addressed the research questions by adopting a longitudinal cross-sectional research design which draws on the principles of phenomenology. This explored those 'parts' of the phenomena which were implicit in the lived experiences of the research participants (van Manen 1990).

Chapter 3 examined debate within the phenomenological literature which relates to how it is possible for the researcher to transcend their own understanding of the world. Doing so allows the researcher to arrive at an interpretation of human experience and identify the essential features or essence of a phenomenon (Giorgi and Giorgi, 2008).This interpretation should not be mistaken with the researcher making generalisations about human nature. Rather, it points to the possibility of what this experience is whilst acknowledging that the establishing of meaning will always be tentative and incomplete (van Manen, 2011).

In chapter 5, the 'parts' of the participants experience were drawn together to identify essential themes which constituted the longitudinal experience of the nine participants in this research who were interviewed at critical points in their experience whilst caring for a family member with terminal illness. In chapter 6, the participants' experience of change or stability across time is brought to light through the themes, revealing a picture of longitudinal their experiential change.

Whilst analysing the data and identifying the essential themes, I spent a long time thinking about the lived experience of these participants. This involved scrutinising their words and questioning my own understandings of their experience. van Manen (1990) states:

> *The problem of writing is that one must bring into presence this phenomenon that can be represented only words - and yet it escapes all representation. The writer who aims to bring the object of his or her gaze into presence is always involved in a tensional relation between presentation (immediate "seeing and understanding") and representation (understanding mediated by words).*

Through this process, which involved describing the phenomena through the process of writing and rewriting, I reflected on the accounts of individual participants at different times before standing back to reflect on how these related to the research questions, aims and objectives.

Chapter 6 therefore, outlines how the thematic findings relate to the participants' longitudinal experience. This brings out how the thematic findings relate to the participants' longitudinal experience of change or stability over time It appeared that the patients' illness had influenced the timing of how the role of caregiver emerged for each individual participant. At the same time, the distinct facets of each participant's psychosocial world also influenced how they were individually affected as the patient's illness progressed and their caregiving role developed. These essential themes or aspects of individual experience will be discussed in this chapter though they should not be thought of as general theories about human nature. Rather, van Manen (2011) points out that essential themes are concerned with possible human experience which recognise the determining of meaning will always be tentative. The way in which the themes developed over time suggests that, adjusting to the role of caregiver was not a single event but one which the participants' had engaged with according to how they each viewed taking on the caregiving role; as well as how competent and prepared they felt to fulfil the role of caregiver. Ease of access to reliable and regular contact with medical and nursing services influenced how they each coped with the caregiving role, as well as how confident they each were about their ability to manage ongoing changes. Being practically, emotionally and financially supported in their role by friends and family assisted some of the participants in

maintaining their own physical and psychological wellbeing. The analysis of longitudinal accounts identified inequality in terms of each participants' access to financial resources; this imbalance of resources had a significant impact on those affected, to the extent that they were less able to take regular breaks from the caregiving role. These participants were challenged by managing their caregiving duties, and, in some cases this had resulted in a deterioration in their physical and psychological wellbeing.

Four essential themes were identified from the longitudinal analysis:

1. The family caregivers' longitudinal experience is influenced but not defined by the patient's experience of illness.

2. By offering practical and emotional support appropriate to their needs as they were revealed, the friends and family of caregivers played a key role in supporting them to care for the patient throughout their illness.

3. The caregivers' experiences of engaging with palliative care services were influenced by the reliability and quality of their interactions with medical and nursing staff, especially at crucial times in the patient's illness.

4. There were barriers in place which impacted on individual caregivers' access to financial resources. These impacted on the caregivers' social world as well as their physical and mental wellbeing.

In the next section, I will review each theme in turn by considering how they relate to current literature.

7.2 Essential theme 1 - The family caregivers' longitudinal experience is influenced but not defined by the patient's experience of illness.

The participants in this study were caring for patients with a range of different illnesses. Consequently, the nature of caring tasks changed for each participant as the patient's illness affected their functional condition. Initial interviews revealed how such events had led to shift in the feelings and perceptions participant's as they began to realise what becoming a caregiver would require of them. This shift in understanding resonates with elements described in a theory of caregiving put forward by Brown and Steltz (1999. This theory describes the process of becoming a caregiver is a deeply as an emotional process one where they are forced to confront the reality of the patients' illness diagnosis and acknowledge their own commitment or lack of commitment to taking on the caring role. The current longitudinal study went expanded on this

theory to reveal how the psychological process of taking on the role of caregiver occurred over time. Factors involved in this process were highly idiosyncratic for the participants and included but were not limited to times of change in the illness of the patient they cared for.

The study aimed to gather individual accounts of longitudinal change or stability and In early interviews, it was difficult to get an account of the individual participant's own needs and wants. However, through my interactions with them and subsequent interviews, a clearer picture emerged of how they adapted and coped with the practicalities of becoming a caregiver. Much of the research in this area recognises that stages or phases of change in terminal illness intersect with certain points in the experience of their caregivers (Schulman-Green et al., 2004; Marsella, 2009; Blum and Sherman, 2010; DuBenske et al., 2010; Duggleby et al., 2010). This was the case for the participants in this study where multiple points in the illness of the patient overlapped with their own experience.

An example of this was taking on the role of family caregiver which was a critical point and often shifted at times when the patient's illness deteriorated and demands on the caregivers' increased. This finding resonates with a study by Morris and Thomas (2010) who noted that the caregivers' needs tended to intersect with those of the patient at certain critical points in the illness journey. The study explored the perceptions of cancer patients' caregiver's revealing a crossover of needs for caregivers and patients. Such times were at diagnosis, the end of first treatment, at cancer recurrence and during the time the patient was referred to palliative care services. The current study expanded on these findings by demonstrating that the overlapping of needs is a feature for caregivers throughout many different illnesses. By exploring the caregivers' experiences longitudinally, this research also shed light on how the participants needs differed from the patient's even at times of critical change in the patient's condition. In early interviews, participants expressed varying levels of willingness or preparedness to taking on the role of caregiver. It emerged in later interviews that those who had felt competent to adjust and adapt to the fluctuating needs of the patient were more willing and prepared to continue providing care for the patient until end of their life. Feelings of competence and

willingness were associated with multiple factors embedded in the participants individual social world.

The longitudinal element of this study revealed how participants who had reliable and personalised access to palliative care services felt more confident in their ability to adapt to the needs of the patient. This appeared to influence the nature and quality of their social and familial relationships which helped them to maintain their own physical and psychological wellbeing.

At times of change therefore, participants were looked to a wide range of different resources available to them. It did become apparent that critical changes in illness impacted on participants and patients in different ways. To demonstrate this point, I recall an example from my experience as a bereavement support worker.

It is late afternoon and Susan, who has been providing care for her husband arrives at the hospice with her four children whose ages range from two to seven. Minutes later, an ambulance brings her husband from the hospital where she left him earlier to collect the eldest child from school. She begins to apologise for bringing the children to the hospice explaining she had not been able to organise childcare at such short notice and she had to catch two buses to the hospice. She told me about her hopes for her husband during his stay were that he be comfortable and settled in a place where he had chosen to spend the last months and weeks of his life. Yet for herself, the admission meant for the next few weeks and months Susan must cope with negotiating travel arrangements to and from the hospice while balancing her time between visiting her husband and attending to the needs of her young children.

This example tells of how both patient and caregiver were affected by changes in illness, yet between the lines of their individual stories of change, there ran a narrative which, for Susan at least had extended beyond the course of physiological change and it was at this point that her story of illness change diverged from that of her husband's.

For the participants in this research, the point of referral to palliative care appeared to be a significant event. The longitudinal design of the study meant I was able to explore some of the reasons for this. Diagnosis of terminal or life limiting illness led to a time of uncertainty for the patients' and their families'

where participants tried to develop an understanding of the patient's illness and likely progression. Some looked to gain a greater understanding through their interactions and conversations with medical professionals. It became apparent that the terms used by clinicians were sometimes confusing for patients and their families especially when medical professionals used different terms in conversations about the patients' illness and death. The point of referral to palliative care has been identified as significant in terms of its effect on both patients and their caregivers. Shulman Green, (2004) describes this juncture in caregiving as a 'crossroads' where the role of caregiver becomes focussed on their communication with medical staff as they negotiate new systems of care against the backdrop of accepting the patient's health status and impending death. For many in this research, this point in the patient's illness was remembered because it was time when they were introduced to new services. Consistent with certain elements of this study, many participants said it had taken a while for them to be able to appreciate their own position in the palliative care setting. Most spoke of the referral to hospice services as having been a time of reflection and realisation as they each came to terms with their own internal grasp of the patient's illness and decline

Research has recognised that using clear unambiguous terms in consultations with family members is important. These conversations influence the understandings and expectations of patients and caregivers in palliative care (Hui, Zohra, Neha, Rony, De La Cruz, Kim, Kwon, Hutchins, Liem, and Bruera, 2014).

Terms commonly used in conversation with medical professionals ranged from idioms like 'end-of-life-care' 'hospice care' and 'palliative care'. It seemed that participants were reluctant to ask too many questions in these consultations. It later emerged that this was due to a hesitancy to instigate a conversation about what referral to this kind of service meant in terms of the patient's prognosis. One participant for example said they understood the hospice was a place where people were referred to when they were dying. Even for those participants who were aware that the referral did not automatically imply the patient's impending death, this referral appeared to be significant in terms of treatment options.

I noticed that many participants used euphemisms to refer to changes in the patients' illness which may have been a coping strategy to reduce the threat and panic associated with terminal illness

Prognostication of life expectancy however appeared to be important in providing a framework for understanding the likely course of illness. Some turned to different sources for information about the patient's likely illness trajectory and life expectancy.

A number of authors have conceptualised the corresponding changes in the patient's illness and caregivers' experiences as 'transition-like' in terms of their predictability (Schulman-Green et al., 2004; Kralik, Visentin and Loon, 2006 Marsella, 2009; Blum and Sherman, 2010; DuBenske et al., 2010; Duggleby et al., 2010; Penrod et al., 2010; Janze and Henrikson, 2014; Hurley, Strumpf, Barg, and Ersek, 2014). This thinking has been extended to suggest that the caregivers' journey through terminal illness is directly comparable to the patient's experience of illness progression (Shulman-Green, 2004; Marsella, 2009; Duggleby et al., 2010; Blum and Sherman, 2010; Janze and Henrikson, 2014; Hurley et al., 2014; Gardiner et al., 2015). Although there are points of similarity between the findings of this study and those of other studies, this research did not support the idea that the caregivers' experience paralleled the illness experience of the patient they cared for in terms of predictability or understanding.

Instead, the findings of this longitudinal study suggest a multifaceted and contextually bound process of change for participants. The diverse ways in which this was exhibited support an idiographic caregiver-driven picture of change rather than one which corresponds to the predictable pathway of the patient's illness trajectory.

The concept of transition is a term which has been used to describe change in many different organisations and discipline's including healthcare. The findings of this study resonate to some degree with a definition of transition offered by Kralik (2006) whose review of health transitions state that,

> *transition is a convoluted process whereby the individual redefines their identity in according to a disruptive life event.*

> *(Kralik, 2006)*

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Many of the participants in this research spoke about how the patient's illness had a progressively disruptive influence on their own daily life and routines. This included times when they had to take on new responsibilities such as washing, dressing and feeding the patient which was especially challenging for participants living with their own long term health condition. Aside from these core demands (Fletcher, 2012), points out that caregivers are tasked with navigating their way through healthcare systems. Participants said they were taking on new and unexpected responsibilities for example making sure the patient's medication was reviewed and administered on time as well as making appointments and driving the patient to hospital appointments. Some were caring for a patient with more specialised needs requiring them to exercise an enhanced level of expertise with a lack of formal training for this shift in the level of care. Those who had not support other than that of local authority carers said they were often unable to take regular breaks from providing care. Participants said they found providing care for a close family member emotionally draining as they lacked the emotional detachment afforded to trained medical staff. These findings are consistent with those of other caregivers studies (Galvin, Todres and Richardson, 2005; Andrews and Seymour, 2011; Baile, Palmer, Bruera and Parker, 2011; Abma, Oeseburg, Widdershoven, Goldsteen and Verkerk, 2005; Ewing and Grande, 2018).

These results are also comparable with factors highlighted in as model of family caregiving proposed by Fletcher et al., (2012). However, the model proposed is limited in that while it points to a broad number of factors which impact on caregivers across the disease trajectory, unlike the current research, the proposed model does not afford an in-depth exploration of longitudinal experience nor shed light on how these aspects of experience impacted on caregivers at an individual level. The model is further limited in that it was developed from the results of a literature review of the experiences of caregivers of cancer patients. This limits its applicability in terms of how it can be used to inform research relating to individual caregivers of patients with other disease trajectories.

Several the participants said they had begun to provide care for their family member in an uninformed way. Many reflected how they hadn't realised at the start of the patient's illness, what would be involved, how much would be

required of them or how long the caring role would continue for. The findings in this study supports the work of Blum and Sherman (2010) whose focus is on transitions which are common to patients with cancer and their family caregivers. The study aimed to explore how caregivers often feel obligated to provide care for a family member who is terminally ill and often feel guilty if they need to take a break from their caregiving role.

These results would seem to be compatible with the work of Bridges (2003) who makes an interesting point about the two interrelated concepts of psychological and circumstantial transition. Transitional change, according to Bridges, occurs when there is an alteration in a condition or a shifting of circumstances such as the longitudinal experiential shifts in the experiences of the participants in this research. Conversely, transition is characterised by the psychological process through which individuals adjust to or align themselves to circumstantial change. So, there were times during this research, when caregivers were responding to changes in the patient' illness and, at these points their experiences were comparable. At other times the participants were describing their own psychological responses to changes in the patient's illness.

The unique nature of the family caregiver's experience was the focus of a review by Shearkhani (2016) which highlighted how the caregiver role underwent change on multiple levels during the time they interact with health care systems. Review findings indicate the stages and phases of the family caregiving trajectory is uniquely influenced by the particular circumstances of individual family caregivers. The idiosyncratic nature of the caregiver's experience has been he focus of other authors (Burns et al 2007; Blum and Sherman, 2010; Ewing and Grande, 2013). The current research goes to further by exploring the lived experience of caregivers in real time during the time they provide care for a family member accessing palliative care services.

7.3 Essential theme 2 - By offering practical and emotional support appropriate to their needs as they were revealed, the friends and family of caregivers played a key role in supporting them to care for the patient throughout their illness.

The longitudinal study unveiled a major impact of providing care for someone with a deteriorating health condition was having less time available to spend time with other people. Prioritizing the escalating needs of the patient above

their own meant participants gradually spend less time with friends and family members who played a role in providing them with practical and psychological support.

Social isolation was touched on in early interviews as participants gave precedence to their interactions with professional care services who played a key role in how they coped and adapted to providing care. In later interviews, participants appeared to be developing their own strategies to help them adapt to new tasks and increasing levels of caring.

Some participants spoke in their early interviews about providing care whilst managing their own pre-existing health condition. Through my interactions and interviews with participants, I observed how most of the participants began to feel the physical and emotional effects of providing care.

For some, the support of family and friends was already in place, and these were spoken of in initial interviews as playing a key role in how prepared individual participants were to continue in the caregiving role. The topic of preparedness was a feature which emerged in successive interviews, and it emerged that those who felt they could rely on the support of friends and family throughout the patient's illness were more likely to focus on the positive aspects of being and remaining in the caring role.

Throughout the longitudinal study, it became apparent that not all participants had access to reliable support from friends and family. By glancing backwards and forwards in their interviews it appeared that this factor determined their attitude and description of becoming a caregiver.

It seemed asking for help wasn't an easy thing to do and some received offers of help but said it wasn't regular or reliable. Having to ask for help felt like another aspect of caregiving to manage. On participant said she felt abandoned and frustrated by this open-ended offer when she had twice asked a family member for support, but they were not available at the time or date required.

For others, there was a process involved in coming to terms with being able to accept support especially from family members. One participant said in early interviews that he felt able to cope with caring for his wife. He and his wife both said in group sessions that they didn't think it fair that their children should carry the burden of caring for a parent. However, by his third interview, the participant said their children had become progressively more involved in the caring

scenario insisting that it was their right and not their responsibility to care for her. It is encouraging to compare these findings with the work of Saban and Hogan (2012) whose study observed how individual caregivers especially value the practical and emotional support offered by family and friends. The current research expands on these findings to explore what aspects of support were especially valued as well as shedding light on how there is a process for caregivers during which they are able to identify their own individual support needs and where these may or may not be adequately met.

There was an aspect of self-care which participants said was an unanticipated benefit from the support of friends or family members who provided direct care for the patient. Being able to leave the patient with a trusted other meant the participant was able to take a break from the caregiving scenario to do simple things like run errands, meet a friend or in some cases being able to just leave the house was said to be an indulgence.

Some of the emotional support received by the participants was more nuanced. Being able to socialise with friends and family as opposed to being supported by them was described as especially enjoyable. This was referred to as a time of engaging in light-hearted recreation and meaningful connection with others. A key aspect of the emotional support provided by friends and family was having someone to talk to about how they felt they were coping with providing care during illness rather than how the patient was coping with their illness. These findings, to some extent mirror those of Epiphaniou, Hamilton, Bridger, Robinson, Benyon, Higginson and Harding (2012) who interviewed home-based palliative caregivers during the time they were adjusting to the caregiving role. It was noted that caregivers in the study coped by drawing on support from family and friends who provided them with distraction, mental stimulation and emotional release from stress. A recent longitudinal study using self-report questionnaires completed by family caregivers of patients with advanced cancer was conducted by Ullrich, Marx, Bergelt, Benze, Zhang and Wowretzko (2020). Results of the study show the main support requirements of family caregivers are not directly linked to the patient's illness but to the social, cognitive, and psychological needs of the caregivers themselves. These findings resonate strongly with those of the caregivers in this study which demonstrate that change and stability in the longitudinal experience of caregivers were influenced

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by their access to support from friends and family as well as the quality of their relationships with palliative care services. Though this study adopted a longitudinal approach by collecting quantitative data on two specific points in the patient's admission, the current study adds another layer of meaning to the needs of caregivers in palliative care by interviewing participants at key moment of change in the perceptions and understandings of individual caregivers.

A study by Henriksson, Carlander and Arestadt, 2015) observed that caregivers who felt prepared to take on the responsibility of caring were seen to have higher levels of hope and lower levels of anxiety. The current study observed an association between the preparedness of caregivers and the amount of social support available to them which may have been the result of feeling more hopeful and less anxious about their ability to provide care. Many said how caring for the patient around the clock demanded much of their time, energy and attention. Feelings of tiredness and fatigue were experienced by most though these negative effects were eased by the presence and input of friends and family who contributed to supporting participants in diverse ways. One participant spoke of creative ways that family had provided support by 'swapping places' with her daughter on occasion. This had a twofold benefit in that it relieved her of the caregiving role whilst allowing her to see her grandchildren.

Some of the participants spoke of feeling frustrated by the monotony of their world of caregiving. The repetitive nature of performing hourly and daily caring tasks gradually replaced the routine of their working world. This led to a change in identity which was a challenge for some who gave up their working roles or changed the working pattern of their lives to provide care full time the patient. This aspect of the caring experience was especially difficult for those providing care in the home who said they felt confined and trapped by the caring environment. At such times, the mere presence of friends and family were a welcome mental diversion to the caring routine. A study by Hricik, Donovan, Bradley, Given, Bender, Newberry, Hamilton, Given and Sherwood (2011) describes the daily presence of caregivers in the caring scenario as one where they become subsumed or enmeshed in the care situation. Some participants described being caught-up in the caring environment as 'not a path I would have chosen' and saying they were 'stuck here'. Hricik et al (2011) highlights

the importance of friend and family at times when caregivers felt anxious about the future and this was a recurring theme for the participants in this research. The probability of providing care into an unknown future was noticeably heightened in those participants who had specific concerns about their own wellbeing. Some said they were fearful that their own health would be a barrier for them in providing care for the patient at home until the end of their lives. These concerns were greatly reduced in the participants who were able to rely on the practical hands-on help with caring from friends or family members. Being able to rely on the practical and emotional support of friends and family boosted the participants perceived competency levels and improved feelings of reward at feeling confident about coping newly emerging situations. Feelings of competence and reward among the participants in this study contributed to their coping strategies in the moment. However, the fluctuating nature of their own wellbeing remained a cause for anxiety for some throughout all their interviews as they expressed feeling uncertain of their capacity to provide care in the future. The participants who expressed feeling competent to care were generally more prepared to continue caring for the patient until the time of their death. This finding is supported by research conducted by Stajduhar, Funk and Otcalt (2013) who described how caregivers learn to provide care by a process of trial and error, seeking information and drawing on the previous experience and support of friends and family as well as healthcare professionals. The support and guidance provided by friends and family had an indirect impact on the caregivers' ability to improve their own skills. The current study built upon this research by identifying some of the things that support the learning styles of individual caregivers as well as shedding light on why some caregivers may be hesitant to take on the caregiving role over an indeterminate period of time. Friends and family encouraged the participants to practice self-care strategies as providing care took up progressively more of their time and energy. Those who used self-care strategies felt more equipped and accepting of the uncertainty of being a caregiver. It is interesting to compare these findings with those of Male, Fergus and Stephen (2015) who analyzed data from a group of online caregiver's revealing how their caregiving journey was characterized by major downs and hard-won ups. Self-care strategies were reported to combat feelings of inadequacy by helping caregivers to recognize and accept the limits

of their own competency. The major downs referred to in this study related to with the immense amount of pressure the caregivers felt to be a supportive presence for the patient throughout their illness. A possible explanation for these findings might be the online context of this study where participants were comfortable with openly expressing negative feelings in an online forum. My research notes revealed that times which were especially challenging for participants tended to be discussed by them spontaneously and during informal conversations. I noted times where the participants spoke of not feeling able to cope, saying how unprepared they felt to provide specialized clinical care. I noticed that none of them spoke so candidly during their interviews suggesting such open expression may be more difficult in a face-to-face research interview context. I argue that the participants may have felt less comfortable about sharing their feelings so freely in a less flexible approach to data collection. Honest and open sharing too place where the participants were encouraged to speak frankly about the rewards of providing care as well sharing their feelings about the negative aspects. The benefits of this kind of open dialogue and sharing has been seen in other studies. The benefits of being able to express feelings openly with friends and family has been identified as helping caregivers to identify and focus on the positive aspects of providing care (Stajduhar, 2003; Stajduhar and Davies, 2005; Andershed, 2006). Henriksson et al. (2015) however questions the evidence that caregivers are able to maintain a positive attitude throughout the palliative care period. The review highlights that much of the research identifying positive thinking styles in caregivers are conducted with bereaved caregivers suggesting these strategies are easier to employ retrospectively. It may be that feelings of reward associated with being a caregiver come to the surface more readily in the post-bereavement period when individuals are able to reflect on the support they received from friends and family when they are not inundated with caregiving tasks. My research notes document that, participants who emphasised the positive features of providing care were more inclined to do so outside of their interviews. It may be that the participants were more likely to reflect positively on their experience spontaneously outside of the interview context. I argue that this feature of providing care longitudinally may not have been brought to light had I adopted a

more structured approach to data collection where participants were invited to reflect on their experience solely during their interview.

7.4 Essential theme 3 - The participants' experiences of engaging with palliative care services are influenced by the quality and reliability of their interactions with medical and nursing staff. This is especially pertinent at crucial times in the patients' illness.

Throughout the data collection period which spanned eleven months, I had the opportunity to explore the caregivers' interactions with nursing and medical professionals.

Much of the care provided by the participants in this research took place in the patient and caregiver's own homes. This was often said to be not the optimal place to provide care for several reasons highlighted by King et al (2004) who highlights the importance of taking an anticipatory approach to community palliative care nursing where friends and family members are given the chance to develop a relationship with a medical and nursing staff involved in the patient's care.

Providing care in the patient's home enables friends and wider family members to become involved with caregiving. In this research, all those who were involved in providing care felt reassured when they had developed a rapport with medical staff involved in the patient's care. This was the case even for those who did not experience an out of hours crisis. Where there had been poor or fractured communication with nursing services, participants said they felt anxious and uncertain about their caring skills which made them doubt their ability to manage the patient's symptoms at home.

There are tools available to assess the caregivers needs for support and information when providing care at home. Many of these are developed from a nursing perspective which aim to measure the caregivers' need for support during the time they provide care. A study by Ewing et al (2013) highlights the impracticability of many of the tools currently in use. This has resulted in an unrealistic and incomplete picture of caregiver support being developed especially as the caregivers' needs change and fluctuate over time. In line with this research, many of the caregivers found it easier to identify the changing needs of the patient rather than their own. When discussing their own needs, caregivers often talked about the kinds of things that would make the process of

providing care more straightforward and beneficial to the patient. It was difficult for them to name and talk about their own psychosocial needs although this did become easier across interviews. By developing rapport with individual participants, I was able to ask more direct questions about what would be of benefit to them in their current circumstances.

This study discovered that it was important for caregivers to have a named person allocated to the care of the patient. Knowing that they would be able to speak directly with someone who was familiar with the patient and their illness, helped to alleviate their anxiety and improve their confidence especially when caring out of hours.

Being responsible for monitoring the patients' symptoms and interpreting changes in their condition can be an anxiety provoking experience especially for family caregivers. Many said they felt lacking in the kind of practical and emotional skills necessary to provide specialised care outside of a clinical space. Caregivers who employed carers from a private care company to assist them in providing care said the biggest advantage of using a care company was that they were able to pick-and-choose which support staff attended the patient on any day. This finding provides further evidence that caregivers value being able to entrust the care of the patient to someone they are familiar with and who understands the particular needs of the patient.

 Much of the caregiving literature is written using the medical model of providing care. Many of these suggest a pattern in the way caregiver's seek information and support form healthcare professionals (King et al., 2004; DuBenske et al., 2008; Duggleby et al, 2010; Ewing and Grande, 2013; Ventura et al., 2014). This would suggest that caregivers are likely to seek support and information more frequently when the patient is in the later stages of their illness.

The current research does not support this although the findings did resonate closely with a study by Duggleby et al (2010) who encapsulated this aspect of the caregiver's experience in a key overarching theme of navigating unchartered waters. The theme suggests that although the caregivers' experiences were linked to the patient's phase of illness, knowledge of illness did not provide the caregivers with certainty in terms of being able to predict their own ability to cope with fluctuating illness over time. It appeared that some caregiver's strove for certainty by seeking information and support from a

variety of sources. Many turned to the internet or medical textbooks and journals for information about the patient's condition. Most were hypervigilant of even the smallest change in the patient's condition or demeanour. Some appeared to be hesitant to contact medical professionals until they felt certain that changes in the patients' condition were an indication of illness progression. A study by Armes and Addington-Hall (2003) points out that part of the difficulty in monitoring changes in the patient's symptoms arise from knowing when to report changes to health care professionals. In the absences of clear guidelines or education about the patient's symptoms from healthcare professionals, the participants were left to monitor the patient's pain levels by trial-and-error. In line with this study, the caregivers in this research became focussed on changes in the patients' symptoms rather than their own need for support in dealing with change.

Many said it was difficult for them to predict how their own need for support with providing care would change. It emerged that individual caregivers varied in terms of when they thought they would need most help. Where this research differed from other caregiver studies was in revealing that their support needs were less tied to changes in the patients' illness and more in line with other factors. The amount of support available from friends and family members influenced how and when they sought support with fluctuating illness. However, the quality of their relationships with palliative care services and the nature of their relationships with individuals mainly determined how comfortable they were about seeking information and support from medical services. Again, having a named individual or a single point of contact within the medical team who knew the patient eased caregivers' anxiety and influenced how they individually drew on support from services.

The uncertainty of not knowing what to expect and when to expect it was expressed by participants in this study. Such crises occurred when there was a change in the patient's condition but were also likely to arise at time when they were feeling tired or overwhelmed with circumstances not associated with the patients' illness. Undoubtedly such times of vulnerability acted as tipping-points for individuals who were already feeling burdened. In terms of uncertainty as a transition indicator, this did resonate with elements of a mid-range transition theory developed by Meleis, Afaf, Sawyer, Im, Eun-Ok, Hilfinger, Deanne and

Schumacher (2000) and Bridges (2003). The theory accentuates the effect of uncertainty during a time of changing circumstances which can impede the individual's ability to incorporate wider changes into their lives.

Meleis et al., (2003) further states that where there is change in multiple domains, or where patterns of transition are driven by sudden or unexpected change, the process of incorporating change into their lives is lowered and sometimes halted. The participants who were able to respond to uncertainty by seeking information or support for their individual needs were more likely to feel confident about continuing to provide care until the end of the patient's life. Evidence based tools to identify the needs and difficulties of caregivers with specific illnesses across time are available. However, as discussed in chapter one, such interventions do not capture the ways in which individual caregiver needs are likely to vary. Those who engaged with support said they felt better equipped to deal with sudden and unexpected illness events. However, others were reluctant to invite anyone else into the caring scenario saying they were already swamped by the amount of people and services involved in the patient's care.

Some spoke about their experience of having multiple teams and services involved in their care. In each case, this had led to misunderstanding and confusion when they were given misleading information about the patient's illness and who to contact for help with different aspects of the patient's care. This highlighted how fragmented and disjointed access to individual support services acted as a barrier making them doubt their own capacity to prepare for and cope with caring for the patient at home as their illness progressed.

7.5 Support seeking

The findings reveal multiple occasions when a change in the patient's condition coincided with the caregiver requesting practical guidance and support from palliative care services. Some conducted their own internet searches of the patient's illness in the hope of gaining a clearer understanding of the patient's symptoms. This gave them a clue to how they might need to make changes to their home or in their caring approach across the illness trajectory. Having support to help meet the changing needs of the patient has been associated with improved caregiver health outcomes in a study by Cianfrocca, Caopnetto, Donati, Lancia, Tartaglini and DiStasio (2018). The need for help with the

practical aspects of caring in the home was also raised in a study by (DuBenske et al., 2008).

Improving awareness of the patient's illness and accessing training to prepare them for the future and training was a feature of many participants in this study. Many said the unpredictable nature of the patient's illness was stressful. It is impossible to prepare for the unknown and most referred to the changing and variable process of providing care. Some said there had been at least one occasion where they were unsure whether to call palliative care services to ask for help or guidance in managing the practical aspects of caring for the patient. Dealing with changes in the patient's illness was the most common reason for requesting practical help or seeking information from services. This reflected a variation in individual levels of perceived competency among the participants. A study by Funk, Allen and Stajduhar (2009) discovered that caregivers who felt competent to deal with unanticipated events in the course of caring were also more confident in their own self-worth and identity as part of the patient's support team. The authors also drew on the aspect of security to point out how caregivers felt secure in their ability to provide care in the long term when they were satisfied with the service provided by the health care professional assigned to the patient. Those who felt confident in the palliative care support provision said they were open to the idea of providing care until the end of the patient's life. In this sense, their experience of service delivery impacted on how prepared and equipped they felt to provide care for the patient throughout the remainder of their illness.

Feelings of competency influenced the likelihood as well as the timing of how and when participants drew on support from services. There were times when participants said they felt physically equipped to cope with the demands of caring. This did change though, and many had needed to call on additional support from a wide range of social and health service teams. Maureen, for example, initially spoke of herself and Alan as a team who had provided care for each other at time of ill health. Though Alan's health status remained stable across time, Maureen experienced a flare up of her own long-term condition and she looked for support from outside services. The study by Funk et al., (2009) confirms there is an association between how secure caregivers felt and the ease of availability to care, information and support from services when

needed. In this research, many of the caregiver's placed their own support needs secondary to those of the patient. When speaking of caring for their own needs, most said they wished to stay well so they could continue providing care for the patient. The importance of having reliable access to support for those with their own health needs was raised as an issue of concern. Others said they hoped support from services would be available to them if they became ill during the caregiving process. Being able to maintain their own health, played a significant part in whether or not they would continue to provide care in the long term.

Most of the participants in this study had plans in place to provide care for their family member until their death and this may have been a reflection of their confidence in service provision. A study by Funk et al., (2009) highlighted how family caregivers rely on the guidance and expertise of healthcare providers when coping with end-of-life situations. As in this research, caregivers needed to feel confident that well-timed access to competent professional services would be available for them when required.

7.6 Information seeking.

Access to information and knowledge about the illness trajectory enabled many of the participants to feel prepared for the future by planning ahead for possible changes and challenges in care. This was in accordance with a study by Hurley (2014), who drew attention to how family caregiver preferences for care changed at times when phases of illness led to unanticipated challenges in providing care.

The findings of this research do not however support the idea that particular circumstances or changes in illness will automatically trigger the need for increased care. Rather this longitudinal study suggests an idiosyncratic process of change and adaptation for individual caregivers where their need for support in caring fluctuates. It seemed that caregiver's need for more information or support was driven by the quality and reliability of support available to them from medical professionals as well as the support of paid or unpaid care from friends, family and outside agencies.

Information about the patient's death involves having difficult conversations about the patients' illness decline and death. My interactions with groups of caregivers over the data collection period revealed a commonly held belief that

discussing the patient's death openly would hasten the timing of it. Despite this, many of the participants appeared comfortable and discussed the patient's illness decline openly saying they wanted to be prepared for the patient's death. Being prepared seemed to involve making the right decision about the place of death. For all participants the right place was the place for the patient rather than for their own convenience or comfort. Many had been active in seeking information about things like what to expect in terms of looking for signs and symptoms which may indicate decline or the end of the patient's life. These conversations had been initially with medical staff before they spoke to the patient about their end-of-life preferences. Two of the participants said they had an idea about the patient's end of life preferences, but they had not had the opportunity to discuss this subject with hospice staff.

In this research participants became active in their information seeking behaviour at certain times when there were changes in their own perceptions of the patient's general demeanour or behaviour. On occasion this had involved holding seeking information from professionals, but many turned to internet searching for information about the patient's illness. A study by Janze and Henrikson (2014) conceptualises the move into palliative care services as a transition in the awareness of the patient's death for family caregivers and this did resonate with the findings of this study to a degree. However, information seeking appeared to be related to a need to understand and prepare for changes in the patient's illness so the participants could be prepared for changes in their illness related needs. Family members often have their own appreciation and understandings of treatment goals in palliative care as well as how these differ to those of curative care (Burns et al., 2007).

There was evidence in this research that participants sought information in accordance with their readiness to hear bad news or as a way of preparing for the future. The findings provide further evidence that coming to terms with the patient's illness is an individual process which may include preparing for the patient's death. (Burns et al., 2007; Morris and Thomas, 2010; Penrod et al., 2010). Ronaldson and Devery (2001) conceptualise the transition to hospice care as a process of change in hope for family caregivers where they move from being hopeful of an improvement in their illness towards wishing for a good death for the patient. This process is understood as a fluctuating acceptance of

the patient's death which is said to be an important part of the caregivers' own transition process when the patient moves into palliative care services (Shulman-Green et al., 2004). The participants in this research varied in the kind of information they wanted and when they wanted it which suggested that each patient and caregiver dyad were coming to terms with the end of the patient's life in their own ways and time.

Brown and Steltz (1999) suggest there are specific cognitive processes family caregiver's experience when providing care for a patient at the end of their life. Elements of this model reverberate with the findings of this research. For example, this was evident in how family caregivers strove to implement the wishes of the patent by taking responsibility for coordinating the final days and hours of the patient's life. In this research, many participants had been discussing and making plans for illness progression with family and friends for weeks and in some cases months before engaging with palliative care services. This was most apparent for those who had been caring for two or more years. Plans involved making specific modifications to their home in readiness for when the patient's mobility became impaired or to enable to patient to die in their home as they wished. Others spoke of improving their fitness level to enable them to continue in the caring role in the near and distance future. Three had received special training in preparation for when the patient's care became more specialised.

Aspects of these findings broadly support those of Penrod et al 2010) who found there was a greater need for input from palliative care services when more specialised skills were required of the participants. While in this study, there was an increase in the need for support from palliative care services in anticipation of a change in the patient's care requirements. However, there were differences in the kind of input required. These appeared to vary according to the caregiver's perceived level of competency and motivation to adapt the patient's needs.

Each caregiver's preparedness for the caregiving role played a part in how they interacted with palliative care staff. Many spoke of the positive aspects of being a caregiver at times when they felt a sense of achievement at having learned new skills. A longitudinal study of Canadian family caregivers was conducted by Donovan et al., (2010). This study explored the influence of culture on Dutch

caregivers living in Canada and found that the caregivers moderated their approach to caregiving to conform to the normative practices of the organisation providing care for the patient. It is possible that the immigration status of Dutch participants residing in Canada influenced the behaviours of the caregivers in this study. In this research, the participants' attitudes to caregiving differed according to a number of factors. One of the most dominant influences was the relationship between the patient and the caregiver. There were factors at play such as social and cultural norms and these underpinned the caregiver's motivation to care. Many participants used words like duty and loyalty when expressing their reasons for taking on the caring role. However, these beliefs did not influence the way they approached their caregiving role or how they co-operated and interacted with palliative care services or hospice staff.

A further finding was observed in relation to those participants who said they had enjoyed the sense of collaboration with medical and nursing services. Interacting with hospice staff appeared to enhance the quality of their experience as well as their interactions with hospice staff. As well as fostering an caring alliance with hospice staff, those who developed a rapport with staff, also spoke of adopting positive coping strategies and taking care of their own needs. To an extent, these findings resonate with a study by Blum and Sherman (2010) which suggests that fostering shared a sense of alliance with caregivers presents a way for medical teams to support caregivers in practicing self-care. The adopting of positive coping strategies by caregivers has also been noted in other studies to be part of a wider strategy of self-care and had the effect of enhancing the caregivers' ability to cope on the long term. (Blum and Sherman, 2010; Cavers et al., 2012).

7.7 End of life conversations

Whilst it is recognised that no one has the capability to predict the exact time or date of the patient's death, Hupcey, Fenstermacher, Kitko and Penrod (2010) suggest the emotional burden of family caregivers is improved when health care providers hold timely honest conversations with patients and caregivers at times of change in illness which indicate a move towards the end of the patient's life. It was the ethos of the particular hospice involved to create opportunities for patients and their families to discuss their wishes and concerns about the patient's end of life preferences. An open communication policy around death

and dying was promoted and there was literature with information about end-of-life choices freely available in areas where they would be seen by patients and family members. Flyers promoting end of life workshops were available for visitors to take home and read as well as literature about planning for end-of-life preferences. These topics were also frequently discussed at the day hospice, the DHCSG and BOFA groups.

These findings correlate closely with previous studies where nurses were seen as occupying a unique position to have such difficult conversations with caregivers A study by Penrod et al., (2010) highlights the position of nurses, suggesting that nurses are well placed to offer a range of supportive interventions to the caregivers of dying patients because of the rapport they develop with the patients and their family members. However, successful and timely interventions require an understanding of the caregiver's individual readiness to engage in meaningful discussion (Grande, Stajduhar, Aoun, Toye, Funk, Addington-Hall, Payne and Todd, (2009). The participants in this research varied in their how ready they were to engage in discussions about the patient's illness and end of life. Although the wishes of the patient were the caregivers' main consideration, my conversations with participants revealed the timing of these conversations were driven by the individual caregiver's readiness to bring this sensitive topic out into the open. The findings illustrate diversity in this aspect of the caregivers' experience and adds to the existing knowledge that the uptake of palliative care interventions is dependent on the specific concerns of individual caregivers (Grande et al., 2009).

7.8 Essential theme 4 There were barriers in place which impacted on individual caregivers' access to financial resources. These affected the social world of the caregivers as well as their physical and mental wellbeing.

The financial cost of providing care for the patient was the most persistent cause of anxiety for participants in this research. Most participants were providing or had been responsible for providing around the clock care for the patient in their home. This had a greater impact on those caregivers who had responsibilities outside of their caring role and those who worked outside of their caring duties.

One participant provided care for her mother who lived a few miles away from her home. Having to leave her own family to care for her mother came at considerable financial and emotional cost. Despite an overall increase in the number of UK family caregivers who undertake to provide care for family members with terminal illness in their home, there remains a lack of research which captures the caregivers' worth in terms of the economic contribution they make to the UK economy (Gardiner et al., 2020).

As the patient's illness progressed, the financial impact on each caregiver increased, leaving some of them feeling anxious about the future. A key finding of this research was how each caregiver's access to financial resources influenced the quality of their experience and how this changed or stayed the same over time.

Many participants in this research expressed a need for financial assistance to help pay for private care to support them helping the patient to stay in their own home until the end of their lives. They spoke of being in the system in applying for carer's allowance and two participants said they were too busy to engage with all the form filling. A lack of financial support to assist caregivers with home care for terminally ill patients in their home was highlighted as a key unmet need for caregivers within a systematic review of the unmet needs of caregivers as identified by the caregivers themselves (Ventura et al., 2014).

The financial cost of providing care for the patient in the long term was a major cause of concern for many of the participants. Their accounts told of the difficulties they had experienced, and these will now be explored.

7.9 Funding palliative care in the UK

Financial support from statutory care services is available for caregivers' but few participants were aware of what was available to them or how to access it.
 Little is known about the cost of providing specialist palliative care in the United Kingdom. A review of the cost of providing palliative care to patients with terminal illness in the UK underlined several obstacles in assessing the real cost of financing care provision to this particular group (Gardiner, Ryan and Gott, 2015).

This was partly because most of the studies included in the review were qualitative studies which explored the cost of care from the perspective of NHS providers. Only two studies described the cost of providing informal care.

Reasons for this apparent lack of transparency were cited as the use of different approaches and methods to capture cost and activity data. This made it difficult to understand and appreciate the impact of funding on individual caregivers and how informal caregiving, especially for palliative care patients is costed in the UK. Of note was that the review emphasised how hospice and informal caregiving were not included in cost analysis studies of palliative care delivery. In 2015, Marie Curie commissioned a report which drew attention to inequities in the availability of palliative care to certain UK groups. This topic was raised in a critical debate by Gardiner et al., (2020) who outline a lack of equity among certain groups of caregivers in palliative care and how they are systematically disadvantaged based on their socio-economic and employment status. This effect was apparent in this research and will now be discussed.

7.10 Fair Allocation of Palliative Care

For clarification, the terms equity and equality are both used in this thesis in relation to the fair allocation of palliative care services. Equality as a term is used to refer to how services are targeted to all service users equally. Equity refers to the way services are targeted to service users according to their individual requirements. The difference in these terms becomes relevant in a study by Stajduhar et al., (2019) who points out that palliative care services are less equitable and often poorly delivered to individuals living in socially deprived areas, residential care homes, criminal justice settings or mental health institutions. There was evidence of inequity within the participants in this research and one participant described a "post-code lottery" approach to the allocation of home care services available for her mother. Inequity was also seem in how those participants who were computer literate were more confident about engaging with bureaucratic systems. This gave them faster and improved access to information about the availability of practical and financial support than those who lacked the skill and knowledge to use a computer. The participants with more stable economic resources certainly experienced less financial uncertainty, worry and burden. Where there was a lack of adequate funding and access to financial support for the caregiver, this had a negative impact on the physical and mental wellbeing of the participants. These findings provide further evidence that caregivers of palliative care patients who experience financial burden are at increased risk of having their emotional and

physical needs unmet while caring for someone with palliative care needs (Brazil, Bainbridge and Rodriguez, 2010; Ventura et al., 2014; Stajduhar et al., 2019). The current research builds upon this research by exploring how the unique needs of caregivers from certain socio-economic groups impact on individual caregivers over the course of the patient's illness.

Under the current UK system, people diagnosed with a terminal illness are entitled to be assessed for support by the local authority. Support can take many forms, for example practical support may include alterations to the home to improve the patient's mobility, a home care worker may be provided to visit the patient at home or a place at a residential day centre may be made available. Financial support is also available as a direct payment to the patient to help them pay for the cost of their care. Patients with a terminal diagnosis who are expected to live less than six months are prioritised for access to funding which means they are not forced to wait to be assessed for eligibility to funding. The waiting time for all who apply is currently in the region of seven days to three months, according to Carers UK (2019). Within the UK system, patients who are dying can be fast tracked through the application process provided they can provide medical evidence that they have six months or less left to live. This system is intended to make it easier for the patient with terminal or life limiting illness to access benefits speedily. However, for those patients whose illness is difficult to predict or who may be expected to live longer than six months, this means they are confronted with a wall of bureaucracy and increasing care associated costs.

Responsibility for completing the application for funding was discussed by the participants in this study who had submitted the application on behalf of the patient. According to Gardiner et al., (2020), all applicants face a long and protracted claims process, which is frustrating and difficult for applicants to understand clearly. The participants' accounts corroborate the findings of this report and participants' spoke passionately about heir frustration at the seemingly over-complex questions especially around the patient's eligibility criteria.

Some were in the process of applying for funding which was said to be one more time-consuming process to endure. Two participants in the process of appealing a previously failed application for funding told of the decision support

tool which was used in the assessment process to measure the severity of the patient's illness. This was said to be overly bureaucratic and extraordinarily difficult to fathom with guidelines which were open to being interpreted differently by different people.

One participant had become so frustrated by the amount of time he had spent communicating with the local authority that he had employed a friend to act as an administrator on his behalf. One participant had abandoned their claim altogether because it was consuming the amount of time they had left to spend with the patient. Many had personal savings to help bridge the gap between applying for and receiving funding to help with unexpected expenditure. There was, however, a reluctance to draw on financial support from family and friends though they felt less anxious knowing support was available as the patient's illness increased and their savings dwindled.

Afentou, Jarl, Gerdtham and Saha (2019) draw attention to how the significant financial strain experienced by caregivers of terminally ill patients becomes increasingly more costly as illness develops. Non-medical costs were raised as incidental costs by some of the participants in this research. Many spoke of the cost of buying special food to encourage the patient to eat. Two participants had to pay extra for a specially adapted wheelchair friendly transport taxi to take the patient to appointments. Alison said she had paid for accommodation the night before Paul's hospital appointment so she could be sure of getting him dressed and ready for his appointment time. These costs were associated with solving immediate problems and responding to the urgent needs of the patient. One participant had taken out a personal loan to pay for a specially adapted wheelchair because there was a waiting list at the hospital and 'he needs it now not later'. These accounts began to feature regularly in my research diary. They add weight to research which has stressed the financial and emotional toll associated with caring for a patient at the end of their life (Duggleby et al., 2010, Hupcey et al., 2010).

7.11 Caregivers' needs assessment

Support for the caregivers' own needs is available from statutory care services but few of the participants were aware of what funding was available to them or how to access it. This was especially the case for those providing care for a patient whose illness onset had been sudden or unexpected. The local authority

carers' needs assessment has been described as an essential part of developing an integrated health and social care system. The assessment is aimed at enabling caregivers to continue to provide care for the patient at home for as long as possible (Guberman, Keefe, Fancey and Barvlak, 2007). However, this did not appear to be the case for the participants in this research, many of whom experienced financial hardship because of providing long-term home care for the patient. Many of the participants did not seek help or funding until they had experienced considerable financial challenges which made them question their ability to provide care in the long term. Two of the participants had been in the caregiving role for a few months prior to the referral to palliative care services. They had been unaware that they were entitled to apply to the local authority for an assessment of their own needs. This could have been because the participants in this research tended to focus their attention on meeting the direct needs of the patient above all else. Nolan (2001) posits that the caregiver assessment tool is a useful resource for caregivers to use when making the decision to take on the caregiving role. This was not supported in this study, where participants spoke of taking on the role of caregiving in a variety of ways for several reasons, none of which involved engaging with an assessment tool. Some participants indicated they had assumed the responsibility for providing long-term care for the patient in an uninformed way without having considered the long-term economic implications or how these would affect them. As previously stated, individual participants varied in their awareness and understandings of the aims and goals of palliative care. It seemed that some of the participants had an expectation that the patient's current level of disability was temporary or short-term. Two of the participants were surprised to hear about the availability of funding for their own needs. It appeared that their only focus was that their partner would recover from their illness, and, with the right amount of care, be able to return to a normal life.

7.12 The cost of financial uncertainty

The impact of financial uncertainty on the mental health of caregivers is raised in an article by Hanratty, Holland and Jacoby (2007). The research notes how the financial strain on caregivers increases their burden and worry as well as impacting negatively on family relationships. The participants who felt confident about being able to cope with the financial implications of caring for the patient

were generally less anxious about adapting to changes in the patient's illness. This research shed light on how some patients and caregivers were systematically disadvantaged on the basis of their socio-economic status at a time when they were in need of support from palliative and end of life services. This responds to some of the questions raised in the critical debate around equity and the financial cost of informal caregiving in palliative care Gardiner (2020).

The accumulation of financial costs impacted on some participants psychologically which built up over time and adversely affected their relationships with the patient and wider family members. One participant contacted me to tell me of her mother's death and said she was left feeling overwhelmed by a cascade of financial demands on her own financial resources. In line with a literature review by Janze and Henrikson (2014, there are varied cost associated with each stage of the caregiving process. It became apparent in this research that many were faced with incidental costs such as taking time off work, modifying their home and the cost of travelling to appointments. These costs had increased over time and one participant reduced her hours at work as well as leaving her own family to move in with her mother. This not only reduced the time and costs associated with travelling but she found her access to financial support to help with the increasing cost of caring was limited while she was in full time employment.

This finding of a lack of support for participants who wish to remain in employment is consistent with a report comparing support for caregivers in six countries. The countries involved in the report were comparable in terms of how their health care systems function Gardiner, Robinson, Taylor and Gott (2019). According to UK employment law, employees are entitled to take a 'reasonable' amount of time off from work to deal with emergency situations or to attend to the needs of a dependent relative. However, permission to take time off is left to the discretion of the individual company. Similarly, individual companies vary in their policy and whether this time is paid or unpaid. There may also be consequences for individual employees in terms of their pension credits and employment record. An example of this was one participant who was granted paid leave from their job when the patient was diagnosed with a terminal illness.

However, this was reduced after six months even though they were still providing provide care for the patient.

Participants who had alternative ways of funding care, for example those who had a private pension, were generally more adaptable to the changing needs of the caregiver. This impacted on how prepared they felt to continue in the caregiving role. One participant described himself as fortunate because of his workplace pension. He used this to pay for a private carer to deliver his wife's personal care. Being able to pay for someone to bathe and dress his wife every morning meant they had breakfast together every day. The free time also enabled him to spend time outside the caring environment seeing friends and attending voluntary work in a library. Having access to this kind of personalised care helped him and his wife retain a sense of ordinariness in their lives during her long illness.

Taking regular breaks from caregiving empowered participants to maintain relationships including their relationship with the patient and with others within their wider social circle. Duggleby et al., (2010) discusses the importance of maintaining normality in the process of caregivers coming to terms with terminal illness. This aspect of coming to terms with being a carer was demonstrated and appeared to be consistent across time for the participants in this research Penrod et al., (2010) suggests that the caregivers' perceptions and anticipation of the patient's death is driven by a need or a desire to establish a new sense of normality in their lives. This effect was evidenced to an extent in this research where caregivers strove to establish continuity of care for the patient as well as establish a reliable support network for themselves. It also appeared in this research that where reliable and personalised access to services was established, the caregiver's ability to adapt to the changes in the patient's illness was increased. These two factors combined have been recognised as key elements which positively impacting the social and familial relationships of caregivers (Gott, Allen, Moeke-Maxwell, Gardiner and Robinson, 2015). This research goes beyond this to explore the longitudinal process whereby establishing reliable access to care and adapting to changes in the patients' illness enabled the caregivers to maintain their own physical and psychological wellbeing.

7.13 Strengths, limitations, contribution, and recommendations

This study has emerged at a pivotal time for research policy and service provision for caregivers as the Social Care Secretary announced a proposal to respond to the needs of carers by strengthening support for them as a vital part of a sustainable health and social care system (Carers Action Plan 2018-2020). One of the strengths of this study was the LQA approach, using phenomenology to explore change and stability within the accounts of individual participants as they provided care for a family member across time. Phenomenology was used to provide detailed descriptions of their experience and offer insight into their experience as it unfolded across time.

The longitudinal element of the research enabled me to move backwards and forwards across accounts to explore how caring for a family member with a terminal illness, changes or stays the same over time. Specifically, this approach shed light on the similarities and differences in the experiences of the participants' accounts and highlighted how these were the same or different to the patient's experience of illness.

7.14 Engaging with participants

The longitudinal design of the research required me to be in regular contact with research participants during the recruitment and data collection phase. An advantage to this method was that, building rapport with participants helped to lessen the possible effects of a power imbalance, which has been noted as a complication to the participant researcher encounter (Bashir, 2019). Through my engagement with participants, I was able to develop an alliance with them, which I sense made it easier for the participants to come to a decision about whether or not they wished to take part in the research without feeling under pressure to do so. In addition, the level of rapport I built with them early in the research process meant they were more comfortable with sharing their experiences with me during interviews, some of which were deeply personal. Calman (2013) points out that the researcher's level of engagement with participants can present an issue within longitudinal research. Calman states that the researcher must ensure they carefully and sensitively manage their exit from the research field at the end of the data collection period. My departure from the research field was negotiated with hospice staff and volunteers who regularly work with the participants. I strove to ensure that the participant/

researcher relationship was brought to a close in a clear and unhurried way at the end of data collection. This was done by announcing my withdrawal several weeks before exiting the field. Many of the participants came to say goodbye to me in person and most expressed their appreciation at having had the opportunity to share their feelings and contribute to research in the area of future caregivers.

According to Snelgrove (2014) there is a risk that the researcher who engages in interaction with participants' outside of the research process may be unconsciously biased by the level of their engagement with the participants and their stories. The choice of a hermeneutic phenomenological approach to analysis acknowledges the interaction between participant and researcher (Hammersley and Atkinson, 2007). With this in mind, I endeavoured to minimise this risk of bias in the analysis of data through a process of reflexive engagement and this is demonstrated and reported throughout this thesis. In addition, during the analysis of data I continually questioned my emerging understandings of individual participant's accounts, interrogating and reappraising my own understandings of the data. During this time, I was in regular contact with my supervisory team where I gave a rationale for my decision-making processes during the analysis of interview data and emerging findings.

7.15 Recruitment difficulties

There are challenges for researchers wishing to recruit participants who are caring for patients affected by active disease (Addington-Hall, 2002). There were nine participants in the current study which is a good size for an in-depth exploration of experience using a phenomenological longitudinal approach (Smith 1999). However, obtaining this number did present several challenges; some of which related to my own expectations. Early conversations with nursing teams led me to believe that recruiting participants to the study would be a collaborative and straightforward process. As discussed in section 4.6 of this chapter, I had anticipated there would be some issues associated with gatekeeping and I had taken steps to address these. However, I had not anticipated that there would be delays as the result of nurses not being comfortable about approaching people.

I made attempts to keep nursing staff involved with the recruitment process by being available to discuss the progress of the research and sending regular updates. One of the nurses told me she wasn't sure when to approach caregivers and another said she was mindful that one particular participant was coping well at the moment but was in a particularly complex domestic situation and it was hard to predict how it would impact on her in the future. From this process, I learned the importance of providing satisfactory education and information to those involved in recruitment, especially around how and when the topic of participation might be broached with potential participants.

I also found a potential barrier to recruitment in what appeared to be patients acting as gatekeepers to their family member. After receiving an expression of interest form from one woman, I called to discuss the research and arrange a time for her first interview. She told me that she had changed her mind after discussing it with her husband who said he didn't' want her upset by discussing his illness with anyone outside the family who may not understand.

7.16 Reflections on being a counsellor and becoming a researcher

I would like to take the opportunity for some personal reflections on how conducting this research has transformed many of my previously held beliefs about being a counsellor who works with caregivers and being a researcher with an interest in exploring the longitudinal experience of caregivers in palliative care.

Early in the PhD experience, I felt a nervous sense of adventure as I moved from being a volunteer working within a charity to being a student within a large university. I had always enjoyed reading and to be in a role where reading was not only enjoyable but expected seemed like a luxury.

I spent a lot of time researching around the topic and attending workshops to familiarise myself with the different designs and stages of the research project. After some early issues with gaining ethical approval, I began to have meet with various contacts and discuss my research ideas with them. Initially I had approached two GP surgeries' and three hospices. I had some experience of working as a researcher with caregivers in a hospice during my MSc It soon became apparent that working with bereaved family caregivers and working with those caregivers providing care for a family member in real time would involve a complex process of gaining NHS ethical approval.

It was not until ethical approval was granted and I began to recruit participants to the study that I began to reflect more widely on my experience and assumptions about the research topic, the health service in general and my own interaction with individual caregivers.

The excerpt from my research diary in June 2016 was written after my initial interview with one of the caregivers at the hospital.

I felt unusually anxious about the interview room questioning if it was comfortable and wondering if we would be interrupted by people passing by. I have used this room on many occasions and know it can be noisy at certain times of the day. With this in mind, I scheduled the interview at a time when I hoped it would be quiet.

I felt uneasy as I waited for the participant to arrive. Suddenly awkward in this new role of researcher. As a counsellor, I usually meet clients in reception and walk with them to the room.

It suddenly occurred to me that clients usually meet with me through choice, and many arrive saying they feel relieved have time and space to talk about their feelings. As I researcher, I felt like an imposter because my reason for meeting them was not to give them space to explore their feelings but to ask them questions about a deeply personal experience.

After the interview I noted some of my feelings.

I became worried about upsetting them and unsure of how I would respond if they became upset. Suddenly, I was hyperaware that the boundaries of a researcher are different to those of a counsellor.

Looking back, I see my assumptions at the time were that my researcher role was to gather data and that somehow, this was less important than offering them support. My research diary tells the story of how I frequently struggled to not-be-a-counsellor. This meant I initially lost focus during interviews by focussing on exploring their feelings of loss and picking up on where they expressed sadness, anger, anxiety or blame. After these early interviews, I found myself thinking about them for many days and my clinical counselling

supervisor commented on how these participants had become a regular feature of my supervisory sessions.

At the end of my second year as a PhD student, I stepped away from my role as bereavement support officer to focus on data collection and analysis. Part of the reason for this was because I felt physically and emotionally stretched by the two roles. Looking back through my research diary, I see that I was also beginning to question the way I oriented myself to the caregivers I regularly encountered. This was a difficult process because I believed myself to be a 'good' counsellor shown through my practice. However, I was at a place where I wasn't sure about my role of researcher. I was beginning to analyse the interviews my self-concept was challenged by listening to the questions I was asking. I found it an online resource where I could read the experiences of other LQA researchers and hear how they went through a process of finding the right boundaries for them and their participants'. I have never returned to my bereavement support work although I hope to do so in the future.

This crisis of self-concept did have advantages during the analysis of data. I became adept at questioning and re-evaluating my own understandings of the participants accounts to arrive at what GADAMER (1985) refers to as a fresh understanding of the participant experience.

7.17 Interviews

In recruiting participants to the research, I sought to recruit caregivers of patients with mixed diagnoses. My rationale for this was to prioritise the voice of the caregiver over the patient's illness as the focus of this research. With this in mind, I selected to use an approach which has been described by Thompson et al., (2002) who posit that movement across time is characterised by transitional experiential 'strands' or key moments of chronological change in a given experience, which combine in different ways to influence how individuals perceive and make sense of their ongoing experience.

During data collection, I noted that the critical moments defined by the participants were largely associated with changes in the patient's symptoms. This suggested that the participants experience had been given shape by changes in the patient's illness. A small number of the reported changes did emerge from conversations between the caregiver and medical staff though in all cases the participants spoke about how these conversations had changed

their perspectives in some way which was crucial to their experience. It emerged that many of the participants were hypervigilant of extreme and subtle changes in the patient's demeanour and their experiences were shaped by their interpretations of disease-related changes as well as how they perceived such change. Study retention was impacted by the death of three patients and in line with the limitations stipulated in the ethical guidelines from the LREC, no further data was collected from these caregivers. Though I aimed for diversity in the areas of age, gender, and the patient's illness type, all participants who took part in this research were white and well-educated. It is possible therefore that the issues raised in the key findings are limited to those caregivers in this category. Many of the caregivers I met chose not to take part in this research and it is possible that those who did take part were caregivers who felt they had the time available to participate in the research.

7.18 Use of Pictor

Using the Pictor chart did not appear to enrich the interview process, indeed, for some participants it seemed to distract them from talking about their experience freely. On reflection, the level of informality in my own interaction with participants may have presented a barrier to their understandings of the chart as a representation of their own experience. All participants who opted to construct a Pictor chart as part of their interview requested that I stay in the room while they completed their chart. One of the participants asked me to write names of individuals he wished to represent on post-its and, under his direction, position them on the paper. It could be construed therefore that, in this instance, this participant's chart represented a depiction of our joint understandings of his experience. Another participant may have been seeking validation when she asked me if she had put the post-it in the 'right' place. Again, it is questionable whether this patient's chart was a true depiction of her own experience. Using the Pictor technique as part of their interview may have presented the participants with an unwarranted chore as these participants did not appear to have any difficulty verbalising their experiences to me without the need to draw on the chart. Overall, the use of the Pictor has been a learning experience for me, as a researcher, which, despite the limitations yielded rich and detailed accounts of individual participants' experiences. Reflecting on using this technique as a guide to be interviewing, if I were to use the technique in future

interviews, I would ensure potential participants understood that during the chart construction I am required to leave the room or sit in silence in another part of

7.19 Contribution to knowledge and research

There is a growing recognition that support for the caregivers of patients with terminal illness should be driven by the caregivers' own perceptions of need during the course of the patient's illness (Guberman et al., 2007). Assessing the needs of patients should take into account the individual psychosocial factors which impact on their caregivers' ability to provide care for them over the course of their illness (Guberman et al., 2007; Grande and Ewing, 2019; O'Brien et al., 2019) The aim of the research was to explore whether, and in what ways, the experiences of caregivers for people with terminal illness are similar or different to the patients while accessing palliative care services over time. This aim was achieved, and the findings add to existing literature by the way it has captured the unfolding experiences of caregivers from their own awareness and appreciations of critical moments which marked a shift in their experience. As far as I am aware, this is the first study to focus exclusively on the experiences of family caregivers in palliative care contexts across time by exploring the psychosocial dimensions of their unfolding lived experience. Despite the limitations to this research, which are recognized and have been discussed in the previous section, the key findings of this thesis have made an original contribution to knowledge in the field of family caregivers in palliative care settings in three key areas

7.20 What is unique to the experience of being a caregiver for a patient with terminal illness

In this research, the participants shared their unique understandings and appreciation of changes during the time they were providing care for the patient. Many of the participants were active in monitoring and seeking information about changes in the patient's illness. Being sensitive to such changes was understood as hypervigilance or an increased state of alertness which informed how they each adapted their caring style to meet the patient's fluctuating needs. This process of adapting meant they were responsible for managing situations both inside and outside of the illness scenario. Examples of these situations were their changing economic or employment status, their individual health needs and the way they negotiated their own personal and professional support

networks. A significant finding of this thesis relates to the financial impact of caregiving on the participants, and this adds to an already growing body of research in this area. This finding was woven subtly throughout the accounts of some participant accounts across time, and this presented them with an enduring source of frustration and anxiety. The impact upon these individuals was evident and diverse, varying according to their individual sociocultural position. A review of the literature revealed only one other qualitative study which presented empirical evidence capturing the financial cost of caregivers in a New Zealand palliative care setting (Gott et al., 2015) To the best of my knowledge, this is the first empirical research which draws attention to the financial impact on family caregivers who were in the process of providing care for terminally ill patients in a UK palliative care setting.

7.21 In what ways are the caregivers' experiences similar to the patients'

Both the participants' and patients' experiences were influenced by the quality, as well as how accessible, the nursing and medical staff were. Those who experienced continuity of care from nursing and medical staff in their homes said they valued seeing the same person visit the patient regularly. These participants said they enjoyed working with those who visited them regularly in their home and spoke of forming an alliance with these service providers. A reciprocally influencing relationship was seen for those participants who had access to reliable and personalised access to services. This improved the participant's sense of competency where they felt more competent and able to adapt to the fluctuating needs of the patient. Where these two factors were in place, the quality of the participant's social and familial relationships were positively influenced by enabling them to maintain their own physical and psychological wellbeing.

By exploring the ways in which the caregivers' experiences were similar to the patients' and what was unique to the experience of caregivers, the aims and objectives of the research were achieved. This has furthered the current knowledge base relating to how caregivers are impacted by taking on the caregiving role and how their interactions with palliative care services impact on them individually over time. The findings did raise further questions regarding future research and policy. I would like to recommend the following for teaching policy and research.

7.22 Teaching and Education

Caregivers take on the role of providing care for a terminally ill family member in a variety of ways. It is therefore important that they are fully aware of the part they play in supporting the patient when they embark on providing care. To support them in this role, it is imperative that they are valued for their role as a member of the patients' health and social care team. This has implications for health and social care professionals who have a role to play in supporting them to adjust to their role as caregiver and to manage fluctuations in the patient's illness as well as their own physical and psychological wellbeing over time.

The predicted increase in the number of people accessing palliative care services (Gardiner, Brereton, Frey, Wilkinson-Meyers and Gott, 2014; Ewing and Grande, 2018) and the impact of this on those who provide care for them (Rhodes and Shaw, 1999; Knighting, 2015) presents an opportunity to enhance the skills and awareness of the family caregiver role within a range of educational and clinical settings. This could be achieved by improving current knowledge and skills in the area of supporting caregivers by incorporating these into undergraduate and post-graduate taught nursing courses as well as in the syllabuses of health and social care assistants who wish to specialise in this field.

7.23 Policy

Family caregivers increasingly play a key role in providing care for family member with terminal illness in their own homes (Harrop et al., 2014). According to The Care Act 2014 (Penhale et al. 2014) local authorities and social care organisations have a duty of care to support them in this role. This includes advanced planning by thoroughly assessing their individual support needs early on in the patient's illness and at different points throughout the time they are providing care.

Many caregivers reported difficulties in understanding the process of being assessed and most are unclear about who they need to contact to have their needs assessed. These obstacles are thought to have been the result of a lack of coordination across different organisations as well as health and social care settings.

Supporting caregivers in palliative care is a key policy issue yet there is minimal research available on the topic of how the process of assessing caregivers

could be embedded within palliative care practice (Diffin, Ewing, Harvey and Grande, 2018). Person-centred intervention tools to support caregivers in palliative care settings have been developed by researchers (Ewing et al., 2013; O'Brien et al., 2019). These incorporate an assessment of the caregiver's individual psychosocial support needs which may act as a barrier for them in providing care in their home for the duration of the patient's illness. However, so far the tools have had limited approval from the organisations in which they have been implemented. This is largely because they require training staff to use the tools and there have been challenges to incorporating the tools into the existing practices of the organisation. Agencies are generally resistant to implementing new tools which required expense in terms of time and staff training costs (Guberman et al., 2007; Diffin, Ewing, Harvey and Grande, 2018). In line with the recommendations outlined in the 2018-2020 Carers Action Plan, one way for the Social Care Secretary to respond to the needs of caregivers may be to encourage health and social care services to work with the other palliative care organisations to ensure that all adult caregivers who access the health and social care system, at any level during the patient's illness, will be given the opportunity to collaborate with a named individual assigned to them. They could work with them on formulating an ongoing assessment strategy which would reflect their own fluctuating physical and psychosocial needs.

7.24 Research

The financial toll of caregiving increases exponentially over the course of the patient's illness as the patients' needs are prioritized over all else. Financial support from statutory services was often difficult to access and involved an excessive amount of red tape as well as attending interviews with benefit advisors. One way to get quick access to financial support is through a medical assessment where a doctor or nurse can confirm that the patient has less than six months to live. However, many patients in palliative care have illness trajectories which are difficult to predict so they are not included in this category. Costs are incurred as the result of multiple factors, but often include the cost of buying extra or special food and medication for the patient, as well as the cost of equipment and paying for transport or accommodation to get to hospital appointments. Other costs noted in this research were more indirect, such as those related to changes in their own health or employment status. There is a

lack of research investigating the financial impact of caregiving for family caregivers of patients with terminal illness. It is recognised that there are practical challenges to for those caregivers wishing to remain in employment. According to the 2011 Census, the majority of carers were balancing their caring role with full time or part time employment. Financial support and advice are important to caregivers, though as this thesis was being written, a campaign by Marie Curie and the Motor Neurone Disease (MND) Association has commenced and is in the process of lobbying parliament to improve financial support for patients at the end of their lives. This would also have implications for caregivers in terms of their household income. Future research could focus on the wider financial consequences of caregiving and explore the rules around employment, so caregivers are not penalized for taking time off work to care for a terminally ill family member.

7.25 Study quality

The quality and validity (or trustworthiness) of qualitative research is evidenced using a different set of concepts to those applied to qualitative research. Quantitative research seeks to produce findings that are generalizable across contexts or reliable and valid across time. However, there are no strict rules or universally agreed guidelines that are applied to evidence qualitative research outputs are of a high standard. King and Horrocks (2004) point out that there are a set of guiding principles, which can assist researchers in fulfilling their professional and ethical obligation to ensure high quality in research outputs by offering insight and understanding into the phenomena being studied. Yet, there is much debate around what criteria can be used to determine that this is achieved.

The objective of qualitative research in terms of establishing quality and validity is to demonstrate good scholarship and pass the 'so what?' test (Sendelowski, 1997). Yet, quality is a many-sided concept that differs according to the context and aims of the qualitative research study (NICE guidelines, 2012). Broadly speaking, guidelines must take into consideration the significance of the research question and the rigour of methods applied. The aptness of the researcher's interpretations and the clarity of their writing are further features which will assist reviewers and other researchers in the critical appraisal of the study findings (O'Brien et al., 2019).

From a range of proposed guidelines for ensuring quality in qualitative research, I chose to utilise an adapted version of the consolidated criteria for reporting qualitative research (COREQ) (Tong, 2007). The checklist (see appendix 8) was developed from an extensive search of qualitative journals and reference lists from major medical journals. Items selected for their usefulness in helping researchers achieve clarity when reporting on the study process, design, analysis, findings and reflexivity are grouped into three separate domains.

7.26 <u>Domain 1</u> This takes the unique position of the researcher into account and makes clear how their own experience may influence their observations and analysis of findings.

Within this thesis, I have attempted to verify the quality and trustworthiness of the research findings by providing a rationale for the decisions made during the planning and execution of the study. I have been consistently open within the writing of this thesis about how and where my own position as a palliative care researcher and previous experience with family caregivers impacted on my decision making. This level of transparency has improved the trustworthiness of the research.

According to Polit and Tatano Beck (2010) the credibility of qualitative research is demonstrated by the degree to which the reader can trust that the process of data analysis addresses the intended focus of the research topic. Throughout the thesis I make known my decision-making process in relation to interviewing participants from three areas of the same hospice. Similarly, with how I recruited participants' and my reasons for utilising a longitudinal qualitative cross-sectional approach to data gathering. The literature review chapter shows how the review search process and findings underpinned the formulation of the research aims and objectives.

A particular strength of this research is evident in how I documented my thoughts and judgments during my prolonged involvement with research participants in the data analysis period. Conversations held in peer debriefing sessions with research colleagues and discussions held in supervisory sessions reinforced the creditability of the study further (Wheeler, 2001)

7.27 Relationship with participants

All researchers hold a privileged position in the research scenario and there are strict ethical guidelines available to help them manage the potential power

imbalance that can occur between the researcher and the researched (Mitchell and Irvine, 2008). There is a growing body of research which explores the concept of power within the research participant encounter (Bashir, 2019). The dominant assumption within the literature, however, assumes that the researcher holds power over the participant because of their level of expertise (Downey et al., 2007; Mitchell and Irvine, 2008). Bashir (2019) suggests that in a bid to address potential inequalities of power and to protect participants deemed to be vulnerable, the researcher may make choices that render them more vulnerable to that of the participant. My aim was to minimise the power imbalance as much as possible and to ensure that participants did not feel under any pressure to take part in the research out of a desire to please me. I was also aware that they may have been under the impression that taking part in the research was compulsory or it formed part of their overall care whilst at the hospice. These issues were minimised by making my position as a researcher clear in the participant information sheet (appendix 1). This makes it clear that I am a PhD student at Sheffield Hallam University and this message was repeated prior to every individual participant's interview. I also wore a Sheffield Hallam University badge while on hospice premises as a way of reinforcing this message.

When presenting the research to potential participants at various hospice groups, I endeavoured to make my position as a researcher clear by wearing a Sheffield Hallam University Badge. This helped to reinforce the message and minimise the possibility of participant's mistaking me for a member of hospice staff.

7.28 Domain 2 addresses the design of the study and prompts the researcher to demonstrate how they adhered to the philosophical underpinnings of the research approach consistently through the planning and design of the study.

Within this research, I endeavoured to ensure that the research methods I selected are in line with phenomenological philosophy and the Human Science Research method proposed by van Manen (1990, p.107).

I recruited nine participants to the study; six were interviewed three times and all nine were interviewed twice. Reasons for this are documented elsewhere in this thesis. Much of the literature on phenomenological research methodology

does not directly address the topic of idea sampling size the sampling size (Williams et al., 2011). It is not unusual within published phenomenological studies, to see sample sizes of ten or fewer. This is because the aim of a phenomenological research study is to 'honour the richness of the individual's account' Smith and Eatough (2006). My primary aim when making decisions about sample size, was to collect the individual longitudinal accounts of those who share a particular relationship to the phenomena under research (Heidegger 1962). Malterud, ae al (2015) discusses the significance of information power which prioritises the quality and clarity of dialogue between the participant and researcher. This was also a consideration when making decisions about the inclusion and exclusion criteria for the study. Diversity in terms of the participants age, gender and the illness of the patient was sought as a way of seeking variation in the experiences of individual caregivers regardless of the patient's illness.

The timing of interviews was determined by each participant's perceptions of change rather than imposing my own ideas or assumptions of change or similarity across time. I used the same interview topic guide for all participant interviews. I made a decision not to adjust the interview guide between the participant's first, second and third interviews. Changing the interview topic guide between interviews would have risked impeding the emergence of fresh topics which may have surfaced since the participant's previous interview and which may have significance for them in real time (Farr and Nizza, 2010). The current study involved using the Pictor technique, which has been used in a variety of studies to represent episodes of collaborative working with different groups of specialist and general nurses in health and social care settings. (King et al., 2013; King, Brooks and Bravington 2014; King, Bravington, Brooks, Melvin and Wilde, 2017). My aim in using this technique was to assist individual participants to give voice to their experience in a novel way. This approach has been used in phenomenological studies which explored the learning styles of medical students in clinical settings (Berkhout, Helmich, Teunissen, Vleuten and Jaarsm, 2017). Hardy, King and Firth (2012) also used Pictor to increase make known the experiences of lay populations by exploring the experiences of patient and caregiver dyads as they access m multiple health care services. My reflections on using Pictor are documented within this thesis.

7.29 Domain 3 calls upon the researcher to demonstrate where they have been systematic in documenting and recording stages of analysis and interpretation of data. This can prove challenging in phenomenological research where the aim is to highlight complexity and ambiguity across individuals in given contexts and settings (Dahlberg et al., 2008).

I returned to the data multiple times recording and documenting my decision-making process and justifying my reasons for modifying each version of the template. Each version was identifiable by the version number and that date of analysis. I also circulated copies of each template version to colleagues and supervisors as well as discussing my decision trail in detail. This level of organised and logical reflexiveness is an important element of qualitative analysis where researchers are often called on to justify their decisions throughout the planning and conducting of their research (Finlay, 2002). There was a delay in interviewing participants and writing the findings chapter. I left the research setting some months earlier with a goodbye celebration which was attended by many of the participants. Because this had been such a decisive and safe way to leave the research setting, it was decided by myself and my supervisory team at the time that member checking would not be appropriate with these participants

In using an adapted version of the COREQ checklist, I strove for clarity in all stages of the research process to produce a study trustworthy quality study.

7.30 Concluding thoughts

My interest in the different way caregivers experience providing care for someone during terminal illness, began many years earlier. Through my work in a hospice setting, I noticed differences in how individual caregivers responded to the admission and to managing the practical, emotional and logistical challenges inherent in caring for the patient. Central to the stories of the caregivers I met, was a narrative of love and loss, however, at some point their stories diverged, becoming more personal and the variations in their individual experience became more visible. Around this time, I unexpectedly became a caregiver for a friend who was diagnosed with cancer. So, my motivation for conducting research in this area was both personal as well as professional.

I was aware that the knowledge base regarding caregivers in palliative care was dominated by an approach underpinned by the assumption that the experiences

of caregivers in palliative care would unfold along the same illness focussed way as the patients' illness. Based on these ideas, the term transition had been extensively used by researchers investigating the experiences of caregivers in palliative care contexts (Williams and Mccorkle, 2011).

In adopting a qualitative longitudinal approach, I aimed to avoid a medicalised view of their experience by interviewing individual caregivers at different points of change in the process of caring. This involved using the caregivers' own perceptions of change to their experience rather than one based on the patients' illness trajectory.

Conducting this study has challenged me in ways I had not envisaged and after eleven months in the research field, I began to grasp the complexity of the caregivers' undertaking. It became apparent that the caregivers who took part in this study experienced multiple episodes of change to their ways of being in the world. One significant change was how they managed caring for the fluctuating needs of the patient whilst negotiating their place within the palliative care setting.

Reliability was a key requirement for the participants in terms of their access to palliative care services especially with regard to managing the fluctuating needs of the patient in their home. It appeared to be of great importance to the participants that their access to palliative care services was reliable and available to them at the point of their own and the patient's need. Having different teams involved in the care of the patient led to increased levels of anxiety for caregivers who stove to establish relationships with key individuals' who could be relied upon to support them in caring for the patient over time. Being supported to cope and adapt to changes in the patients' illness led to an increase in feelings of reward and preparedness. It appeared that the caregivers' feelings of competency and preparedness fluctuated but when they were enabled to maintain their relationships with friends and family these were significantly enhanced. Coping was a concept which looked dissimilar for different caregivers but in many instances, their relationships with friends and family was regarded as a form of self-care which had a positive effect of their ability to cope as well as their physical and psychological wellbeing.

Of note was that there was inequality among the caregivers in terms of their access to financial resources. Some participants experienced greater financial

burden than others because of several factors which have been discussed. Having access to adequate funding was a further factor which impacted on the preparedness and ability to cope with caring for the caregivers in this research.

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Appendices

Appendix 1 - Participant information sheet

On University Headed Paper

Participant Information sheet

Study Title	**Family Caregivers' Experiences in the Palliative Care Context: A Longitudinal, Qualitative Study**
Chief Investigator	Annie Dunsmore-Dawson
Contact address	Room S002 Department of Health and Wellbeing Sheffield Hallam University Collegiate Crescent Sheffield 10

I am a PhD student at Sheffield Hallam University and would be grateful if you would consider taking part in a study I am conducting with caregivers of palliative patients who have been involved with services at this hospice. The study has been approved by the hospice ethical committee but before you decide whether to take part, it is important for you to understand what taking part will involve. Please take your time to read this information carefully and discuss it with others if you wish. I will be attending groups at the hospice until December 2016 so feel free to ask me if there is anything that is not clear to you or if you would like to take part in the study. In the meantime, here are some frequently asked questions.

What is the purpose of this study?

The main purpose of this study is to get a better understanding of what it is like for caregivers who are caring for someone with palliative needs. This is because this experience has been recognised as a crucial time in the lives of people who are caregivers.

What will be involved if I take part?

Taking part will involve being interviewed by me on at least two occasions between now and the end of December 2016. This may be at the hospice, at your home or at the university. The interview will involve me asking you questions about your experience of becoming and being a caregiver. The reason for interviewing you more than once is that I would like to form a picture of how or if your experience of being a caregiver has changed during this time .

What are the possible disadvantages of taking part?

I recognise that this may be a difficult time for you and appreciate your taking time to talk about your experience. It is possible that the interview will touch upon topics, which you may find difficult or upsetting. If you do find the interview difficult, you will be able to stop at any time. We can then discuss together whether it would be helpful for you to take a break before continuing; or you could choose to discontinue the interview altogether.

Why have I been invited to take part ?

You are being invited to take part through your attendance at the Breath of Fresh Air group at the hospice.

Do I have to take part?

No you do not. Taking part in this study is entirely up to you. If you decide to take part then you are asked to sign the expression of interest letter enclosed and return it to me at the university in the pre paid envelope provided. I will then contact you and we can decide where you would like to meet and when. The decision to take part is entirely your own. No part of your or your loved ones care by the hospice care team will be affected by your decision.

What are the benefits of taking part?

You may not receive any direct benefit from taking part other than knowing that the contribution you make may help improve care and support for others caregivers in the future.

Expenses and payments

You will not be paid for taking part in this study. However, if we arrange an interview at the university I will be able to offer you a parking permit.

Will my information be confidential?

All information will be completely confidential. Information used in any report will not have your name or any of your details written in it so that you will not be recognised by anyone who reads it. All your personal information will be anonymised, stored on an encrypted usb device and held on a password protected computer. This will be destroyed after the study is finished in accordance with university protocol.

Are there exceptions to the code of confidentiality?

Yes there is an exception which is that, in the unlikely event that, during the interview, you disclose some aspect of your care that raises concerns, I am obliged to discuss this with my supervisory team for your own safety and wellbeing. They may see fit to raise this with the professionals involved.

What happens if I change my mind after the interview (s)

If you change your mind you can contact me up until the end of July 2017 quoting your participant number and, if you request it, all or part of your information will be withdrawn from the report.

Who will read the report and what will happen to any findings from it?

The research is part of a university degree course from which, I expect to write articles and give presentations based upon its findings. It will be read by a university panel who will judge it for its academic merit and it is hoped it will improve care in the future for patients and caregivers at this and other hospices.

Who is sponsoring the study?

The sponsor of the study has the duty to ensure that it runs properly and that it is insured. In this case, the sponsor is Sheffield Hallam University.

Who has reviewed this study?

All research that involves NHS patients or their caregivers is looked at by an independent group of people called a Research Ethics Committee, to protect

your safety, rights, wellbeing and dignity. This study has been reviewed and accepted by the research and ethics committee at Sheffield Hallam University, the hospice and the Local Research Governance Consortium (LREC) who review all studies involving NHS patients or their caregivers.

Who do I contact if I wish to take part or for further information?

You can contact me, Annie using the envelope provided or by asking the community care nurse to contact me with your information. Alternatively you can email me or my supervisors at the Department of Health and Wellbeing, Sheffield Hallam University.

What if there is a problem or I want to complain?

If you have any queries or questions please contact:

The chief investigator: Annie at: adunsmore-dawson@shu.ac.uk.

Alternatively, you can contact my supervisory team at Sheffield Hallam University, Centre for Health and Social Care Research. Hospice staff have their contact details.

If you would rather contact an independent person, you can contact Peter Allmark (Chair Faculty Research Ethics Committee) p.allmark@shu.ac.uk; 0114 225 5727.

Can I find out about the findings of the study?

Yes. All participants can request a short version of the report and a full copy will be made available to those who request a copy. Thanks for taking the time to read this information sheet.

Annie Dunsmore-Dawson

Appendix - Study reply form

Study Title	
	Family Caregivers' Experiences in the Palliative Care Context: A Longitudinal, Qualitative Study
Chief Investigator	**Annie Dunsmore-Dawson**
Participant number	

Please tick to confirm

I confirm that I have read and understood the information sheet relating to the above study. ☐

I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

I understand that my participation is voluntary and that I am free to withdraw from the study at any point without   giving any reason. ☐

I understand that I have the right to withdraw my data after my interview(s) and at any time up until ☐
date

I give my permission for any interview to be audio recorded and to be quoted anonymously in any report arising from the study. ☐

I understand that individuals from Sheffield Hallam University or from the NHS Trust may look at relevant sections of data collected during the study when relevant to the research. I give my permission ☐ for these individuals to have access to a recording of my interview or a copy of the transcription

I agree to take part in the above research ☐

Signed...Chief Investigator

265

Date……………

Signed………………………………………………………………………Participant

Date……………

Appendix - Consent to participate

On University headed notepaper

<div style="text-align: right">

Annie Dunsmore-Dawson Room S002
Department of Health and Wellbeing
Sheffield Hallam University
Collegiate Crescent
Sheffield 10

</div>

Consent to interview.

Family Caregivers' Experiences in the Palliative Care Context: A Longitudinal, Qualitative Study

Participant number.....................................

Please tick to confirm

I confirm that I have read and understood the information sheet relating to the above study.

I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

I understand that my participation is voluntary and that I am free to withdraw from the study at any point without giving any reason.

I understand that I have the right to withdraw my data after my interview(s) and at any time up until August 2017

I give my permission for any interview to be audio recorded and to be quoted anonymously in any report arising from the study.

 I understand that no person other than the researcher, her supervisors and on rare occasion's academic examiners will have access to audio recording or copies of the transcription of my interview.

I agree to take part in the above research

Signed..Researcher

Date...............

Signed ....Participant

Date..............

Appendix – Expression of Interest Form

On University headed notepaper

Expression of interest to take part in research study

Family Caregivers' Experiences in the Palliative Care Context: A Longitudinal, Qualitative Study

I am willing to be interviewed by Annie as part of her project.

Name
(print)..

Address...

....

Telephone
number...

Email (if applicable)...

Signed..

Date...

Please return this form to me in the envelope provided or contact me on 07753172834 if you require further information.

Appendix - Debrief letter

ON UNIVERSITY HEADED PAPER

Research Study: Family Caregivers' Experiences in the Palliative Care Context: A Longitudinal, Qualitative Study

Dear

Thank you for participating in this study. One of the main aims of the study was to explore and understand what it is like for family caregivers who are caring for someone with palliative needs. Your contribution to this study is therefore valuable and very much appreciated. The responses you give will be used to help better understand the perspectives of caregivers who provide care for a family member the way you do. It is further hoped that the information you have provided may help improve services for other caregivers in the future.

If you should feel the need to talk further about your experiences or if you feel upset in any way after taking part please feel free to contact The Counselling Co-ordinator at Overgate hospice who is [name of contact].Their number is [contact number]

If, for whatever reason you later decide that you no longer want your responses to be part of this research than please contact me before [date]. Alternatively, you can contact my supervisory team at Sheffield Hallam University, Centre for Health and Social Care Research. Hospice staff have their contact details.

No part of your care by the specialist palliative care team or Overgate hospice will be affected by this decision,

Thanking you once again,

Annie Dunsmore-Dawson

Appendix - Data Management plan

1. <u>What data will I collect or create?</u>

I intend to collect up to 10 recorded and transcribed interviews with participants with digital images of charts they produce reflecting their experience.

2. <u>How will my data be documented and described?</u>

Data will be documented logically and clearly according to content and structure. Changes to versions and descriptions of data will be recorded to ensure clarity and transparency for myself and my supervisory team.

This will include:
• information about when, why, and by whom the data was created
• what methods were used
• an explanation of codes used for storage**.**

3. <u>How will my data be structured, stored, and backed up?</u>

Interviews will be transcribed as HTML files and stored with images as pdf files on a password secure computer and on the university network storage system. Electronic data to be stored only on password secured computer equipment and storage devises and audio recordings and equipment to be transported in a lockable case.

4. <u>What are my plans for data sharing after submission of my thesis?</u>

It is anticipated that results will be disseminated via academic and practitioner journal articles, presentations to participating hospices and conferences. The final report and thesis will be placed in the University Repository.

5. <u>What are my plans for the long-term preservation of data supporting my research?</u>

According to the data preservation and storage policy at Sheffield Hallam University

Appendix - Interview topic guide

- If you are comfortable, I will begin recording now for approximately 50 minutes. As we have discussed, If there are any questions you do not want to answer then just say so or if you feel uncomfortable at any point then please tell me and we can stop the interview. Is that clear?

- Could we begin by you telling me in your own words how you became x's caregiver? (the verbal and non-verbal responses will drive further questions as the researcher explores the participant's beliefs, experience and perceptions)

- Is this in your home/their home/the family home?

- What sort of things have changed for you in that time do you think? (the verbal and non-verbal responses will drive further questions as the CI explores the participant's everyday sociocultural world including neighbours or friends who may have played a part in supporting them throughout caring)

- How did you become involved with the palliative care services and what has this experience been like for you?

- ? (the responses will drive further questions as the CI explores prior held beliefs and perceptions of hospice or palliative care)

- What or who provide you with support? (Palliative carer services, friends, family, religious or spiritual /beliefs/customs, holistic/ counselling services /groups)

The interview continues for between 40 to 50 minutes depending on the participant and their comfort. The participant is asked if they have anything they wish to ask the CI before the recording is stopped and the patient is debriefed (see debrief letter appendix 4)

Appendix - Consolidated Criteria for Reporting Qualitative Research (COREQ)

Adapted from Tong et al (2007)

Question	How Addressed
Domain 1 **Personal characteristics**	
Interviewer	All interviews were conducted by the Researcher
Credentials	BSc (Hons) Counselling with Psychology MSc Res
Occupation	PhD student and hospice volunteer worker
Experience and training	- BSc (Hons) Counselling with Psychology 11 years' experience of working with patients and families in a hospice - MSc Res with carers in palliative care 4 years working as a bereavement support worker - Attended Better Grief Course
Relationship with participants	
Researcher / Participant relationship	No relationship was established with participants prior to study commencement?
Participant knowledge of the interview aims	Participants were aware that I was conducting a research project for my PhD study at a university in Sheffield.
Interviewer characteristics	That I was not a member of staff but a researcher at the university.
Domain 2: Study design	
Theoretical framework	Qualitative Study
Methodological orientation and Theory	Phenomenology
Participant selection	
How were participants selected?	Purposive

How were participants approached?	via hospice staff initially
How many participants were in the study?	9
How many people refused to participate or dropped out?	14 refused and three conducted only two interviews because their family member died.
Reasons?	Refused on the basis of having not enough time/too distressing to discuss the topic/patient objected.
Setting	
Where was the data collected?	Hospice and the home of two of the participants.
What are the important characteristics of the sample?	See inclusion and exclusion criteria
Data collection	
Interview guide	Semi structured interview guide (appendix 7) .
Repeat interviews	2 or 3 repeat interviews
Audio/visual recording	Interviews were audio recorded.
Field notes	Methods chapter
Duration	Each interview lasted between 50 minutes to an hour.
Data saturation	Data saturation was dictated by the time restraints of the research study.
Domain 3: Analysis and findings	
Data analysis	Thematic analysis
Description of the coding tree	In the Findings chapter
. Derivation of themes	No themes were identified in advance of the analysis in keeping with a phenomenological approach.

Participant checking	It was decided that member checking would not be appropriate with these participants
Reporting	
Quotations used in thesis	Quotations from individual participants were used in the thesis and these and these were identified according to the participant pseudonym and which interview the quote was from.
Data and findings consistent	There was consistency between the data presented and the findings?
Clarity of major themes	Major themes clearly presented in the findings?
Clarity of minor themes	Themes are described using examples from the participants data.

Appendix – NHS REC Approval

NHS

Health Research Authority

Yorkshire & The Humber - South Yorkshire Research Ethics Committee

Unit 001
Jarrow Business Centre
Rolling Mill Road
Jarrow
Tyne and Wear
NE32 3DT

Telephone: 0207 1048091

> **Please note:** This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

01 August 2016

Ms Annie Dunsmore-Dawson
Chestnut Court
Sheffield Hallam University
Collegiate Crescent
S10 2BP

Dear Ms Dunsmore-Dawson

Study title: A qualitative study using visual and verbal data to reveal the experience of being a carer in palliative care.
REC reference: 16/YH/0201
IRAS project ID: 198424

Thank you for your letter of 27 July 2016, responding to the Committee's request for further information on the above research [and submitting revised documentation].

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Mrs Helen Wilson, nrescommittee.yorkandhumber-southyorks@nhs.net.

A Research Ethics Committee established by the Health Research Authority

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Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a **favourable ethical opinion** for the above research on the basis described in the application form, protocol and supporting documentation [as revised], subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

pp

Dr Ian Woollands
Chair

Email: <u>nrescommittee.yorkandhumber-southyorks@nhs.net</u>

List of Figures