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**“There’s no manual for being a carer”**

**A Phenomenological study of becoming a  
carer from home to hospice care**

**Annie Dunsmore-Dawson**

A Thesis Submitted to the University of  
Huddersfield in fulfilment of the  
Requirements for the degree of Master of Science  
by Research

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Finally to my late Brother **Gordon Briggs** who died during the writing of this thesis.

“May you be blessed upon your journey as I was blessed with you on mine”.

### **Abstract**

Carers of people with cancer and other life limiting conditions often fail to appreciate the scale of the caring task and frequently do not identify with the label of carer. This is especially true when care takes place in the home and the patient is their spouse. When caring in the home is no longer workable, patients are offered palliative care as an inpatient at a hospice. This juncture in caring has been identified at policy level as a significant life event for carers which impacts on carers in idiosyncratic ways (Duggleby et al, 2010). As they realign themselves to a changed reality, they are faced with negotiating their position in their lived space as well as the new illness setting.

The process of caring and the carers' task of aligning themselves to a changed reality and renegotiating their place in the two settings has been conceptualised in a variety of ways. Because their experience unfolds in a medical arena, support for carers has been coordinated in line with their response to the patient's illness. I would prefer to see support for carers that recognises their experience as being separate from that of the patient and which would correspond more closely to the carers' unfolding experience. This could be achieved by support staff getting to know the distinctive historical and cultural influences that impact on the carer and the patient when they face the distressing impact of moving between care settings at end of life.

Influenced by the work of van Manen (1990), this research utilises interpretive phenomenological analysis (Smith and Eatough 2006) and is supported by template analysis (King and Horrocks 2010) to illuminate salient features of the move into hospice care from home care that were pertinent to seven different carers from two hospices.

This study uncovers the fragile and changeable quality of the carer's world when adjusting to caring for a family member when from the familiar setting of home to the unknown care surroundings of a hospice.

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## **Chapter 1: Introduction**

The picture which is not clear at the time becomes lucent with recollection

*Mary Wesley. The Camomile Lawn*

### **1.1 My interest in the topic**

The move from home care to hospice care marks a shift in direction for patients and the families of people with cancer. The End of Life Care Strategy (DOH, 2008) affirmed the central role that carers play in providing support for others by recommending that the needs of carers be individually assessed and documented by multidisciplinary teams involved in end of life care. Key aspects of this shift remain understudied in palliative care research despite the recognised psychosocial effect on carers (Williams and McCorkle, 2011).

I first became interested in the different ways that carers respond to the change from home to hospice care whilst working as a volunteer at a local hospice where I regularly came into contact with family members arriving to visit friends and relatives on the inpatient unit. When they were visiting for the first time, I would chat to friends and relatives before taking them into the inpatient unit. At the same time, I would try to gauge their feelings about the admission. Frequently, I noticed distinct differences in individual reactions especially from those who had been the primary carers at home before the admission. It seemed that their individual responses were strongly associated, not only with their views of this event, but also their expectations from this point onwards.

To demonstrate my position, I will detail two distinct and unconnected examples.

*Susan* was the mother of four children ranging in age from two to seven years. Her husband was a patient in the hospice, having been brought in by ambulance from hospital earlier that day. She arrived with her children, a mixture of tired, hungry and bored infants and straightway began to apologise for bringing the children with her. She explained that she had to catch two buses to the hospice from where she lived and she had not been able to organise childcare yet. On speaking to her, it became clear that her expectation of this admission was that her husband could be allowed to die in

a peaceful place and yet for her, in that moment, the admission meant having to negotiate travel arrangements alongside the practicalities of balancing visiting her husband and organising childcare for their children.

The eldest child, seemingly oblivious to the significance of the change in nursing setting, promptly announced that she was “at big school now”. Explaining to those present in the waiting room how she had not been able to go that day because of “the buses”, she proudly wore her “big school” uniform. By way of an explanation for the striking gap in the middle of her crisp white blouse where her school tie was missing, she spoke of how the tie had been ordered during the summer holidays and her mother had not been able to pick it up yet because of “visiting Daddy and the buses”. For this little girl, the admission also highlighted the problems of using public transport; notably a delay in wearing the longed for tie, a badge of office which signified her arrival into a new category of maturity.

*Tom* arrived in reception with his wife having come from the hospital in time to meet the ambulance bringing their only son to the hospice for what was thought to be the last days or weeks of his life. Requesting to wait in the reception area for him to arrive by ambulance, they explained how they wanted their faces to be the first he saw when the ambulance doors opened. We talked, and both parents had clear expectations of this admission; the word gratitude peppered their dialogue, including gratitude for having such a wonderful son and that he had lived long enough to gift them an adored grandchild. They acknowledged the importance of time and specifically how it was fast running out for them. They had heard good things about the hospice and were glad that the precious time they had left would be spent there. The meaning shared by this family was that of reclaiming power from a disease that had shaped much of their life and had been ‘hidden’ in the human growth hormone injections taken many years earlier by their son that were meant to boost rather than limit his quality of life.

Both families had been involved in caring at home for people with different illnesses, which had presented them with differing demands. There were differences in the practical, emotional and logistical repercussions in each case. Beneath the stories

of illness however, lay a narrative about more than the course of physiological change and it was at this point that their stories diverged.

Although loss was central to the experience of both these families, the way that each family 'storied' their experience was different and this seemed to impact on the meaning of the experience for each of them. Kleinman (1988) describes this storying as empathic interpretation which, he asserts, charts a changing system of meanings which can be accepted as an account of their lived experience. He further states that this is the "very stuff of care" for those who provide care for the chronically ill over time.

### **1.2. How does palliative care differ from curative care?**

For clarification purposes, in this study curative medicine is understood as a treatment orientated branch of medicine where the approach to health care relies on scientific knowledge and analytical thinking. The patient's symptoms act as the 'clues' for diagnosis and elimination or interference to the cause of illness. In curative medicine, there is little focus on the patient's psychological or spiritual condition as a discrete area of interest. Palliative care is targeted towards the relief of pain and suffering for patients and their families, including the restoration of functional living where possible. The patients' and families' own values and choices are the focus of care planning, but these do not include taking action that may slow down or speed up the patient's death

This study is concerned with those who have palliative care needs and their carers. The word palliative originates from the Latin word *palliare*, meaning to cloak. This type of care differs from curative care in its specific focus on quality rather than preservation of life concerns, which include the existential needs of patients (Olson, et al, 2011).

In 2002, the World Health Organisation (WHO) issued a global perspective on palliative care. This took into account that physical, spiritual and psychological symptoms of chronic illness become more difficult to manage as illness progresses; it further stated that palliative care should be applied as soon as illness is recognised as being chronic or terminal, rather than beginning when the patient does not respond to curative treatment. This perspective included providing care for carers

and family members (Sepulveda et al, 2002) whose physical, spiritual and psychological suffering is related fundamentally to those of the patient (Wittenberg-Lyles et al, 2011).

Consequently, palliative care can be made available at any stage of an illness which is life limiting and many patients and their families in this situation opt for inpatient care by a multidisciplinary team in a hospice. Here their physical, spiritual, psychological and social support needs are met by such a team throughout the remainder of the illness trajectory and for the family following the patient's death.

### **1.3 Who is a carer?**

Many people assume the direct caring duties of others and yet do not identify themselves as carers especially when caring for a friend or family member (Morris and Thomas, 2001; Hardy, 2012). More frequently, they identify themselves with familial labels meaning that for many the responsibility for caring is assumed rather than agreed upon. The Department of Health document: *Recognised, valued and supported: next steps for the Carers Strategy (2010)* aims to support those with caring responsibilities by helping them to recognise the value of their contribution early in the caring process and to identify themselves as carers. At the same time, the strategy encourages involvement from wider social and family members which would minimise carer strain on individuals, as well as assist in establishing support networks for others involved in the caring process

### **1.4 The referral pathway into hospice care**

Admission into hospice care is not always a move from one type of care to another. Referral to palliative care services can occur for many reasons such as respite care, medication review and in today's changing landscape of surgical procedures, palliative care can be in conjunction with surgery for symptom control. Schulman-Green (2004) observed the importance of timing in this admission, noting that referral late in the illness trajectory was associated with a negative effect on carers 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 and this change of focus is likely to be met with an array of responses (Schulman-Green 2004).

For carers, the decision about where care should take place must take into account a myriad of differing influences (Stajduhar and Davies, 2005), not least of which are their own and others prior held perceptions and associations of hospice as a place of death (Baile et al, 2011). Hospice care focusses on lessening the physical, psychological and spiritual effects of illness for patients and carers and these effects can differ widely between individuals even within the same family or group of people involved in caring. This being the case, it is not surprising that factors that appear to be imperative to one carer may be of little or no consequence to another. One thing that is common across all carer experiences is the way that, at such times, carers and families face fresh concerns that challenge relationship dynamics and strain communication between patients and carers especially when there are differing levels of acceptance of the patients' illness and impending death (Schulman-Green, 2004)

Changes in caring focus can be difficult for carers 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 carers who maybe had not perceived themselves as being in need of care but rather as having been tasked with managing the illness situation (Molyneux et al, 2010).

Stajduhar and Davies (2005) highlighted ways in which the decision to provide care is made in an uninformed way, often not taking into account the issues involved in caring over a prolonged period. With little emotional detachment, the financial and practical issues of daily living emerge over time and these must be negotiated together with on-going caring responsibilities such as functional changes in the patient's condition, where carers will be required to take on more specialised and unfamiliar nursing related roles.

The carer's decision to provide care at home is frequently reported as an emotional rather than a practical choice (Stajduhar and Davies, 2005), made with the personal autonomy and quality of life of the patient at the forefront of the carer's

considerations. One aspect of managing care comprises making the decision about the optimum place for continuous patient care which fluctuates as illness progresses and the patient's functionality declines. This critical juncture forces carers to appraise care objectives and has led to this period being hypothesised as a transition (Schulman-Green et al, 2004; Sutherland, 2009).

The 2011 Palliative Care Funding Review drew attention to increasing survival rates among those affected by life limiting disease which points to the process of caring for a terminally ill person becoming more prolonged and wide-ranging than ever before. Alongside this, government aims to allow more people to die at their preferred place of death. This is likely to increase the number of people providing formal and informal care at home where clinical tasks must be performed, despite a lack of training or preparedness for such responsibilities (King, et al, 2004). This has clear implications for future carers of individuals with cancer.

### **1.5 The future for palliative care**

The End of Life Care Strategy (2008) and the 2011 Palliative Care Funding Review (2011) are two key documents that draw attention to the increase in survival rates among those with chronic disease. Implicit in this acknowledgment is the recognition of an increase in demands for carers as they assume responsibility for the protracted and complex physical, emotional, medication and nutrition related needs of the patient (Williams and McCorkle, 2011). The Palliative Care Funding Review refers to the unique nature of interventions in this field of care, and for funding purposes, classifies illness as occurring in four phases (stable, unstable, deteriorating and dying). It is argued however, that the compartmentalizing of stages and phases of illness does not take into account the inherent fluctuations in life limiting illness nor does it keep in mind the unique understanding of the carer as illness progresses (Timmermans, 1994). Having identified the issues surrounding the transition into palliative care I aim to review current literature as it relates to carers who provide care in various settings at the end of life.

## **Chapter 2; Literature Review**

*He always thought that Touie's long illness would somehow prepare him for her death. He always imagined that grief and guilt, if they followed, would be more clear-edged, more defined, more finite. Instead they seem like weather, like clouds constantly re-forming into new shapes, blown by nameless, unidentifiable winds."*

— Julian Barnes, *Arthur & George*

### **2.1 Introduction**

In the previous chapter, I drew attention to individual carers' responses to the move from home to hospice care as the focus of my research. With this in mind, I have drawn attention to factors inherent in this move that may or may not impact on carers in differing ways. For example, factors such as ways that the carers' react to the change of caring focus from caring for someone with an illness to caring for them as they move towards the end of their life. The way that carers integrate themselves into the changing illness setting also has an impact on their experience as does who initiates the decision for a change in care setting when curative care is no longer an option for the patient. There are a myriad of factors that impact on how and why this decision is made and these are some of the pertinent factors that affect how carers respond when the move to hospice from home care is made.

It has been noted that aggregate statistics on differing illnesses vary, so for example cancer patients' illness trajectories on average differ in terms of predictability from those with other long term conditions (Morris and Thomas, 2001). In the past, carers' experiences have been assumed to unfold in the same aggregate patient focussed way (Williams and McCorkle, 2011). Based upon such ideas, crucial points in illness have been offered as evidence of transition for those living with chronic illness (Koch and Kralik, 2001) and yet carer support requirements frequently do not correspond along a predictable pathway in line with the illness trajectory of the patient.

This literature review will explore research and theory that relate to the transition from home to hospice care for carers whilst caring for a spouse or family member with a life-limiting illness.

## **2.2. Concepts of Transition**

Transition as a concept has been used in many different organisations as well as health and palliative care. The current study is concerned with the experience of spousal carers as they move from home to hospice care. This move is amongst many changes that carers face during the caring process, leading to it being conceptualised as a transition (Marsella, 2009). Bridges (2003) makes some important points about the difference between circumstantial and psychological transitions, stating that change is a circumstantial event such as the change of caring context in the current study. By contrast, he asserts that transition is an internal psychological process through which individuals incorporate change into their lives. Research shows that because this erratic process of change and adjustment occurs over a period of time, there may be many episodes of transition in one experience of caring for a dying person (Du Benske et al, 2008; Duggleby et al, 2010).

Kralik, et al. (2006) conceptualises transition as a period of change during which individuals redefine themselves whilst integrating new and shifting conditions into their world. Her review of transitions as it applies to health care draws attention to the changes that have taken place within models of transition relating to health and social science research in the last three decades. Chick and Melesis (1986, cited in Kralik, 2006) underlined how carers and other individuals in the illness scenario can be affected by transitory response effects, such as feelings of disconnectedness and detachment.

## **2.3. Caring in context**

For carers of palliative patients based at home, caring takes place during a period where they are in an on-going process which is both unpredictable and non-linear. This is in contrast to theories of transition as a stage based process such as were proposed by (Kralik, 2006). This literature review aimed to bring together understandings of transition as it applied to health care. And identified a lack of theory surrounding transition as a phenomenon. The lack of an established model leaves a deficiency in frameworks for understanding. She further emphasises the interactive relationship between the individual in transition and their environment by

placing the person at the centre of an active system comprising individuals and their relationships in historical and political context.

Caring around the clock at home leaves carers vulnerable to higher levels of anxiety especially out of normal working hours when accessing professional help or advice is more difficult (King et al, 2004). At such times they are confronted with a barrage of information about who to contact and what to do in case of emergency (Duggleby et al, 2010).

The EOLC Strategy (2008) acknowledged the transient nature of caring throughout illness, stressing that carers practical and psychological needs should be met across differing settings.

The concept of transitions in nursing is acknowledged as being significant (Davis, 2005). However when we look at how transitions impact on those providing informal support, there are relatively few studies particularly in the area of palliative care (Williams and McCorkle, 2011).

A literature review by McGuire et al (2012) highlighted the need for naturally occurring longitudinal research with carers at end of life suggesting that prospective research based upon the illness trajectory of the patient, would uncover the challenges of carers in real time. McGuire's purpose was methodological rigour aimed at measuring outcomes and improving nursing practice. Whilst I agree that prospective research would illuminate the carer's unfolding experience, the aim of qualitative research is to capture the richness of individual carer experiences and I argue that, imposing a patient trajectory based model, built upon disease and presumed to be reflective of carers' experiences might not reveal the carers world 'as lived'.

#### **2.4. Caring over time**

The context in which transition occurs defines the way in which it is understood and views of transition as sequential are applicable to a number of research areas. However when viewed in this linear way the picture appears somewhat one-dimensional and, I argue, does not give a full picture of the carers' experience of the transition into hospice care. When applied to individual responses to change over

time, transition can be a uniquely disruptive psychological process of adjustment and orientation in which individuals are engaged in responding to emerging conditions. Moving from caring at home into hospice care is a key event in the life of patients and carers that has been recognised by transition theorists, such as Kralik (2002) who observed that individuals who are living with chronic illness are in an on-going process involving movement in any direction making the non-sequential nature of illness transitions distinct from other types.

Patient and family readiness to opt for hospice care have been found to act as a barrier to referral (Schockett et al, 2005) as have attitudes to hospice care by referring physicians (Andrews, 2011) and oncologists (Fadul, 2009) as well as those of the patients and their carers (Baile et al, 2011). Early referral to hospice care has benefits for carers who are able to access support services which help to support and establish them in the new caring position. Schulman-Green (2004) noted that late referral into hospice care was associated with negative effects for carers and family members, whilst for carers in the home, the referral to hospice was noted as being associated with a shift in emphasis from caring for an ill person to supporting a dying person, leading to a change of focus which is likely to be met with varied individual responses. The changing landscape of surgical techniques means that palliative care can be offered in conjunction with surgery for alleviation of symptoms. Referral to hospice care has been associated with a decline in hope for patients and their families (Rodriguez, 2009) and this change in the caring environment can prompt a rise in levels of stress especially for carers who have been providing care in the familiar environment of home. Communication between the carer and patient is an important factor at this time when conversations about the best place for care can be difficult especially for carers who frequently do not see themselves as being in need of help from health care agencies (Northouse et al, 2000). This indicates that, at such times, priority is given to the wishes of the patient (Stajduhar and Davies, 2005) and family dynamics are challenged as differing levels of acceptance of outcomes are highlighted.

The carer's value and position in palliative care has been acknowledged by government in the End of Life Care Strategy (2008) as well as the response

document, *Recognised, Valued and Supported: Next Steps for the Carers Strategy (2010)*.

These documents specifically draw attention to the carer's need for support during the patient's illness trajectory and include caring in both home and hospice settings. The aim of this document is to recognize the value of carers and support those with caring responsibilities by confirming their eligibility for support from specialist palliative care services. Morris and Thomas, (2001) noted that prior to 1980, those who provided care for patients with life threatening illness were merged under the more general title of family. Carers do not always identify themselves with the label of carer, being unable to distinguish their actions of caring from those of 'attending' to the needs of a spouse or family member (Hardy 2012). One reason for this could be that, agreeing to the role of carer occurred as a process rather than a single event (Morris and Thomas, 2001). Wittenberg-Lyles et al, (2011) observed the reciprocal nature of the physical pain of the patient and the psychological pain of the carer, noting that carers are inclined to becoming so focussed on their duty of care towards the patient, that they consider their own needs to be unimportant (Morris and Thomas 2001; Wittenberg-Lyles et al, 2011). Hardy (2012) noted that carers often decline practical or financial assistance from outside services because they do not make a distinction between their meeting the role of carer and fulfilling their marital or familial responsibilities. The notion of caring as a responsibility was also highlighted by Carlander et al (2010) who asserts that the boundary between being someone's carer and taking care of a family member in need is particularly difficult to define when caring for a relative or spouse.

### **2.5. Caring against the backdrop of loss**

The provision of care from diagnosis of the illness up until the time when curative medicine is no longer viable is considered to be a distinct period in the illness trajectory (Hanratty et al, 2012), which confronts carers with the impending death of the patient. However there may be factors that blur the line between when care or treatment is curative and when there is little or no hope of a cure but care or treatment is continued nonetheless. A lack of consistent clarity in clinical consultations (Fadul, 2009) as well as the carer's own fluctuating levels of acceptance of the patients approaching death (Schulman-Green, 2004) was cited as a barrier to patients and their carers engaging with palliative care.

Research suggests that being forewarned of the death of a spouse will assist in adjustment to loss in the post death period. This phenomenon has been referred to as anticipatory grief (Aldrich, 1963; Costello, 1999; Cheng, et. al 2010). Anticipatory grief (AG) is thought to help carers before and following the death of someone close by presenting them with an opportunity to prepare for the bereavement and lessening the impact of post bereavement loss. Costello and Hargreaves (1998) considered that AG differs from post death grief in that it begins early in the process of adapting to loss, adapting to the knowledge of the loved one dying. In studies of individuals living with AG (Costello, 1999; Coombs, 2010) also noted that, AG occurs in a cumulative way and consequently the emotional intensity of the grief process is more protracted than in post death grief. .

AG can be understood as the cognitive, social and culturally embedded responses to the anticipation of loss. If then, we accept that grief irrespective of type, is revealed in behaviour, then it must be considered that behavioural expression of grief is deeply embedded within individual cultures and social structures (Walter, 2007).

There are numerous factors that impact on carers' psychosocial well-being whilst caring for a family member during chronic illness (Whittingham, 2012). Furthermore, Coombs (2010) noted a lack of clear definition of the concept of AG, but in drawing on qualitative studies she uncovered the complex interplay of social, emotional and cognitive process involved. She further notes the effect of changes within familial and wider social network dynamics which impact on how AG is experienced when individuals are coping with the stress that can accompany living with dying.

Sullivan (2003) explored the dynamics of hope and hopelessness to understand how individuals adjust to anticipated loss, specifically noting that individuals hope (and grieve) for things that go beyond hoping for an outcome that relates to illness. They also desire ease, poise and even redemption for themselves and others.

Niemeyer (2006) puts forward a theory of grief which incorporates idiosyncratic constructions of loss rather than focussing on the individual's response as being either 'normal' or 'abnormal'. He further suggests a view of individuals as being in an active process of finding their way through the experience of loss rather than as a passive sufferer of this life event.

This view of loss would embrace the whole person in context by giving shape and depth to carers' behavioural and embodied interpretations in the pre and post death period, rather than imposing a construct that describes a behavioural response.

Caring for someone as they approach the end of their life involves a multiplicity of practical responsibilities which has consequences for the carer and wider family members. For example the degree of care needed often requires a level of skill which palliative care nurses have undergone specific and dedicated training to acquire. The intensity of this level of caring does not afford the carer regular breaks such as a professional might have in a daily work schedule. Lynn (2000, cited in King et al, 2004) highlighted this point alongside the unfamiliarity of nursing tasks and the carers' lack of confidence, and requisite skills. A further point was made in reference to the professional detachment that palliative care nurses are able to exhibit which are not afforded to the spousal or family carer.

Whilst providing care at home, the carers are living with their spouse or family member close to death (Carlander et al, 2010) by being confronted daily with the functional changes of caring for a spouse in their own home. According to Hutchins (2007) the experience of living at home with a person nearing death has been labelled as 'living with dying'; furthermore, Melesis et al (2000) hypothesized this experience as being a major life transition on the basis that such an experience will challenge the identity of carers and other family members as they change their definition of self in the social context, acquiring new skills and abilities whilst also modifying their behaviour to fit in with their role as carer.

## **2.6. Becoming accustomed to caring in an unfamiliar place**

The move from home into hospice care requires adjustments on multiple levels for carers as they negotiate the changing aspects of their everyday world. Apart from the geographic and practical movement, this change requires a period of inner adjustment which involves adapting to emerging conditions which is acknowledged by Kralik (2006) as a life event. Much of the current literature does not take into account the individual meanings of home for carers and yet I argue that the carer's individual perceptions of 'being at home' are likely to be central to this experience. For carers, the move from home care occurs in a framework of meaning-making

described by Neimeyer (2001). Furthermore, perceived meanings of the term 'home' have different connotations for each individual and the term can refer to a number of locations (Moore, 2012; Charleston, 2008). This would suggest that individuals vary in their responses to moving from home into hospice care because they are responding to something that is unique and personal to them.

The scope of beliefs and concepts relating to what or where home is differs widely and the term itself has a wide range of meanings; for instance home can relate to a town, city of birth or neighbourhood (Cuba and Hummon, 1993; Hildago and Hernandez, 2001). Common to many of these concepts is the idea of home as a physical location however according to Manzo (2003), the psychological construct of home is not limited to physical settings but can refer to feelings of connection to a broader area or space. For some individuals, their psychological perspectives link the construct of home to a place of sanctuary or one where retreat and protection from unwanted influences is offered and where energy can be restored (Moore, 2000; Clarke and Uzzell, 2002).

A sense of ownership and territory has been associated with understandings of home (Moore, 2000) with emphasis given to the significance of time of residency and space. It may be that consistency of residency would be likely to afford individuals the opportunity to engage with wider members of the local community and establish important social bonds which then become an integral part of the concept of home over time, reinforcing the notion of 'at homeness' by attachment to selected people or places (Charleston, 2008). Seamon (1979) suggests that 'at-homeness' can be understood as a phenomenological state which he refers to as:-

*'the usually unnoticed, taken-for-granted situation of being comfortable in, and familiar with, the everyday world in which one lives, and outside of which one is visiting'* (p. 70).

The phenomenon referred to by Seamon (1979) is also embodied in the interaction between people or facets of the experience that combine to bring about a sense of 'at homeness'. Ahlzén (2011) also raises the issue of an effortless state when referring to 'at homeness' as possessing the qualities of regularity and balance. The consistency and order of carers' lives is interrupted by illness when caring in the

home and this results in a 'strangeness' and a sense of being 'ill at ease' (Svenaesus, 2011; Hardy, 2012). I suggest that the experience of being at home is highly individual which explains why, even when several people share the same time, space and circumstance, they will share differing appreciations of it.

## **2.7. Summary and rationale**

I have reviewed current literature and outlined definitions of what is understood generally by transitions; I have explored how transition has been conceptualised specifically in relation to healthcare with particular reference to how these impact on the carer's lived experience. Decisions that impact upon the timing of entry into palliative and hospice care have been examined with reference to pertinent factors that influence this experience from the point of view of carers and clinicians.

Although current research gives an overview of these points it does not address the experience as it occurs in context nor does it account for cultural, historical and familial factors that impact upon the experience for carers. McGuire et al (2012) highlighted the need for intervention studies with carers at the end of life and suggests that these relate to the carer's experience in real time and over the period of interest. This study will explore the carer in context as well as their individual perceptions of 'at homeness' which, I argue, is crucial to understanding this particular period in the carer's experience of caring during terminal illness.

## **Chapter 3: Methodology**

### **3.1 Introduction**

My interest in this topic arose from observing carers who had been caring for someone with cancer at home before the patient was admitted for inpatient palliative care at a hospice prior to their death. I became curious about how and why the experience of caring appeared to be different for some carers than for others. It became apparent that that the best way to understand their experience was through empathic identification (Finlay, 2005) allowing me to position myself as near to the carer's experience as was possible.

### **3.2. Research Question**

#### **a) Stating the question**

The research question therefore is: How do carers experience caring for someone with cancer in a hospice after having provided care for them at home?

#### **b) Introduce methodological approach**

Once the question was identified, I sought an interpretive research approach which would allow me to explore the lived experience of carers in depth by using the individual accounts of each participant as well as making comparisons across accounts. To achieve this I needed to factor in the particular social, cultural and historical aspects that may have influenced the perceptions of each carer. With these goals in mind, I considered the most appropriate approach was a phenomenological one

### **3.3. Phenomenology**

#### **a) Overview and rationale for choice.**

Considering the implications of the research enquiry I contend that a phenomenological approach is the most appropriate because it provides a solid philosophical background for focussing specifically on understanding another's view of the world.

### b) Overview of philosophy of phenomenology

According to Langdrige (2007), Edmund Husserl (1859-1938) is regarded as the founder of phenomenological philosophy. This philosophy uses the term 'phenomena' to refer to 'the appearance of things' rather than 'the things themselves' (Spinelli, 2005). Husserl's descriptive phenomenology suggested that it is possible to uncover the essence of phenomena by epoché and phenomenological reduction (Langdrige, 2007; Rodriguez, 2009) and later identified the concept of the life world which he saw as the basis of philosophy and was described by Todres (2008) as a continuous stream of living that acts as a reference point for human accounts of experience

### c) Heidegger, Merleu-Ponty and the existential hermeneutic turn

Building upon the work of Husserl, Heidegger (1889-1976) challenged the notion that it was possible to stand back and investigate the essence of 'things in their appearing' without allowing for the influence of context, language, culture and history on events as they occur. According to Langdrige (2007), the hermeneutic turn in phenomenology describes the time when the emphasis of description was supplanted by a move towards interpretation of text, which happened when Heidegger proposed a greater focus upon the interpretation of 'things in their being', which is to say those things as they are located in the world in which they exist.

Following on from Heidegger's ideas, Gadamer (1995) stressed that to fully understand experience it must be appreciated that our experience is created by our own individual viewpoint which is both limited and enabled by our individual history and culture. Merleu-Ponty subsequently introduced a style of existentialism that has had the most direct impact on contemporary phenomenological psychology (Langdrige 2007) by highlighting the way that individuals experience the world by 'being in' and 'interfacing with' the world. Merleu-Ponty (1962) remained true to Husserl's method of description by a process of phenomenological reduction and bracketing off what is already known. However he did not believe that it was possible to yield 'a God's eye view' or transcendental truth about phenomena and his focus became on uncovering the essence of lived experience as it exists now through the lens of the individual's lifeworld as introduced by Husserl.

#### d) Phenomenological methods.

There are different approaches to the way that phenomenology is used to inform methodology. A descriptive approach relies upon the lived experience of the individual to provide the narrative of 'the things themselves'. Whereas, an interpretive approach has a greater focus on the meaning of things as they are located in the lived world of the individual as they relate to context, language, culture and history (Langdridge 2007). According to Langdridge (2007) hermeneutic phenomenology is a method which involves thematically analysing data with reference to aspects of the lifeworld philosophy of Husserl, existential and hermeneutic philosophy. Interpretative phenomenological analysis (IPA) has its roots in hermeneutics, which places more emphasis on the interpretative approach than the descriptive and encourages engagement with pertinent psychological literature. To assist me in the analysis of data I utilized an approach called template analysis which was developed by Professor Nigel King at the University of Huddersfield (King and Horrocks, 2010).

#### e) My chosen approach.

The methodological framework I selected draws upon the principles of phenomenology which originated as a philosophical movement and is valuable for understanding lived experience. I utilised van Manen's (1990) version of hermeneutic phenomenology to guide the interview process and analysis to build in an element of flexibility. This corresponds closely to Husserl's feature of intentionality which refers to the fact that we are aware of the world by being in it but states that awareness of the world does not equate to being conscious of it. In this approach the researcher's position in the interpretation of data is acknowledged (Koch, 1999), where interaction between researcher and participant fosters a dialogue which encourages the participant to use their own words to bring to life those themes that are vivid and grounded in lived experience. To use an example from one of the interviews in the present study, one participant repeatedly used bodily metaphors to express his indescribable pain. The use of metaphor helped him to express the indescribable by making a comparison so vivid that he held his chest while rocking back and forth in what seemed to be a gesture of self-comfort as he told me:

*Yeah it was shock (pause) it were like a rocket to the core of your body*

The participants were potentially vulnerable by being recently bereaved and I argue that a rigidly procedural method to data collection would have been inappropriate. Likewise a hermeneutic approach was selected because it takes into account the context and condition of understanding (Gadamer, 1985).

#### f) Template Analysis (TA)

TA is a method of data analysis that has been used in phenomenological studies (King 2004; Rodriguez 2009; Turley 2011; Hardy, 2012) being particularly suited to pragmatic research enquiry in real world settings because of its usefulness in organising data. The formed template acts as a coding frame and facilitates exhibiting of the hierarchical arrangement of themes as well as aiding the identification of relationships that occur within the data.

I transcribed the recorded interviews verbatim as soon as possible after each interview finished, then read the interviews line by line as is suggested in thematic analysis of text (Van Mannen, 1990). The re-reading of interview texts was utilised as a way of immersing myself in the data and becoming acquainted with the fundamental nature of the experience by the identifying of sections of text that appeared to reflect its essence. This process was carried out alongside connecting with field notes made immediately following each interview whilst listening to the recording. From this process I was able to identify phrases, expressions and passages that appeared to reveal the phenomenon.

In the second phase of analysis I turned to the research question, looking for instances where selected units of text pertained most closely to the experiences of the participants. The units of text became the essential themes which were the basis for constructing the hierarchical template by serving as a summary of the participants' understandings and making known their experience. Van Manen (1990) speaks of '*balancing the research context*' and to achieve this, I repeatedly revisited the template in order to remain orientated to the essential themes. There were many instances where I stood back whilst organising the data to re-acquaint myself with the research question and evaluate how the themes contributed to the overall phenomenon. According to King (2004) reviewing and adapting the template in this way allows the researcher to consider the data at varying levels of specificity and detail. Finally a template was arrived at that provided a visual account of the

transition and conveyed the participants' experiences in a coherent and flowing manner.

TA has been utilised in cases where there are a lot of participants (Brooks and King, 2012) and is also useful in studies such as the current one where the focus was more on idiographic case by case analysis of individual transcripts (King et.al, 2012)

### **3.4. Design**

#### **a) Access to Participants**

I recruited caregivers from two hospices sited in South and West Yorkshire. I aimed to achieve a balance between closely defining the participants' experience and allowing for sufficient variation to permit other significant elements of the experience to be revealed. Carers in end of life settings are considered a vulnerable population because of the sensitive and stressful nature of their task (Stevens, 2009). Wilson et al (2013) outlined some of the difficulties in recruiting from these populations, one of which was interfacing with parties who were responsible for the maintaining and adhering to ethical codes in individual settings.

Such individuals are referred to as gatekeepers and for this study, I requested that a member of the family team play a 'gatekeeping' role in participant recruitment as a secondary precautionary measure against causing distress to participants. This involved meeting with the recruitment team at each hospice and asking them to ensure that, based upon their knowledge and contact with each carer, the participants were psychologically equipped to answer potentially sensitive questions about their experience.

#### **b) Sample and recruitment**

Participants were purposively sampled from hospice records according to their experience and these inclusion/exclusion criteria:

##### **Inclusions**

1. The participants identified themselves as having been a carer at home for someone with a terminal illness, before the patient was admitted into in-patient hospice care for a period of a least five consecutive days during the course of their illness.

2. The death of the patient was no less than three months and no more than one year prior to interview.
3. Participants who were considered by the 'gatekeeper' to be psychologically prepared for answering sensitive questions relating to their experience.

### Exclusions

1. Those carers whose spouse or family member had been admitted to the hospice from a hospital or residential care rather than from home.
2. Carers who had been identified by a health care professional know to them as being unsuitable for interview based upon their physical, cognitive or emotional state.

Smith and Eatough (2006) point out that the aim of collection and analysis should be to 'honour the richness of the individual's account'. Within published qualitative – and especially phenomenological - studies sample numbers of ten or fewer are common because of the focus on detail in accounts and the ideographic approach (Williams et al, 2011). As far as practicably possible, I aimed to obtain a range of carer perceptions of the experience by seeking diversity in relation to gender, relationship to the patient and illness diagnosis.

Table 1 shows the pseudonyms of the participants and patients, all of whom were spouses with a cancer diagnosis.

**Table 1 Participant Details**

<b><u>Participant</u></b>	<b><u>Patient</u></b>	<b><u>Relationship to Patient</u></b>	<b><u>Patients disease</u></b>	<b><u>Hospice</u></b>
John	Julie	Spouse	Ovarian Cancer	A
Robert	Donna	Spouse	Lung Cancer	A
Alice	Fred	Spouse	Prostate Cancer	A
Frank	Caron	Spouse	Bone Cancer	A
Phillip	Penny	Spouse	Brain Cancer	A
Bernard	Anita	Spouse	Bowel Cancer	B
Betty and Susan	Ron	Spouse and daughter	Nasopharyngeal Cancer	B

### c) Interview Context

All qualitative researchers need to consider the setting and context in which the research takes place (Rodriguez, 2009). Context and setting of the interview can impact upon the research relationship (Ireland & Holloway, 1996). With this in mind, all participants were given a choice of where they preferred to be interviewed. Robert and Phillip requested to be interviewed at the hospice and an interview room was made available which was away from the inpatient unit and purpose built to foster a feeling of physical and psychological comfort for interviewees. I was able to sit close enough to them for me to observe their non-verbal communication whilst at the same time, not invade their personal space. The remaining five participants requested to be interviewed at their respective homes and these were conducted in line with the University of Huddersfield's lone worker policy. My role of interviewer incorporated perceiving by 'being with' participants and this was highlighted when during one home interview, at the participant's request, the daughter joined us in the lounge where the interview was taking place. Her presence had an interesting effect and led to a change in the energy and direction of interest when the women energetically co-constructed their account of having been part of a family caring in the home before moving into hospice care.

### d) Interview Procedure

All interviews were conducted face to face and audio recorded with the participant's permission. Using semi-structured interviews with a loose interview topic guide (appendix 3), I began by asking the participants about themselves and, as the interview progressed, I broadened the dialogue to include their role as carer to the palliative patient. I used the participants' responses as a guide to encourage reflection and explore areas of interest as they emerged during the interview whilst steering questions towards the topic of relevance.

During the interview I paid attention to my own and the participant's verbal and embodied responses to my questions and to my own reactions to them. These were recorded in field notes following each interview. Finlay (2005) advocates a research process that assists the possibility of empathy through a process of 'reflexive embodied empathy' where the researcher reflectively engages with the relational connection that exists between researcher and participant, thereby maintaining their

own position as a researcher whilst empathically identifying with the experience of the other.

Audio recordings were stored on a password secure computer and will be destroyed five years beyond the submission of the thesis. Arrangements for further support were negotiated with the Family Care Team before the interview. At the end of the interview participants were fully debriefed (appendix 5) and provided with information about where they were able to access further support should they need to do so.

#### e) Analysis

I aimed to maintain a sense of participants as individuals with their own experiences whilst comparing and contrasting accounts across those experiences. To achieve this, I initially read three of the transcripts line by line, making mostly descriptive notes in the margins. This allowed engagement with the data and drew my attention to repeated phrases or significant sections of the text before clustering together and ascribing meaning to groups. Following this I began the process of gathering general codes which became more defined and explicit as they were grouped together and these formed the first version of the template (appendix 6).

#### f) Ethics

##### i) Confidentiality

All participants were anonymised by the use of a pseudonym with no information used in interview transcription allowing identification of the carer, the palliative patient or the hospices involved. A lay report will be made available for participants and participating hospices if requested.

##### ii) Psychological support for participants

I am familiar with this particular client group from working in a hospice setting and from conducting interviews for my third year project. I am therefore aware that participants who are newly bereaved may be vulnerable to psychological harm. Thus certain safeguards were put into place, for example, participants were informed of the procedure for withdrawing their data from the study; the information sheet (appendix 4) explained to participants that they had the right to decline answering any questions they found upsetting; if any of the participants had become upset

during the interview, I would have given them an option to taking a break before continuing or, if they preferred, to discontinue the interview. Following the interview, all participants were be thanked for their participation and debriefed by me (appendix.7) .This included providing participants with a resource pack containing information on how they may access support should they feel the need in the future.

### iii) Researcher safety

When interviews took place in participants' homes, I worked in accordance with the lone worker policy which states that interviews are scheduled for daytime and I had access to a mobile phone at all times. A member of the research team was informed of the time and venue of each interview. Following each interview, I telephoned the member of the research team to confirm that the interview was finished and I had left the venue.

### iv) Identifying potential conflicts of interest

It is possible that caregivers at one of the hospices did recognise me from working on reception when they visited the hospice. To avoid role conflict, all correspondence was on university headed notepaper and I conducted interviews in a different environment from the one in which they would have seen me working. I restated before the interview commenced that I was conducting research for the university project and not working for the hospice.

### v) Quality

Researchers have a professional and ethical obligation to produce research that is of high quality and will offer insight and understanding about the studied phenomena (Hardy, 2012). In qualitative research there are no universally agreed guidelines that can be applied to assess whether the interpretation of analysis is consistent with the findings. King and Horrocks (2004) suggest that as a guiding principle, researchers should aim to establish the credibility and transferability of their work by providing as detailed a description of both phenomena and context as is practically possible.

In order to achieve this I aimed for methodological consistency throughout the research process and this is outlined in the analysis section of this chapter.

The application of TA to the data has been audited by having a record of each version combined with keeping a research journal which documents my decision making process throughout the developing of the template. I have been transparent in the analysis process through the documenting of my decision trail and this can be used to allow other researchers to trace where and when I adjusted the template and my reasons for so doing. Copies of the merging template were discussed with supervisors who critically examined it at different stages and these were kept as part of the auditing of my decision trail (Whitehead 2004). During the writing of the findings, analysis and discussion chapter, I circulated copies to selected peers for their review and feedback.

## **Chapter 4: Essential findings**

### **4.1. Chapter introduction**

This chapter begins with an overview of the participants by providing information about the particular circumstances of the seven carers who took part in this study.

The interview transcripts and field notes taken during or immediately following the interview were analysed and formed the basis of the constructed template; the first version of the template (appendix 6) and final template (appendix 7) have been presented in A4 format for ease of reference to the reader.

The findings will introduce the participant's stories and outline the process of thematically analysing the data by exploring individual themes and sub themes. This will utilise the participant's own narratives to best illuminate their reported experiences and highlight issues that are interpreted as being of significance to them

Previous literature will be drawn upon to reveal the lived experience of carers during a change in caring setting.

### **4.2 Introducing the Participants**

#### **Participant 1 John**

At John's request the interview took place at the home he had shared with his wife Anne. Greeting me at the door he raised his eyes to the 'for sale' sign in the garden explaining that since Anne's death the house felt "*too big*" He told me he was not used to speaking about his feelings and appeared eager to tell me that Anne was "*upstairs err you know her ashes*" while photographs and keepsakes scattered all corners of the living area acted as further confirmation of Anne's presence.

My impression was of a man devoted to his family who were his principal source of strength and support even to the exclusion of non-family-others. He spoke of not wanting help or support from anyone other than the family whilst caring at home.

I sensed he was a man who needed 'structure' and when he reflected on having cared for Anne at home and in hospice. The feelings he described oscillated between anger, accepting, and despair and surviving, using his body to express the

pendulum like feelings and employing euphemism to communicate his disbelief of what had happened to his wife and to how he was coping with it. An example of this was when he expressed his feelings of shock at his wife's death which followed months of deteriorating illness where he described "*physical feelings which rock you to the core of your body*" and "*it was like being kicked in the face*". On the day of the interview he was suffering from tinnitus which he attributed to "shock", although he told me that his GP had diagnosed his condition as hay fever.

A point of pride for John was his ability to 'manage' and maintain normality following his wife's discharge from the hospice with the "*err medicines and all that and the injections*". He said that one of the ways he had felt able to cope was by drawing upon his work which he equated with being able to think clearly and logically as this was a skill which was an advantage to him in his role as manager in the mining industry.

*I had to get my miner's head on and keep a clear head and it worked*

It seemed that he had struggled with the domestic tasks that had been role related tasks.

### **Participant 2 Robert**

I met Robert in the foyer of the hospice where he took charge of the situation straightaway by leading me through the hospice corridors to the interview room stopping on the way to chat with staff members and introducing me to them. With formalities over, he settled into the interview beginning his account and took a keen interest in the study. His manner was of someone wanting to be useful and throughout the interview he kept checking that his account addressed my research question, asking:

*Is this what you want to know?*

His account of his and Donna's marriage was told as if recalling a mesmerising novel which encompassed elements of romance, humour and tragedy while his demeanour conferred a sense of having been on a forty two year adventure. He acknowledged his sadness at distressing events in his life but was keen not to dwell

on negative aspects of experience preferring to place them aside in line with the family philosophy of remaining positive, stating:

*...you can't live in negativity erm we never have done hopefully the kids won't ever either because it's a great attribute*

His story provided a context in which he spoke of how he perceived having cared at home and in hospice during Donna's illness. Both had chosen to engage with hospice services and to integrate themselves into hospice life early in Donna's illness by attending day care as a way of gathering information and marshalling support as well as offering support to others. Supporting others seemed to come naturally to Robert and Donna, yet at the same time it seemed to place distance between them both as a couple and between other patients and carers. I sensed Robert was more comfortable with giving than receiving support and had allied himself with hospice staff, becoming active in facilitating support groups and fundraising. This engagement with hospice services had provided him with an environment where he could be actively engaged and immersed; one could say he 'made himself at home', an idiom that captures Robert's 'way of being'. His assuredness meant that he marginalized illness related boundaries so that planning Donna's funeral and fulfilling a lifelong ambition were both framed with the same tone of entertainment

### **Participant 3 Alice**

Alice requested to be interviewed at the home she had shared with Fred and was waiting outside for me when I arrived; as I headed down the steps into the house I got a sense of entering a dark hole. Alice was surrounded by tissues and telephones as she seated herself on a sofa looking out of the partially curtained window. She appeared armed in the face of the suddenly frightening version of the world she once knew.

There were a few family photographs around the house but a display cabinet containing many of Fred's cameras dominated much of the lounge space.

Her narrative was of sorrow and separation which permeated her relationships with others now that she was on her own and no longer 'Alice and Fred'. She told me she missed the support of others that was available throughout Fred's illness but was

now available only if she specifically requested it, which was something she found difficult to do. As she recalled her experience, I visualised a woman on a boat, anchorless and without a map. She told me:

*Nobody tells a carer what to do there's no book written to tell you what you have to do*

When I asked her what sort of things she would write in a book if she was to ever write one, I was surprised that she did not highlight the kinds of things that appear in much of the literature such as practical, financial information or support. She was keen to speak from her own experience and of what had helped her rather than list specific areas where she had felt unprepared for the task of caring. There was a noticeable change in her demeanour which I took to indicate an increase in self-esteem when she spoke of how she had acquired new resources through the experience of caring for Fred. Expanding on this, she related how she recently formed a friendship with a lady whose husband was dying and who she had been able to help by drawing on her own experience, reflecting how she may not have been able to help without having been through the experience herself. The reciprocal nature of the relationship these two women shared had given further meaning and value to Alice's experience. As if buoyed by this story, she went on to give incidences of how being without a book of instructions had led her to new and sometimes daunting experiences which had changed the way she related to her surroundings and how she saw herself within the world; as well as how she related to others. I was left with the impression of the house and Alice being brighter and more airy when I left than when I had arrived and I attribute this to Alice's narrative journey which had moved from suffering to empowerment, as her story had unfolded over the course of the interview.

#### **Participant 4 Frank**

Frank requested to be interviewed at home and provided me with meticulous directions about how to reach his house and other details such as where to park. This nervousness was apparent at other times throughout our meeting and he appeared anxious when I arrived and the slight tremor in his hands and his voice made me think of him as fragile. He was not a well man and was being supported by his family following knee replacement surgery.

Early in his account of his experience he revealed a mistrust of some of the medical staff by whom he had felt patronised, when he perceived they had withheld information from him about the seriousness of Caron's condition.

Caron's clinical condition provided the framework for his account and he used medical terminology to story his experience. His familiarity with medical practices and language arose out of his experience as a health professional which was something he chose not to share with medical staff. However, he told me that he thought it would have been prudent for them to enquire about the extent of relatives' medical knowledge because it had appeared to him, at the time of caring for Caron, that the medical staff were planning for the end of her life, while the family were still adjusting to the news of the treatment regime. Thus, it had appeared that there was a contradiction in focus for the family and the medical team and this may have led to the communication difficulties that arose. The following excerpt is an example of one such occasion:

*what I knew but they didn't know that I knew she didn't know that I used to work for the health service and then when she were talking she brought somat up and I said to her "you're talking of a DNAR (do not attempt resuscitation) here" and she were taken aback.*

The couple had faced and overcome a number of health related crises during their marriage and there were other incidences where a veil of concealment had been drawn between members of the family when information that was painful to digest had to be communicated. He told me that with hindsight he thought that Caron had been aware that her illness was the recurrence of a previous cancer episode, but she had concealed it from him because of his own health problems and a fear of hospice admission which she saw as heralding the end of her life. He did not share her view of hospice care but understood her perspective telling me:

*They [people in general] still have their own everybody does have different you know you mention a hospice and its dynamite to a lot of people yeah yeah so she finally agreed and er they got her a bed in (hospice)*

It seemed that Frank's previous experience and competency in the medical field had made the process of accepting Caron's death more acutely distressing. He appeared

to have perceived Caron's demise as a proof of his own powerlessness and lack of efficiency.

### **Participant 5 Phillip**

I met Phillip in the reception area of the hospice where we made our way to the interview room in silence. He was very softly spoken and as we began the interview he made no eye contact for a while preferring to focus on his hands before settling on a cord from his coat to twist and turn for the remainder of the interview. This appeared to serve as a comfort object and once he had settled himself with it he seemed more at ease. Thus, he began his account of becoming Penny's carer from the time where he considered that her illness had begun to enter into their world. He used short descriptive phrases rather than sentences with exaggerated facial movements to make certain points (like looking up and screwing his face tightly to express remembering). Speaking at length of his and Penny's relationship, he shared photographs with me that he took from his wallet permitting me to see but not hold the images all of which were taken before the onset of her illness. He told me they are (present tense used) a busy couple who cherished the private time they spend with each other and their children. Crying and laughing he began to express his feelings freely although his expression did not always mirror his emotion, for example he giggled when he told me how he had controlled the transition from home to hospice care although it emerged that this was determined by other factors. These were Penny's deteriorating functional capacity, the anticipation of her death occurring at home and the impact of this upon the children as well as his own ability to cope. He seemed certain that the point of transition for him was when, in negotiation with the medical staff, Penny was moved to the hospice for night and day care. He spoke of this as a 'physical' change which had the paradoxical effect of changing but not lessening the strain on him in the home, saying that:

*Although Penny wasn't there ... she was and she took up most of the time it still seemed as though you were on the go all the time and then coming here...*

A point of clarity for him was when he had felt able to move on with his "new" life recalling an occurrence at Penny's funeral which he felt unable to explain rationally

but was certain that it wasn't "earthly". I thought this was an interesting observation from such a rational individual.

### **Participant 6 Bernard**

I interviewed Bernard at the home he had shared with Anita for the past 31 years. On entering the house I was struck by the many ways in which the home had been adapted to accommodate Bernard's disability which had improved since Anita's death. He told me of his sadness that this improvement had come too late for him to have done more for her while she was alive. He was keen to make sure I had everything I needed and took a keen interest in the research and its aims. I got the impression that caring for others required little effort from him.

He told me that he had a history of depression dating back to the diagnosis of Anita's cancer many years earlier and became emotional when he recalled how she had tried to 'shield' him from the news of its recurrence. He said that during their marriage, he and Anita adopted what he understood to be traditional roles and responsibilities where he had been a breadwinner and Anita had looked after the home. His storying of the illness progression was framed around the transferring of the responsibilities to him, although they remained Anita's domain with Bernard making increasing adjustments to his world to "help her with the home". One of the most difficult things for them to come to terms with was the influx of people into their home meaning he "couldn't get anything done around the house"; and yet it was clear from the way he spoke that he had become very fond of everyone involved in providing specialist care. The move from home to hospice care had been fiercely resisted by all family members and he remained adamant that if he could have continued to look after Anita at home then she would not have gone into hospice care. He was at pains to point out that Anita's admission into hospice care wasn't the result of his inability to manage but because 'we' couldn't control her medication and the symptoms were causing her distress. Their resistance was also because they hadn't known what to expect from hospice care and they had an impression that hospices were a place of no return. On arriving at the hospice he was pleasantly surprised by the amenities for families, the nursing staff to patient ratio and the lack of formality, which facilitated a feeling of entitlement to be there. The thing that had impressed him the most was the cleanliness of all public areas which he said "were

just like hospitals used to be when I were a lad". However, from the moment she arrived, he began planning the day that Anita would return home. Unfortunately that day did not arrive.

### **Participant 7 Betty and Susan**

I arrived at Betty's house expecting to interview her about caring for her husband at home before he was admitted into hospice care. The lingering sense of shock was palpable in Betty's household while three generations of the family engaged themselves in the commotion that was their individual lives. Betty immediately launched into the history of Ron's illness which had slowly disabled and disfigured him over a period of seventeen years. The house was littered with pictures of a smiling Ron who, Betty told me, had always been proud of his teeth. The loss of his teeth was seen by Betty as the first sign that "something was wrong". At some point Betty's daughter Susan entered the room and from here the women began a dialogue that presented as two women attempting to reach an agreement on events at which they were both present but of which it seemed they had differing perspectives.

The things they were able to settle upon were the events where the family as a whole were involved, such as the decision to persuade Ron to have further treatment when his cancer returned and their shock when told that active treatment was no longer an option for him.

The family had attended sessions at the hospital where they learned to administer suction to his tracheostomy site and this made care in the family home possible before Ron's admission to the hospice. The women spoke of "a family agreement" to hold it together" for Ron and I wondered if the family unit was the thing they had contracted to "hold together". They had been particularly sensitive to non-verbal signs from clinical and medical staff and I sensed suspicion when they told how they thought medical staff had tried to spare theirs and Ron's feelings by being less than straight with them about Ron's prognosis.

They spoke at length about the differences in care between the two settings, drawing a rota for round the clock home care for him and of how he became increasingly distressed and agitated as his cognitive ability deteriorated. The decision to place

Ron's continued care in a hospice setting was based on a clinical decision which was made by the district nurse. The medication he was given by the hospice had calmed his agitation however it also meant that he had spent longer and longer periods asleep which they saw as being the nature of palliative care but referred to this as "zonking him out". This effectively ended the possibility of verbal communication with Ron and appeared to signal the first stage of their loss of him as a person.

### **4.3 Overview of Findings**

The aim of this study was to explore retrospectively, the experiences of seven carer's. The participants were recruited from two hospices where each had experience of caring for someone in their home through to the patient moving into a hospice for specialist palliative care. My interest was governed by a desire to understand their lived experience of this journey of care. The literature review draws attention to some of the elements of the caring experience that have been raised as important to carers in other studies and theories. These include points relating to how carers adapt to the change in the caring environment, renegotiating roles and relationships with significant others in the care setting as well as how carers position themselves in the medically dominant field of palliative care.

Frequently carers paid little or no attention to their own needs (Stajduhar and Davies, 2005). Most carers expressed a desire to care at home until the patient's death, but in each case this was unachievable, which meant that there was a point where the decision to move into hospice care had to be faced.

Being aware that certain aspects of the experience under study have been raised, I was mindful of points raised in the literature whilst at the same time seeking to allow the participants freedom of thought and expression to facilitate the sharing of those aspects of the move that best revealed their individual experience. Participants' accounts interwove the practical, social and psychological aspects of adaptation with stories of change at a more private and personal level which were expressed verbally and non-verbally. Their accounts revealed the depth of their experience and generated a substantial amount of rich data

This formed the context of their reported experience and is made known in the first version of the template (appendix 6). The first version of the template was then applied to the data set and amended as necessary to produce the main themes that comprise the final template which can be seen in table 2.

By scrutinizing individual accounts, I was able to organise the data in a way which allowed me to develop themes more extensively in areas that related most closely to the research question whilst maintaining a high degree of flexibility across case analysis. The use of direct quotes allowed me to develop and explicate their experience further whilst giving shape to their experience through the individual participant profiles and field notes taken after each interview. These were later examined at supervisory meetings which proved invaluable as it required me to justify and clearly define the emerging themes for their relevance to the research question.

The themes that make up the final template (appendix 7) reflect how I have understood what the carers told me about their experience and tell of my perceptions when relating to the carer and being immersed in their story in lived time by 'being with' them in embodied relational understanding of self and others (King and Horrocks, 2010; Finlay, 2006). Todres (2008) describes this type of understanding as judgment based caring practice combined with attention to ways of expressing findings which best serves health based qualitative research. From this position, I was able to draw out participant accounts of the value involved in undertaking to care for and be with someone in the process of moving into hospice as well as the strains and challenges.

The carers spoke many times about points where their hopes wilted and I observed that their ways of responding to declining hope varied. One example of where hopes were shattered was the point of referral into hospice care which has which has been associated with a decline in hope for patients and carers (Fadul, 2009). The move into hospice care leads to a change in caring environment which has an impact on their ability to influence care and live up to their role as carer by placing them in a new and unknown context. I will commence to explore the main themes

**Table 2. Main themes that comprise the final template**

<b><u>Theme 1 Becoming Someone's' Primary Carer</u></b>
1.1. Points of Realisation
1.2. Becoming Accustomed
1.3. Role versus Identity
1.4. Relative differences
<b><u>Theme 2 Filtering</u></b>
2.1. The Experience of being at home'
2.2 Getting into position
2.3 Right time and place.
2.4. Active Planning
2.5. Dancing Around
<b><u>Theme 3. The Slipperiness of time</u></b>
3.1. Dimensions of Time
3.2. The Gift of Timeliness
3.3. Buying Time

**Theme 1. Becoming someone's primary carer****T1.1 Points of realisation**

The point at which each participant realised that their role as spouse had merged into one of primary carer varied and resulted in an intersecting of roles for some. It may be that providing care in their home blurs boundaries. When asked to recall their caring experiences, all participants began their account at the onset of their partner's illness, moving on to their partner's decline through illness. Carers' stories were given shape by specific incidences that had personal significance for them and which provided the framework in which their caring experience was revealed. Their appreciation of their role in providing care was something that varied in terms of their awareness of a formal and given caring role. There was also variance in terms of the reported lucidity of this awareness at different points in their caring journey. Of note,

is that in every reported instance, where awareness of the caring role was vivid, there was a greater focus on the demands placed upon them as a carer. Those aspects of the story where they became particularly vivid in their accounts virtually relate to the times at which the greatest adjustments to their lived reality were required, as well as the demands placed on them, and in particular, at points where the disease became more advanced and resulted in caring for the patient as an inpatient in the hospice. John told me of the defining moment when he fully grasped the sway of caring at home for Julie:

*We had very little sleep because I were a bit naive I think I didn't know what to expect I didn't know what was coming ...not really and er the last two weeks well it were like ...the bed time thing you're up down up down so we never got any sleep you know and then she were having trouble with her bowels so she couldn't go to the toilet and just this one night she got up and I must have been asleep and I heard this bang and she were on the floor and she'd messed herself and it were everywhere so I had to clean that up and start to clean the bathroom you know and that were a turning point*

Whilst changes in personality and functional capacity indicated that the world Richard and Diana had taken for granted was being progressively consumed by her illness, issues of temporality were brought into sharp focus for Richard, leading him to seek information to prepare himself for what may lie ahead.

*She'd chat and have cups of tea and ... she used to enjoy that and she'd had her feet done and her nails done at various times she used to love that it was a great boost for her and she loved talking to the nurses she thought that was great and really and lots of chit chat of course and cheering up other people up...when she moved into the...latter stages and the GP said "I think it's about time" and it was the stage when she was on a syringe driver and she was getting more and more sort of a bit doolally and you know I needed to know the signs and ... where you gradually become awash with pain and you don't eat and drink because you can't and ...she'd been on a on a catheter at home and things were getting a bit messy*

It is the norm that when seeking primary medical services, professionals will identify a primary carer [or next of kin] whose role it is to provide the patient with practical

and emotional support and who should be contacted in case of an emergency (Morris and Thomas, 2001). However, when the carer is also the patient's spouse, it may be an assumption that this label will apply to them automatically (Hardy, 2012). The carers in this study negotiated their identity in relation to a number of aspects such as the patient and their illness as well as others who were involved in the medical arena and their wider support networks. However, it was unclear if adopting the role or label of carer was something they discussed with support services but it seemed that the duality of their role as primary carer and spouse or family member was taken for granted. Hardy (2012) suggests it is possible that this assumption arises out of the dialogue between patient, family and medical staff in early clinical discussions. For carers, it seemed that they saw themselves as occupying a space on the periphery of caring before adopting the role more formally. Role duality was prompted by critical incidents which lead to a clearer awareness and appreciation of their responsibilities.

For some participants, understanding that they were regarded as a primary carer to their spouse came at the juncture where they became involved in the patient's treatment in a proactive way. There were incidences where the illness trajectory had been long, and in these cases the awareness of their new role became part of a landscape being changed by illness which involved making alterations to long term plans they had made at a time when continued health was something they felt they could safely assume.

*I retired eighteen months early because we were going to go to New Zealand for three months. Well I gave them a year's notice cause I work for (company name) and during that year Donna was diagnosed with mesothelioma so when I retired we didn't go to New Zealand because when she was at the stage where she needed not exactly looking after but I needed to be at home and erm just sort of care for her a bit and things like that.*

Robert became keenly aware that his and Donna's future needed to contain a more realistic set of goals to accommodate for Donna's changing functional condition.

## **T1.2. Becoming Accustomed**

There are a multiplicity of associations linked to the concept of home, but when the home becomes a place of caring, there are challenges and changes that greatly increase the sense of responsibility for carers (Carlander et al, 2010). These changes also impact on recognised patterns of normality in the home (Given et al, 2011). For Bernard and Anita, illness had woven its way into their lives gradually, eventually becoming an established feature of their daily routine. Bernard's retirement plans were centred on accommodating Anita's deteriorating mobility. His reason for wanting to be at home more was because he was anxious to make up for Anita's perceived inability to fulfil her assigned role as homemaker. Thus, he sought to be available for her by offering immediate practical and nursing related care and support.

*I took er like a retirement but part of it was my choice but part of it was to try and look after Anita and she had her bowel cancer and they operated on it and they said it was successful they'd got lymph nodes and everything removed so everything was OK and to look to a nice future. But she was limited in a lot of things she'd been able to do so from then I started trying to because I wasn't working she was giving me some of her jobs so I was trying to look after her and look after the home as well.*

Anita's illness had presented physical and social challenges to the couple and in order to maintain a sense of normality, Bernard became more flexible in his role at home. However, Anita's inability to 'do' was replaced with a whole new set of tasks to 'do' for Bernard.

The responsibility of caring for individuals with cancer is not restricted to spouses but is often felt by wider family and non-family members (Given et al, 2011). The experience of cancer when lived out as a family has much in common with one where there is one person acting as the designated primary carer (Neimeyer, 2006). When family members are placed together in the context of an illness setting they face adjustments as a group on multiple levels. In doing so, they become mediators of their identity as a family unit.

Recalling a specialised programme of training undertaken by individual family members, Ron's family had suppressed their uncertainties of themselves and their abilities, as well as their fear of the potential outcome and unmanageability of Ron's illness. In order that Ron's wish to be cared for in the family home was realised, they told me how they had moved beyond tasks and responsibilities that were familiar to them with little or no debate. It seemed they perceived a lack of choice in undertaking nursing orientated tasks that were new and technical and went beyond their original perceptions of what care would or could entail.

*Susan: Dad just said he wanted to come home for however long he'd got and could they sort it out for him to come home because up to that point we hadn't done any of his tracheostomy training ... we had to be taught how to do all that*

*Betty: Yeah before he could come home we had to do all that... they taught us in the hospital and that was on-going every morning yeah ...we had to use suction because there was a real danger that if he haemorrhaged ...because he had these massive bleeds you see they were terrible weren't they? They frightened him and I know ...we'd got to deal with it, we couldn't be frightened but Ron was frightened because they weren't just nose bleeds ...I mean one morning he got up and he came in and said to me "you'll have to come in" and I went in and it looked like a war zone there was blood everywhere...*

*Susan: If you'd have said to me before ... Dad was ill "would you be capable of doing that?" all three of us would have said no but when you've got to you've got to...*

*Betty: So we got the Marie Curie nurses coming in to just take a bit of pressure off us at night but that freaked him we ended up cancelling it. He didn't want it and I don't think people realise that you think you're doing the right thing for him but that just freaked him more. He wanted us. Of course he didn't realise how much it was taking out of us.*

For Betty and her family, it was Ron's reluctance to engage with specialist home palliative services that constrained them in the role of 'family carers' and this acted

as a barrier making it difficult for them to be involved with services that could have alleviated the burden of their task.

### **T1.3. Role versus Identity**

The carers were active in managing their own identity as they moved from being a carer who managed illness at home, to being part of a caring team in the hospice. Being the primary carer at home involved taking responsibility for the patient's continued well-being. This task has been identified as a cause of stress for those in palliative care as they strive to meet high standards of care and support especially in the eyes of medical staff who visited the carer and patient at home regularly. It was important to John that he was perceived by professionals as well as Julie that he was able to manage well with caring for Julie at home. In this way, he aimed to alleviate worry and ensure that she could remain at home.

In each case, the carers' engagement with medical staff placed them in a new and unfamiliar social context. For some participants, their comparative levels of nursing skill and expertise meant they perceived themselves as secondary or subordinate to medical and nursing staff rather than complementary to them. Their changing and unsettled perception of themselves grew progressively stable as the relationship with medical staff evolved. They reached a point where they saw themselves as more equally matched in terms of their unique knowledge of the carer and skilled in managing care.

From a carer perspective, it can be difficult to tell if the role of medical staff visiting the home is intended as supportive or supervisory. Yet in all reported incidences, co-operation with medical staff was seen as crucial to providing good quality care. Acting as part of a team does not come naturally to everyone, nor does admitting a lack of knowledge or ability in terms of caring or supporting a loved one.

As Julie's illness progressed, John's lack of ability to provide adequate pain relief for her compromised his perceived sense of self.

*Julie was the brains of the relationship and I was I if there was something wrong with the roof I got up and did that whatever and Julie did everything .... I said "you deal with that you're better*

Part of John's responsibility in his new relationship role, was having to make decisions with potentially far reaching consequences. These were made more difficult by being made against the backdrop of stress in terms of thinking about what was happening in real time as well as anticipating future events.

Within the context of his interaction with specialist qualified medical staff, John was uncharacteristically uncertain of his ability to be Julie's carer, meaning that at times his role and his identity did merge, but at other times they did not. Recognising the functional role that medical staff played in terms of putting together appropriate treatment plans relative to drug type and dosage, some of the participants maintained their identity by recognising their own particular function in providing an all-encompassing brand of care to the patient. This also seemingly served to maintain their individual identity within a variety of other illness settings such as day care and hospitals.

For Alice, there was little or no dividing line between her identity as Fred's wife and that of his primary carer. Similarly, Alice saw no operational limitations to her role, so when Fred was admitted to the hospice, she told me that she "*just*" continued to care for him in the same way she had done whilst he was at home. It seemed as if she maintained her caring identity in the hospice and this was, in part driven by a need to not be viewed in a lesser capacity by either Fred or others.

*I went every day erm at ten o'clock (pauses and takes a deep breath) till my son brought me home at half past eight seven days a week for five weeks... I know that he was in the hospice and they were caring for him but er they couldn't be attentive to him all the time like I could because there were so many people.*

This mirrored the experience of Betty and her family, who had undergone training to provide specialist care at home for Ron, and found the palliative approach of the hospice medical staff to be at odds with the care he had received whilst they had been caring for him at home. Here we see again, the evolved role of carer as expert, performing specialist nursing tasks and acting as educators to medical staff.

*I think in a hospice they just want to keep people as comfortable as possible but my Dad because of how fast the cancer was growing was very agitated so*

*their bigger concern was sedating him and keeping him calm whereas we were more concerned we would have cleaned it ever few hours ...none of us wanted to see him like that you know there was all this gunge behind the trachy er it should have been cleaned before he went in but he got worse quickly so we knew it needed changing didn't we? I showed them [district nurses] how to do it because I thought if Mum was ill or had cold or I had to go back to work they would have to come and help us wouldn't they? So we needed to be confident that they knew what they were doing.*

As the care setting changed for some participants their role became less well defined, whilst for others the setting did not appear to impact on their role as carer. A certain amount of anxiety was present when there were disparities in caring approaches particularly due to the hospice's approach which was palliative rather than curative.

#### **T1.4. Relative Differences**

When families are confronted with the imminent death of a family member, there is a rush of dialogue that I believe to be attempts at meaning making. Arriving at Betty's home, I was introduced to her daughter Susan who requested that she be present through the interview in case Betty got upset. As the interview progressed, I noted that when Betty responded to a question she glanced firstly at Susan for what seemed to be confirmation. A channel of communication naturally opened between the two of them where both women shared their own insights into events surrounding Ron's move into hospice from home care. At times they conferred with each other and at others they simply talked over each other, jointly creating an account of the experience through their interaction.

*Susan: She [District Nurse] rang up that day ...and we'd had three nights in a row where he hadn't slept at all and she said "I think we need to ring the hospice I'll ring and see if they've got a bed" she rang back and said "tell your Mum they've got a bed and we'll sort it out" so they take that decision away from you because I don't think we'd have ever made that decision.*

*Betty: I don't think we would and the thing was at first he was alright although he was restless at night and we took it in turns then to sleep in the back*

bedroom with him ...he was up all night so we were up all night and then he wasn't sleeping all day either so that wasn't good for him...the awful thing about it was once he went to the hospice that was it he was zonked out wasn't he?... he never spoke again.

*Susan:* That's their way you know ...it's palliative care but it's the right thing I think at home we let him do what he wanted if he was ragged and he was up and down and wandering around and beside himself we just let him do that because we're family but in a hospice they wouldn't ... I said "can you do something just to settle him a bit?" but their idea of that is ramming in as much stuff to knock him out you see and that was quite difficult to see

*Betty:* Well then he never came round after that did he?

*Interviewer:* Did you have a discussion with them [Hospice staff] previously about what you could expect to happen?

*Betty:* No I don't think we did ... we didn't really have time to do and he didn't ever speak, he just spoke to you once didn't he?

*Susan:* Yes he said I was getting on his nerves (both laugh) ...you see there are other patients in there that are dying they can't have him up can they and he was in the bed nearest them because they said he was the poorest one there so they must

*Betty:* They must have known have known he hadn't got long and that's why they did it I'm sure.

*Susan:* They didn't keep it [tracheostomy] as clean as we did at home. They weren't as attentive. In a hospice they just want to keep people as comfortable as possible but my Dad, because of how fast the cancer was growing was very agitated so their bigger concern was sedating him and keeping him calm whereas we were more concerned, we would have cleaned it ever few hours and Mum well none of us wanted to see him like that you know er there was all this gunge behind the trachy it should have been cleaned before he went in but he got worse quickly so we knew it needed changing didn't we... so we had to ring [consultant] to say we were in the

*hospice and he came down but ...remember when he looked at my dad and I thought ... it would be better for us to see it changed and it looked clean I just said to (nurse) I said "I think it would be better we as a family would feel better my Mum would feel better if it was just done" and she said "well we don't want to cause him any discomfort"*

*Betty: He did wince a bit didn't he although he was unconscious by this time as far as we know he did wince when it came out only just like a slight wasn't it?*

It seemed that the two women had differing but similar accounts of Ron's care after he left home and arrived in the hospice and I wondered if that was because Susan had been engaged in monitoring and managing Ron's illness as well as her Mother's distress.

### **Theme 2 Filtering**

Accommodating the move between care settings required adjustments on multiple levels and some of these have been documented in previous literature (Morris, 1996; Morris and Thomas, 2001) with the move into palliative care being conceptualised as a junction [crossroad] in a phase or stage of a transition (Schulman-Green et al, 2004) or a move between life and death (Teno et al., 2007). This move, unlike others in illness experience requires a change in nursing care and strategy which makes it particularly laden with meaning for patients and carers as well as medical and nursing staff working in oncology (Fadul et al 2009). In this study, the carers' perceptions of the move from home to hospice care varied in relation to factors such as their individual interpretations of "at home" and how caring impacted on their understandings. Individual carer's motives and feelings of competence in providing care also had a bearing on how they engaged with formal and informal sources of support. Relationships at all levels became particularly pertinent to carers when making choices and decisions about end of life care for their spouse, which also had an effect on others outside of that relationship but who shared their household. Indeed the burden of responsibility is perceived to be greater for carers than patients when the patient is receiving palliative or hospice care (Williams and McCorkle, 2011), and this was apparent when participants recalled how they had wished to ease the psychological and spiritual burden of their spouse, even at the cost of their

own well-being.

I suggest that the change of caring context is a 'filtering' process rather than a fixed transfer of caring action and this theme highlights and explores incidences through the lens of the lifeworld [factions of sociality, spatiality and selfhood] to develop this argument.

### **T2.1. The Experience of Being at Home**

The term home has been construed in a variety of ways (Charleston 2008) and in the context of this study can be understood as those elements of experience that the carers associated with their personal conceptualisation of being "at-home". Sarbin (2005) uses the analogy of the theatrical stage and points to how both stage and setting contributes to the overall performance of an unfolding drama. He further states that in daily life, the meanings we attribute to circumstances are shaped by the places that provide the stages for our experience. I noted that, for the carers who were managing the illness at home, the arrival of medical staff at unspecified times during the day, forced changes in their perceptions and experiences' of the familial space and accustomed routines which had provided a backdrop to their shared social world (Sarbin 2005). These changes emphasized the fact that the once shared space was now fused with the reality of ill health and had come to represent an illness setting. This intrusion threatened to change their understanding of the space that had represented the family home. Phillip recalled how he had cherished time spent at home with Penny and their family. He added that these periods became further valued with the realisation that illness progression meant that these times would become less frequent. He spoke of his resistance to fully engage with the implementation of specialist palliative care home visits.

*...the rapid support team came every night we said "we don't need you to come every night" they said "well we will and if you tell us at the door you don't want us"...they'd come every day to put her to bed if we'd have wanted but we could do that between us...we said "is there somewhere we can ring you to save you coming and you can go somewhere to spend the time with perhaps someone who needs it?"*

Individual conceptualisation of the term home varies between individuals, acting as a description for a way of being in the world that can encompass many different settings (Manzo, 2003). When used by families the term arises out of their shared emotional experiences over time, imbuing their shared environment with meaning and worth. In order to evoke a sense of “being at home”, Ron’s family spoke of using concrete objects from the family home that seemed to symbolise their own collective meanings of their shared family space in the hope that he would recognise them:

*I think the most upsetting thing towards the end was he kept saying “just take me home I want to be home” so he didn’t even know after all that effort he didn’t even know he was home and I’d walk round and say “this is your settee look at that picture dad this is it this is your bedroom” and we’d walk him round.*

By drawing his attention to familiar items, they aimed to evoke a sense of the family home for him and to convey to Ron a sense of contentment in his disordered state.

## **T2.2. Getting into Position**

The forming of symbolic and emotional attachment to places was explored by Sarbin (2005) who draws upon the concept of place identity, using the term ‘narrative emplotment’ to describe how individuals locate themselves within the performance of an unfolding drama by the positioning themselves in a geographical space. The distinction between house and “being at home “ was revealed as Robert spoke of the underlying urgency to buy a home following Donna’s diagnosis. He told me how, for practical reasons, they had lived in separate houses for much of their married lives. However this pragmatic approach to the space from which they functioned in the world changed when contemplating the reality of Donna’s death, when the term was used to evoke a space to be when reaching a final resting place or the end of a journey.

*It was an ideal house we had stacks of stuff we’d been married forty two years we had stacks of stuff in store all the kids’ stuff they didn’t want you know books and things and it’s a big house and it had lots of space so it was ideal. People could come up and stay there was plenty of room for them which was*

*great. It ticked all the boxes... It was just that we were living in rented places and Donna said "I don't want to die in rented"*

His story tells of the change in his relationship with their lived space. They moved from a functional based association where the spatiality of the house facilitated their daily lives, to one where illness impacted on the way in which they lived and enjoyed sharing their home with others.

Of paramount importance for Robert was that Donna would be able to live with poise and dignity (Hardy, 2012) and this aim is among the social, spiritual and existential goals for primary care providers (Carer's Strategy, 2010).

*We wanted to live in R but there was nowhere or there were plenty of houses for sale but they all needed a lot of work and we weren't in a position ...we'd done up houses all our lives and we'd moved lots and done up houses so we knew what was involved and we weren't in a position really to have works being done when she was on the last sort of decline of life... the GP came ...and he said "I can get you in on a Tuesday or Thursday morning" and they came and collected her' ... you see er she was a very popular girl ... she'd texted friends saying "I'm really very poorly now you'll have to speak to R in future " there's about twenty of those that she'd sent out that Thursday morning so she knew it was coming*

This change in Donna's condition signalled to him that the house no longer fulfilled the requirements for her to receive the level of care she needed and deserved. Whilst being active in positioning himself in the hospice setting, he had been setting the scene for Donna's last act by interacting with staff and carers in the hospice prior to her admission.

### **T2.3. Right Time and Place.**

The government document Recognised, Valued and Supported: next steps for the Carers Strategy (2010) recognised the importance of supportive strategies for carers who face many challenges to provide care at home and often prioritise the patient's needs above their own. The sense of satisfaction that carers derive from caring (Carlander et al 2010) may be one of a number of reasons why carers would fail to recognise the limits of their own coping abilities. It may also be that the decision to

care at home was made in an uninformed way, at the beginning of the illness out of a promise to the patient or a desire to preserve an air of normal life (Stajduhar and Davies, 2005).

Hardy (2012) points out that carers strive to avoid being a burden to either the patient or medical staff providing care to the patient. Maintaining their dignity when working with professional carers was important and they sought to be seen as capable and competent carers by giving the impression of responding appropriately rather than reacting to the changing demands of caring.

John told me that he had misjudged the physical and emotional toll that caring for Julie would take in terms of feeling isolated and lonely when the uniqueness of their situation made it difficult to reach out for support from anyone outside the immediate family. He spoke of the series of events that had led to accessing support from medical staff in help for caring at home. :

*John: We had very little sleep because ...I were a bit naive I think I didn't know what to expect I didn't know what was coming (begins to cry)...the last two weeks well it were like the last thing on your mind is you don't ... you're up down up down we never got any sleep you know and then she were having trouble with her bowels so she couldn't go to the toilet (clears throat) and er this one night she got up and I must have been asleep and I heard this bang and she were on the floor and she'd messed herself and it were everywhere. So I had to clean that up and start to clean the bathroom you know and that were a turning point and er we went through the night and I phoned my sister-in-law and she came up and helped and then...I saw a lady from me childhood what I used to play with who worked at (hospice) and she were with her sister and she said "how are you doing?" well she obviously saw. She said "where's your nurse coordinator?" and I said" I don't want help" and she said "John ring her tomorrow"...anyway I rang her and she came straight away and she said "why didn't you say? "well you don't do you? You just battle on and Julie went back into (hospice) and then she er (hesitates) she died two weeks later.*

As a result of John's hesitancy to engage with outside services, he was oblivious to the range of services that were available to him early in Julie's illness trajectory and

consequently was late in accessing support. Hardy (2012) stated that carers often do not realise that health care services apply to them and rarely consider themselves to be the ones in need of care. Although McGuire et al (2012) points out that caregivers are increasingly recognised as the recipients of care themselves.

Early engagement with hospice services and particularly staff enables the forming of important supportive bonds. This was the case with Phillip, whose involvement in the hospice setting began whilst he was still caring at home which led to an informal and relaxed relationship with medical staff. Placing himself in this social context meant that his physical and psychosocial needs were brought to the attention of medical staff who were able to intervene and assist him in making an informed decision on the safest and best option of caring, for him and Penny:

*She came here Friday mornings for day care er and they spoke to her a couple of times about respite but she her initial view was that I was trying to pack her off so I can actually remember I said "you're not going anywhere but if your health is in danger then I've got to do something and that may be you go to (hospice) to give me a break" because it was more or less 24/7... the longest I slept was 3 hours and I came here one Friday and they said "what's plan B Phillip ?" I said "what do you mean?" they said "well you can't do it "so the doctor the social worker the care worker the nurses and Penny and me well they explained it and she said "yes"... the idea being to give me a break ... It didn't work because Penny hated the hoists that they have to use for health and safety reasons they hurt er ... so I ended up staying here most of the day and put her into bed so she didn't have to go in the hoist*

Both John and Phillip's stories demonstrate the importance of connecting with carers as their experience unfolds so that carers' needs and wants are addressed on a personal rather than conceptual or theoretical level. Both men wished to be supported in their chosen care approaches. However, differences in their individual lifeworlds and their own understandings lead to a different experience for each person. Having access to support services can significantly impact on individual carers' experiences during the caring process and in the post bereavement period (Given et al, 2011).

## **T2.4.Active Planning**

Carers who had regularly visited and been involved with the hospice prior to the patient's admission were able to form crucial social bonds with hospice staff members, as well as becoming familiar with the daily functioning and routines of the hospice environment. This also provided them with an opportunity to gather information from medical staff in preparation for what lie ahead. In the same way, connecting with day hospice services provided a place to meet with other people in similar situations and develop support within a group. There did not appear to be a time element to the forming of these connections for Robert who formed close bonds with medical staff as well as other carers and patients when attending the day hospice. Such times provided an opportunity to connect with others via social interaction that arose naturally as staff and attendees spent time together rather than being introduced formally. These relationships proved invaluable at crucial points:

*Gradually from that minute on she started slipping away really, became less lucid; she came in on Thursday morning and she died at one o'clock on the Saturday morning. So my involvement with caring obviously stopped when she left the house but by then the family were up here. We just came down whenever we could, we just came down and chatted to the doctors and things and the chap who you saw me talking to down there he's one of the GP's that covers he was a good insight into what would happen*

In this way, Robert had been active in marshalling support by negotiating his place in the caring situation. Morris and Thomas (2001) suggest that when the carers place in the illness setting is recognised and validated by others, they are more able to take care of their own needs. The support that Robert had received appeared to have equipped him with a degree of equanimity when his perceived role as Donna's hands-on carer had come to an end.

## **T2.5. Dancing Around**

As part of the process of stepping back from the participants and the thematic analysis, I reflected on how I would characterise the way carers represented the experience of deciding on the place for continued care. Focussing on the silent intimate dance between carer and patient and their reluctance to confirm or deny

their preferences, I used the infinitive 'to dance around' to portray how when one person is unsure about the feelings of the other they remain cautious about communicating their own feelings clearly. For some participants, there were unacknowledged tensions around how the decision for hospice care over home care should be made and who should make it, leading them to take up a position with the motives of others in mind. The reciprocity of suffering between patient and carer further impedes clear communication with some carers feeling torn between being near to pain relief for the patient and maintaining their togetherness. I wondered what effect, if any, the title of a particular service would have on the carers' or patients' likelihood of agreeing to engage with hospice services. For example, the day care unit at Overgate is called 'Day care hospice' whilst at Barnsley it is called 'The Limes' and while both are situated in the hospice, they are physically separate from the inpatient unit. For some participants the title 'hospice' is associated with being near to the end of life (Rodriguez, 2009) and the name palliative care has been associated by clinicians and oncologists with a loss of hope and increased levels of anguish for carers and patients (Fadul, 2009).

The move into hospice care is a significant life event for carers and patients (Meleis, 2005); while some carers in this study were hesitant to instigate a discussion about continuing care with the patient, for others there was open dialogue between them about preferences for place of death. Carers arrive at the decision of where care should take place in diverse ways (Stajduhar and Davies, 2005), and for at least two of the participants in this study, there was an unspoken assumption between them and the patient that home care would continue until death. The experience of moving a family member into residential care is made easier when carers are supported by others in the decision-making process (Davies, 2005).

For Frank, his career as a health service worker meant that he had experience of working with people in a hospice setting prior to their death. This made discussing Caron's end of life care options with her very difficult because he knew that being an inpatient did not automatically signal impending death for her, yet he was aware that for Caron and many others, the general consensus of opinion was that the move into hospice care frequently precedes death. He recalled how the subject of hospice care was raised by the Macmillan nurse:

*She'd resisted going into (hospice) the Macmillan nurse suggested it and she said no but eventually she finally agreed I don't know even though I knew (hospice) because I used to take people in for day care so whereas I knew people could go in and can come out Caron said "I'm not going in there because you don't come out" you know so they still have their own opinions everybody does. Mention a hospice and its dynamite to a lot of people.*

Being empathetic and understanding to Caron's fears, Frank did not feel that he could make an impartial contribution to the hospice admission or preferred place of death discussion, so he 'stepped away' from the discussion, leaving it to Caron and the Macmillan nurse.

In a similar way, Bernard was keen to stress that Anita's move into hospice care was not related to his competency in caring for Anita at home. Bernard admitted that he found the labour intensive nature of caring at home stretched the limits of his physical ability, although he was very clear that the decision for Anita's care to continue in hospice was a temporary one that he had neither made nor sanctioned. He told me of his fears and preconceptions of hospice care despite the reassurances of his son:

*There were times when she'd not be able to get out of bed and I'd try to help her lift her into a wheelchair so we had a wheelchair at the top of the stairs and took her to the lift and then I'd have to transfer her from the lift onto that and she'd be watching my face and she'd say "you've had enough you can't do it" you know and then I'd be walking doubled-up...so anyway we went [to hospice] not knowing what to expect. Our son had been... and she said it's lovely...how can anybody say it's lovely? You're going to a place where you might not come back from how can it be lovely? So anyway we went and ... I didn't want her to go still if we could have if there had been any way at all for her to stop here she would not have gone no way. It wasn't that I wasn't managing our problem quite simply was that we couldn't get her medication right.*

Bernard was able to enlist the help of the nurses and wider family members to broach the idea of hospice care which Anita had been reluctant to discuss.

### **T2.5.1. Self and other pain.**

According to Schulman-Green et al. (2004), the time leading up to hospice admission places carers at a crossroads of coming to terms with the patient's changing needs and considering alternative ways of caring. At this point, Phillip was able to consult with hospice staff about the difficulties he faced in caring at home. He told me of his struggle to balance his own emotional wellbeing against the backdrop of Penny's changing cognitive functioning and her need for reassurance.

It has been noted that there is a relationship between the wellbeing of the carer and the patient's condition (Weitzner, 1999, Wittenberg-Lyles, 2011). The interpersonal nature of this connection occurs in the physical, social, spiritual and psychological domains. As the physical and cognitive function of the patient declines, their needs are likely to intensify and this required Phillip to use imagination and empathy to quieten Penny's anxiety, but at the same time it raised difficult moral and ethical questions for him.

*Towards the end she got very ... (long pause) she needed reassurance all the time and it did get quite frustrating I remember shouting at her once or twice and feeling bad about it afterwards (laughs) then talking to the nurses and they said "it's OK" . She'd ask "what time is [friend] coming back?" so I'd say "seven o'clock" but then she'd say "well will you text them and ask them?" and I'd say "no they'll come back have they ever let you down?" And then five or ten minutes later she'd do it again. I used to text myself and show it to her or I'd be talking to my own voicemail so she could hear and pretend [friend] was there or whoever ... it got very hard...she got in her own routine really here so she wanted particular people to sit with her while she watched a particular programme... the physio used to come up and see her so ... and I was here most of the time but I tended to go in and out and talk to the nurses and stuff ... then she had her sister in law to watch Emmerdale with her . So even if I wasn't sat watching it I'd be around and between us we'd said "she's never going to be here on her own" so there was always somebody here ...the nurses used to get her up and shower or bath her later on and ... her sister in law came and did her makeup and her hair and I'd come over a bit later so.*

Nevertheless, Phillip was grateful for the support of others in caring for Penny at home and in the hospice. The benefit of social support was highlighted by Weitzner et al (1999) who cited metastatic disease, poor patient prognosis, long illness trajectory, deteriorating patient symptomology and increase in patient distress as factors that would have an adverse effect on the distress of the carer as well as the patient. This presupposes a mutuality of suffering between carer and patient which I observed in Alice's story. Alice's distress felt like it was 'present' in the room as she recalled attempts to provide pain relief to Fred. This explained the sensation of safety that both she and Fred felt when in hospice care and how she was able to feel confident that pain relief would be available for him at all times.

*They could just not control his pain he had a bad reaction to everything. He had a syringe driver on and the drugs going in there was nobody's business and ...even the staff were "gobsmacked" that's a harsh word isn't it for me to say that but they just couldn't find anything to control his pain. They tried different drugs and each drug had a different reaction so they stopped that and put another one in...and as time went on he felt safe at the hospice he if he was in pain or anything he'd just have to go like that (clicks fingers) and they were there. Here [at home] it could be two to three hours before I could get anybody here which was no good when he was so bad. So he felt safe in the hospice and so did I they were absolutely wonderful they looked after me as much as they did Fred... I think it was easier to care for him in there because if anything went wrong they were there to see (pause) I mean and being at home caring for somebody its quite scary but you just do*

Alice had felt supported and validated by the hospice staff which lessened the burden of car for her and encouraged a collaborative framework in which she could maintain her role as Fred's wife and carer as well as her position in the hospice setting.

### **Theme. 3. The Slipperiness of time**

*There's not much you can do about the length of your life, but you can make it wider and deeper – Anon*

I explored the ways in which carers expressed the movement from being a carer at home to becoming a carer in the hospice, in relation to the ways they spoke about time. Although concepts varied between participants, there was a sense in which they communicated an element of slipperiness to time, making it seem unstable and liable to sudden changes instead of the now predictable system of measuring the distance between unfolding events. Examples were seen when illness had a long trajectory, where caring began by consuming small and barely discernible units of the carer's time. However as illness progressed, the time expended grew until it became apparent that time would expire at some instant unknown moment and would be out of their grasp. For some carers, their individual appreciations of time were of something that was precarious and changeable in dimension. They appeared to have wanted to maintain a 'grasp' of time by readjusting the present in order to stretch out their time together.

### **T3.1. The Dimensions of Time**

Some of the participants began to think of time as conceptually different from the measured units occurring between events. For example, Ron's family were thrown by what they saw as the unusual speed of time in which Ron's illness forever changed him as a person and them as a family. When they were told that his remaining life could be measured in months and weeks they began to shift their focus from the quantity of time available to them and began to think in terms of bringing substance and worth to the family's remaining time together.

The following excerpt chronicles a conversation between Betty and Susan as they apply the concept of time to reflect and make sense of the events surrounding the last period of Ron's life. Of interest is the way their narratives fluctuate as they seemed to struggle to make sense of their experience when collapsing it into familiar ways of charting and appreciating experience.

*Susan: Because it was more about quality of time that my Dad had left at home. That was more important*

*Betty: And he didn't really have much did he I mean D wanted to take him out a couple of times in the car but it [time] was going so fast*

*Susan: Well they told him he had weeks and he lasted eight weeks didn't he? Well he only had six well five and a half weeks at home it took them two weeks to organise a hospital bed and ... it took them two weeks to do that didn't it?... to get us straight? So he actually had five and a half weeks at home so he actually died eight weeks after they'd told him he'd got [cancer] weeks erm months arm and I don't know we'd convinced ourselves that it could be eighteen months you know we didn't think it would be weeks but having said that he couldn't have carried on any longer it deteriorated that quickly.*

Focussing on the time element of Ron's condition, both women agreed that the rate of deterioration became 'rapid' once he was admitted to the hospice which necessitated an increase in his medication and the easing of his pain, but deprived them of time with him as the medication led to a rapid loss of consciousness.

### **T3.2. The Gift of Timeliness**

Susan recalled how she had valued the insightful timeliness of the Macmillan team by relating a particular incident where the nurse had acted as an 'intimate mediator' (Galvin, 2005) between Ron and the rest of his family. Ron's disease had resulted in cognitive changes which were irreversible and affected the way he behaved and this aspect of his illness was particularly distressing for the family. Wright et al (1999) noted that the progressive cognitive changes associated with active disease leads to a loss of mutual understanding between carer and patient as well as extending the carers responsibilities. In this instance Ron's family were grateful for the insight and experience of the Macmillan nurse who was able to use her experience of illness to make judgments that were well timed and enabled Ron to communicate things that were difficult for him to say the family were not ready to hear before Ron's changing cognitive capabilities robbed them of the time to talk over Ron's feelings about his condition as well as his hopes for the end of his life.

*When he first came home and these were really difficult things to talk to him about it and they managed to talk to him in a way where he could come out and then they could talk to us without it upsetting all of us. But if they hadn't have done that so early on he got too poorly and this tumour was pressing on*

*his brain and he was too mixed up and they obviously would have known that but they did it in a very very good way.*

All carers spoke of how they looked to medical staff for advice and information during the lead up to the death of the patient which could have been the result of a lack of experience in such matters. It could also have been an indication that, Like Betty and her family, they were too distressed to discuss the specifics of end of life with the patient or each other. .

### **T3.3. Buying time**

The move from curative to palliative care has been documented as a 'critical moment' in treatment due to the momentous shift in focus for carers (Duggleby, 2010) .The main concerns of care for oncologists in oncology clinics relate to medical problems associated with disease (Baile et al, 2011) and for these specialists, the delivering of 'bad news' can be a daily undertaking. This perhaps, makes it difficult for them to understand why patients and carers would choose not to opt for treatment that would prolong their life. For carers in a clinical context, it is difficult to have a conversation with staff that can make their wishes concrete. For example, wanting to know if their spouse is likely to be well enough to attend a christening the following week-end. Such were the considerations that comprised the lived experience of John and Julie and motivated their choices when being offered more treatment. The expression 'buying time' is used when someone is doing or not doing something in exchange for more time. John told me that the choice he and Julie faced was not as straightforward as it appeared to the medical staff. He had seen the choice as a balance between their longing to prolong the time they had left together and a worsening of Julie's already compromised quality of life by agreeing to further treatment. He seemed to be questioning the price that he and Julie had paid for the extra time that had been 'bought' by Julie's engagement with further treatment.

*He said "oh we're going to we'd like to give you some more chemo" and we said "no we don't want it". They said "we think it's a good thing that you've recovered from this we could buy you time". But what do you think that does to you? ... and we said "no we don't want it". She said "well come on and see me" ... we kept saying "no no no" and she talked us into it. I said "it's up to*

*you Julie you have to go through it “ so we had all this chemo and then and then she'd got ...ascites...yeah her legs oh they were enormous the poor lass and then she ballooned up and then she went into (hospice) then they got there right and then she came home... because they knew she were dying she knew she were strong enough to take this so its let's try this and whatever time they buy ... whether she would have lived any longer or what I don't know. Once we'd made the decision we were content we were just like right whatever's going to happen is going to happen and then it all started again we knew she were dying Julie knew it and she said "no I don't want no more I can't go through that" and they started that ball rolling again the carrot was "we'll buy you more time" and we don't know if they did. What they bought us were a lot of pain and distress to Julie I wish she wouldn't have had that she might have gone through these few months it might have been a bit less but with all the extra pain they bought her and the way I see it is they were just trying drugs on her .*

Other ways in which the value of time became starkly apparent was when carers became acutely aware that they were spending their last few days or hours with their spouse.

Witnessing a loved one's journey towards death was framed as a significant event in the lives of every participant. Facing the transient reality of human life impacts on the way that individuals think about their own humanity which lead some of the carers in this study to search for meaning in the moment; what Finlay (2011) refers to as 'nowness'. Finlay (2011) describes this concept as devoting time to the things that are imminent or about to happen.

The admission to hospice enabled some carers to relinquish tasks that had occupied much of their time during the time they cared at home, as well as impinging on opportunities to be in contact with networks outside the illness setting and other valued aspects of their social world. The positive effects of spending time with family and friends have been identified as bringing a sense of purpose and normalcy into the carers' world that has been dominated by illness (Cooper et al 2008). Added to this, having visitors has been associated with psychological and physiological benefits for patients and carers (Mulhall, 2004; Fumagalli, 2006).

The hospices in this study operate an open visiting policy which allows friends, family and, on occasion, family pets to visit. Yet two of the carers spoke about how they would have preferred more fixed visiting arrangements allowing them to plan and organise their lives in a way that would incorporate time alone together. This would have increased the quality of their connectedness and fostered a more home-like feeling to the hospice setting. Slota (2003) noted that in some critical illness settings, carers and patients often feel the benefit of including obligatory rest periods into the planned visiting policy. Such opportunities for rest and recuperation were taken for granted when caring at home but carers and patients felt the loss of privacy in their shared space at the hospice as being 'unhomelike' (Hardy, 2012).

Phillip related incidences where he had felt protective of Penny during visits and wanted to shield her from friends who were not sensitive to the subtle signs that she was tired or in pain and often stayed too long. He told me how he '*managed*' visiting by using an appointment book which allocated units of visiting time to each visitor:

*Phillip: We actually got an appointment book yeah because... at one point there were fourteen people there which upset some of the people who'd gone to see her as well you know it was overwhelming. So I kind of bought it as a joke (laughs) but one of the nurses said "you've done the right thing there" and people soon realised they can't come unless they ring. We had one problem with one friend...they've known each other for forty years and she just used to turn up but because she was a friend. We tried to be diplomatic but towards the end she became a problem and she caused a scene one day. She was just oblivious to it I think she just thought that it didn't apply to her because they had this special relationship and I talked to Penny about it she said "that's a load of bollocks and you can tell her I've said that". I said "no I won't because I'm not going to offend her it's a sensitive situation she's your friend she thinks she's doing right but she's not" er so we kind of put up with it ... they kept me informed because sometimes she was still here at 1 o'clock in the morning and she wouldn't go. I could have said "you're not coming" but that wouldn't have made anybody feel good and it would have just caused trouble. But we had a huge amount of support.*

*Interviewer: I've never heard that before, it sounds very practical*

*Phillip : Even then it got out of hand a couple of times and there were some days when she'd say "who's coming" and I'd say "oh XYZ" and she'd say "oh can you put them off" and they were fine about it*

Phillip became a mediator between Penny and unwanted visitors which lessened his anxieties for Penny and improved his sense of agency when faced with the knowledge that the only thing he could do was to mediate by organising Penny's remaining time for her.

#### **4.4 Summary**

This research built upon previous studies in which the experiences of carers were identified at key points in the advanced disease trajectory (Marsella, 2009; DuBenske et al 2008; Duggleby et al 2010; Schulman-Green 2004; Given, 2011)

This study focussed upon a particular point in caring during this process by thematically exploring transcripts from interviews with carers recalling their experiences. These were presented in a template which focussed upon their individual experiences as well as drawing upon themes across all the given data to identify similarities as well as differences in participant experiences (King and Horrocks 2010).

I will now extend my exploration by drawing on literature to assist in elucidating the carers lived experience in relation to becoming a carer, firstly in their own home and subsequently in a hospice setting. In the next and concluding chapter I will further consider the essential nature of the study findings, the strengths and limitations of this study. As a consequence, the essential findings will be further explored in relation to existing literature. The ways in which this period of time may be conceptualised by health care workers to improve services for carers in the future will be considered.

## **Chapter 5: Conclusion**

The process of becoming a carer for someone who is experiencing illness involves a merging of several individuals' realities into a shared life world where each of them revise their construct of self in line with their unfolding experience (Spinelli, 2005), as well as the social context in which experience occurs.

### **5.1. Becoming someone's primary carer**

When we think or speak of how we conceptualise identity, we are prone to construe it as a fixed part of our 'selves'. Yet for the carers in this study, identities were not fixed but changed in both sudden and gradual ways. This occurred across changes in the illness of another person, their personal and shared environment as well as their relationships with others on a variety of levels. According to Neimeyer (2006) and social constructionist thinking, individual identity can be understood as transient and multifaceted: a fusion of intentionality and individual meaning constructed in collaboration with others.

This theme sought to capture the ways in which the carers' self-concept was changed by the experience and this differed for each participant. This is in line with theories of identity as a moving and emerging concept according to the individuals unfolding experience (Burr, 2003). Of particular interest was the imperceptible boundary line where the role of spouse or family member changed or merged with the role of carer. Morris (2001) describes the carer's position in the cancer scenario as one of taking part in a shifting process of 'carerhood' in which they strive to adapt to the changing needs of the situation. My data suggests and previous literature corroborates, (Morris and Thomas, 2001; Hardy, 2012) that carers begin caring by being protective of their role as spouse or family member and are reluctant to identify with a term that infers that they are caring out of a sense of responsibility or duty. But as their role evolved to include more complex and specialised tasks, they became more accepting that their caring role was beyond that inherent in 'normal' family relationships. For my participants, taking on the carer role seemed 'natural' almost like an automatic reflex which is to say that it happened without them having to stop and think about it and this would explain why none of the participants could recall the specific moment that one role ended and another began. This could be because

there they emerged as carers from the growing responsibilities they had undertaken without thinking as illness progressed.

Carers displayed flexibility in the assuming of different roles over the course of the period under study. There were times when they were stretched by the nature and amount of caring tasks they performed and at other times they felt diminished by feelings of being helpless to provide the kind of care needed by the patients; this was particularly true of providing adequate pain relief as the illness progressed. A certain amount of adaptability was required of carers, especially in family setups where terms like 'we' and 'us' and 'them' were used interchangeably in line with changing conditions. At other times carers struggled with changes when illness had transformed the shape of their lifeworld so fundamentally it was hard for them to fit into the evolving and fluctuating reality of illness. Hardy (2012) refers to the physical and psychosocial effect of illness as being the interwoven aspects of the combined disease experience which impact on carers and patients together. A lifeworld perspective assisted the elucidation of this experience by taking into account the concrete facets of the carers' everyday experience as practically and bodily lived.

## **5. 2 A moving process**



**Fig. 1**

There have been many conceptualisations that have guided transition in palliative care for example, Schulman-Green (2004) suggested patients and carers were at a crossroads when they begin the transition into hospice care but this suggests that carer's had a choice about which road ahead they chose and this is something I

would dispute. Bridges (2004) described a process of life change with a beginning, middle and an end however this vision of a linear progression over time was not represented in this study with carers describing a non-rhythmic movement accompanied by an uncertain plot.

My own interpretation of their experience was closer to the interminable shifting accounts described by Chick and Meleis (1986) who theorized a passage between process and outcome with attention being drawn to the interplay of context and situation; and Kralik et al (2006) who stated that transition incorporates people's responses over time which may or may not incorporate change.

The change of emphasis in care from curative to palliative was beset with fear and confusion for carers and there were frequent intermittent periods of disruption where they sought stability by turning to others for guidance, seeking information from professionals to questions such as "what will happen and when?" This appeared to increase their feeling of being 'in step' and quell the uncertainty that accompanied sudden changes in pace. There appeared to be many transitions inherent within the move itself as they negotiated their way through extended changes in their own and the patient's health as well as appraising their attachment to the place they had jointly related to as 'home' with its inherent dimensions of selfhood, spatiality and agency.

I envisioned the move between caring contexts occurs as a 'filtering' process rather than a reallocation of the carers' physical or emotional reserves. Fig. 1 shows the effect of filtering on a layered image and demonstrates how filtering lends clarity and depth to certain aspects of its focus whilst other elements appear as a backdrop to the overall occurrence. I suggest that the move into hospice care adds a layer to the carers experience which gives prominence to certain features of their individual lifeworld whilst diminishing others. This theme highlights and explores this idea of a filtering of imports as viewed through the lens of the carers' individual life worlds [factions of sociality, spatiality and selfhood] to develop this argument.

The effect of a filtering process was evident when individual perceptions of their role in caring modified the 'appearing' of things in ways that affected their overall interpretation of the experience in both subtle and intense ways. For example Alice

was resolute with regard to her role as Fred's constant attender throughout multiple shifts in care focus and context during the course of his illness.

*They couldn't be attentive to him all the time like I could because there were so many people... the staff kept saying " how are you doing it ...day after day?" "... when you love somebody you do it don't you?"*

Robert shared this clarity with regard to his role in caring for D and yet it seemed that the move into hospice setting changed the way he perceived his role as carer.

*So my involvement with caring obviously stopped when she left the house*

This contrast in perception and the emphasis given to the things that been of value to them as a couple, led to what appeared to be a different account of caring. I put forward that this was the result of the filtering of priorities and perceptions.

### **5.3 The fragility of time**

As human beings we understand our experience as unfolding across the predictable passage of time. Lives and memories, plans and proposals are made within this structured framework that stretches out beyond where we are able to perceive.

As a result time is something that is taken for granted, constructing our world on the assumption that the future will unfold in the same knowable way as the past.

When recalling their experience, carers drew open distinct events that seemed to have meaning for them. Finlay (2011) states that time can be the medium via which past experiences are transferred into the present or the future. One example of this was when one carer recalled with laughter and rich detail the events surrounding his wife's last day at home. His narrative was one of an escapade and he laughed loudly at particular points, telling me of his wife's great sense of adventure. The whole family had always 'refused' to live in negativity and this had been their 'mantra' following a series of tragic events early in their marriage.

There were similar fragments of experience recalled by carers that were represented as fragile in essence; it appeared that they were holding on to the flimsy segment of time tightly as if holding it in an optimum position. By clasping it in this way, they

appeared to be more able to envision all that was precious about that 'presented' moment.

Last details were wrung out of such experiences, so their favourite TV programme was recorded as a matter of record, as was what someone was wearing and a cat jumping in an the ambulance for its owners last journey. Like an artist creating a likeness, cutting and chopping the story to create their portrayal of the experience.

Time provided a framework for the carers and patients to share their experience. However as they recalled certain events, it appeared that the framework was unstable. From this it is possible to see how the slipperiness of time made some instances seem endless. I pictured them grappling to somehow store time that seemed to be disappearing too quickly, while a similar time or phase of the move was spoken of by another carer as if it had 'slipping through their fingers'. It may be that living near to the death of a significant life partner challenges our assumption of temporal stability by signalling not just the closure of a life but the end of 'oneself' before a new self can begin (Rodriguez, 2009).

Differing appreciations of time were seen in the medical setting which I suggest was linked to the emotional investment of those involved. For example, nurses were able to maintain a level of professionalism by applying their knowledge and experience of time scales in illness whilst carers were approaching the experience for the first time. Nursing staff had access to experience based knowledge that sharpened their appreciation of the speed with which time was slipping away and this was utilised to address important matters between carers and patients which were settled before illness crept in and stole the time away from them.

This was also apparent when treatment options were being discussed with medical practitioners who are entrusted with the care and preservation of the life and health of patients. The question of how to balance quality and quantity of remaining time is uniquely personal and includes how individuals feel about all aspects of their lives rather than solely the medical component. Expert medical opinion may be able to evaluate how much time is left to the patient and carer. However the toleration levels of the diminishing quality of time is a matter which only the patient and carer can determine.

An open visiting policy was in operation at both hospices in this study and this policy has been linked to a paradox for patients as they balance the positive effects of having visitors and the need to feel in control of time available by managing how long the visitors stay (Gray 2008). Some carers assumed responsibility for visiting time, resourcefully allocating stored units of time to visitors as if handing out a token. The amount of time allocated appeared to equate to the closeness of the relationship between patient and visitor. By recognizing the finite nature of time for the patient, the carer became the guardian of this prized resource. As the nowness of death made its way into their lifeworld there was a greater focus on issues of connectedness and intimacy as well as an awareness that opportunities for connection were diminishing in line with time remaining.

#### **5.4 Researchers concluding thoughts**

This study explored the experience of providing end of life care from the perspective of familial carers. The study focuses on the caring, as the patient and carer moves between care settings. The findings strengthen the view that providing care for a family member along the pathway of chronic illness is a significant and idiosyncratic experience.

Adopting differing positions and providing a unique brand of care to their family member throughout this experience, changes their psychosocial environment. Carers fostered a sense of agency in a seemingly choiceless situation carers, and in the current study were empowered to carry out specialist nursing tasks which nurtured their role and position as an expert in providing care. When this position was sanctioned by medical staff, important bonds were formed which led to a de-medicalizing of the carers experience and eased the transfer of patient and care responsibility from home to hospice.

The current study appreciates how individual responses to grief and loss are multi-layered and strengthens the case for longitudinal research with carers and their families as they journey towards the anticipated loss of someone in their care.

When participants brought their experiences to mind, there was a sense of instability to the framework of time which may relate to differing patterns of adjustment since bereavement. Additionally, reflective engagement does not capture the way that

individuals interrelate with others and their physical environment yet this is noted to be embedded within the experience.

I put forward that the experience of caring during the move from home care into hospice care is one where increased demands signal changes in lived time and space and where concrete connections take on an unstable appearing.

These topics reflect my own engagement with the data and are therefore constructed through my own understanding, which may be different if the same data was analysed by another researcher. There were other factors that may have had an impact on the analysis and findings and these are detailed below.

### **5.5 Gatekeeping**

There was evidence of severe gatekeeping at one of the hospices which was resolved but resulted in late recruitment to the study for some participants. This meant that the interviews took place sometime later than the initial 'batch' by which time the template was in the process of development. When the data from these interviews was added, the template underwent a considerable change and this may or may not have happened if these participants' interviews had not have been added. The way the interviews changed the template could have been due to differences in hospice based practices related to policy or nursing practices but the change does highlight the importance of variation in qualitative research and how this can affect findings and outcomes. My aim throughout all stages of analysis was to remain focussed on the research question rather than becoming waylaid by differences inherent in individual accounts.

### **5.6 Ethics**

It is well acknowledged in research (McGuire, 2012) that longitudinal research is the optimum way to capture lived experience in palliative and end of life care. This research initially began as part of a two part study which aimed to capture the experience of participants at varying stages in the process of caring at home through to caring in the hospice. Following a presentation and meetings with clinical governance teams and community district nurses, verbal agreement was given in principle. However there were issues associated with the hospice that changed ethical boundaries and time constraints which made applying for new approval

impractical. This changed the way I oriented myself to aspects of the research for example the methodology and literature review which had been focussed on ways of collecting longitudinal data but became more focussed on a reflective approach.

### **5.7 Researcher Role Versus Hospice Worker Role**

My interest in this topic grew from interacting with carers who were visiting the hospice where I work. Two participants were recruited from this hospice and one of them recognised me from a hospice event I attended a few months before the interview. It is not possible for me to know if the storying of their experience would have been different had another researcher been conducting the interview but I noted in field notes, completed immediately following the interview, that on a couple of occasions she looked at the digital recorder and hesitated before she responded to questions that related to hospice care. I sensed that I was being viewed with misgiving and was mindful that my body language did not portray officialdom although it is possible that they modified some of their stories.

### **5.8 Recommendations for Future Research.**

The study challenged the notion of the caring experience as a transition between two settings or two styles of care. It evaded the identifying of stages or phases of the carers' 'transition' experience by focussing on participant accounts 'as lived' .

The uniqueness of the carers viewpoint during the journey has been earmarked as worthy of individual planning and examination (EOLC Strategy 2008).

This research could be extended by using a research technique such as Pictor (King et al, 2010), which assists the exploration of participants' experience by revealing and visually expressing their roles and relationships in given experiences.

Therefore I put forward that future research would benefit from a prospective study of the carers' unfolding experience as lived over the period of interest using a research technique such as Pictor. The technique involves encouraging individuals to explicate important aspects of their unfolding experience by the creation of a visual chart. (King et al, 2010). Pictor has been used with lay-participants in previous studies (Ray and Street, 2005; Hardy, 2012) and has the advantage of being relatively simple and less demanding of carers time and energy as other methods of

capturing lived experience for example diary methods. This would give the researcher the opportunity to explore wider social and cultural factors that impact on them exclusively as well as others involved in their caring worlds.

The researching of this topic has been somewhat of a journey for me. I began with an interest in how carers adjust when in the transition from home to hospice care. I was, at that time unaware of how prior held beliefs would constrain my ability to see this experience through the eyes of the carers' themselves.

My assumption had been that the carers perceived themselves as being in transition but the truth was revealed to me by one carer when she told me in no uncertain terms.

*"It's all a transition from the time I noticed how he'd landed differently when jumping over the wall"*

Lois

I owe this carer a debt of thanks for moving me forwards as a researcher, helping me to see things the 'way they are' and in a way that education could never have accomplished.

The total narratives of the carers in this study have taken me on a reflexive journey and I invite readers to consider the reported experiences from their own 'being in the world'. The lived experience of End of Life care is transforming for those researching into this phenomenon, the experience can also have a transforming effect on the ways in which our own worlds are interpreted and cherished.

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## **Appendix 1 Information Sheet**

Annie Dunsmore-Dawson

Room HHR 3/04

Department of Human and Health Science

University of Huddersfield

### **Research Study: A caregiver's experience of moving from home care to hospice care**

Dear

I am a post-graduate research student at Huddersfield University and would be grateful if you would consider taking part in a study I am conducting which is interested in carers who have cared for someone at home before continuing to care for them in a hospice setting. Barnsley hospice has approved this study and is keen to learn from its findings as it is recognised that this is a significant time in the lives of those who care. This means that I would like to interview people who have been through the experience of providing care to a palliative patient in these two different environments.

Before you decide whether or not to take part, it is important for you to understand what taking part will involve. Please take your time to read this carefully and discuss it with others if you wish. Also please ask if there is anything that is not clear to you or if you would like further information. In the meantime here are some frequently asked questions.

#### **What will be involved if I take part**

Taking part will involve an interview of approximately 1 hour. This will take place in a room at the hospice or in your home as you prefer. I do not expect the interview to cause you any serious distress. However, if you do find a question upsetting, you will be able to pass on that question, take a break before continuing or stop the interview altogether.

#### **Why is this research needed?**

The main purpose of this study is that we get a better understanding of what it is like for carers who have been the main carer at home for someone receiving specialist palliative

care and then continued to care for them in a hospice environment. This is because this period has been recognised as a crucial time in the lives of people who are carers.

### **Why Me?**

You are being asked because you have been identified as someone who has been a carer by the family team at Barnsley Hospice.

### **Do I have to take part?**

No you do not. Taking part in this research is entirely up to you. If you do decide to take part then you are asked to sign and return the expression of interest form to the university. Alternatively, if you would like to know more about the study and what it involves, you can contact me directly on the telephone number below. I will then arrange an interview at a time and place that suits you most. Before the interview, you will be asked to sign a consent form to say that you agree to take part in the study. . Even after signing you are free to withdraw from the research at any time. No questions will be asked about your reasons for withdrawing. This research is for the University of Huddersfield. No part of your care by the family 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 who care in the future.

### **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 connected to it so that you will not be recognised by anyone who reads it. All your personal information will be destroyed when the study is finished. Audio recordings will be kept in a secure file at the university and then destroyed after five years. In the very unlikely event that during the interview, I discover some aspect of your care and support that raises serious concerns, then I will be obliged to discuss this with my supervisory team for your safety and wellbeing. They may see fit to raise this with professionals involved. As far as possible however this will be done in negotiation with you.

**What happens if I change my mind after the interview?**

If you change your mind you can contact me up until the 30<sup>th</sup> of September 2012 to request that all or part of your information be withdrawn 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 carers at Barnsley and other hospices.

**Who can I contact for further information?**

You can contact me, Annie, using the envelope provided or by calling me on 07753172834 or my supervisors, Professor Nigel King, direct on 01484 472812 [n.king@hud.ac.uk](mailto:n.king@hud.ac.uk) or Brigid Purcell, (Senior Lecturer in Palliative and end of life care) direct on 01484 4720033 [B.Purcell@hud.ac.uk](mailto:B.Purcell@hud.ac.uk). Approval for this study has been granted from [hospice] and the Ethics Panel at the University of Huddersfield. If you have any concerns about the conduct of this study please contact [n.king@hud.ac.uk](mailto:n.king@hud.ac.uk) (Chair of SREP)

**Will I hear about the findings of the study?**

Yes. All participants will be sent a short version of the report and can request a full copy if they are interested.

**Thank you for taking the time to read this information sheet**

(Annie Dunsmore-Dawson)

**Appendix 2 Expression of interest form**

Sent on University headed notepaper

Annie Dunsmore-Dawson

Room HHR 3/04

Department of Human and Health Science

University of Huddersfield

**Study title : A Phenomenological study of becoming a carer from home to hospice care**

I am willing to be interviewed by Annie as part of her project.

Name (print).....

Address.....

.....

Telephone number.....

Email (if applicable).....

A good time to contact me is.....

Signed.....

Date.....

**Please return this form to me in the envelope provided or contact me on 07753172834 if you require further information.**

### **Appendix 3. Interview Topic Guide for Researcher**

#### **Beginning**

A little about the participant *work family (whatever they feel comfortable to share)*

#### **Pre-admission phase**

A summary of how involved the participant became in caring before [patient] was admitted to hospice and how/when did they perceive this as changing?

How long participant had been caring for [patient] at home before hospice care was suggested?

Were they surprised by this suggestion?

What does the participant think was causing them the most difficulty?

What (if any) changes had to be made to accommodate [patient] care at home?

How did that change the feel of the home environment? (if at all)

Had the participant had any contact with the hospice or its services prior to the admission and what (if any) were their general impressions about hospice care aims?

Were support services involved?

*Who/How they became involved/ Ease of access to support for carer?*

On reflection how prepared had participant felt about the changes in required levels of patient care?

### **'Transition phase'**

How did the participant feel when they heard that a bed had become available at the hospice?

What were the participant's initial impressions when walking through the door of the hospice?

*The inpatient unit? Staff in the hospice (all staff from ambulance drivers to receptionist and ancillary staff) the environment (décor/ general feel of the hospice)*

How did participant feel about [patients] admission to hospice care? And did this change? (if so) was this a gradual change they noticed at the time or is it only with hindsight they realise the change?

How (if at all) did the change from home care to hospice care impact upon participant *physical/psychological health*? Be aware of other things the participant may mention

*Their relationship with [patient ]*

*Their relationships with wider familial and social circle*

*Their own health*

*Daily living activities such as eating, sleeping or concentration levels*

### **Caring in the hospice setting**

How informed and involved by hospice staff did the participant feel they had been with regard to [patient] changing condition and care approaches?

What (if any) changes did participant need to make to their daily living when [patient] was in the hospice?

**Use the participant's verbal and non-verbal responses to broaden this to include perceptions of wider activities i.e. / financial changes/ roles and relationships with other members of the family/ work?**

What kinds of support (if any) did the participant receive from others that had been valuable? *Includes practical support for example ways of sharing the responsibilities of caring / accommodation/ group or individual counselling/ other services offered by the hospice such as holistic treatments? (any others)*

Where did support come from?

*Doctors/nurses/social workers/family/social groups (others)*

Was support offered when participant first came to the hospice (how accessible was this ?)

*How much bureaucracy/ red tape was involved?*

How was participant's relationship with hospice staff on all / differing levels?

**Post bereavement (this study does not concentrate on the post bereavement period but I wanted to have an idea about how they were feeling at the end of the interview)**

Does the participant feel differently about the experience now that time has passed?

How (if at all) does the participant feel they have been changed by this experience?



**Appendix 4 Interview consent form .**

**Please tick box to confirm**

I confirm that I have read and understand 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 at any time, without giving any reason,

I understand that I have the right to withdraw my data at any point in the research

I give my permission for my interview to be audio recorded and be quoted in any report arising from the interview by the use of a pseudonym.

I understand that no person other than the researcher will have access to the audio recording or any copies of transcription of my interview.

I agree to take part in the above research

Signed .....Participant



### **Appendix 5. Debrief letter**

#### **Research Study: A Phenomenological study of becoming a carer from home to hospice care**

Dear

Thank you for participating in this study.

One of the main aims in this study was to explore and understand what it is like to care for someone with a life limiting condition at home and then continue to care for them in a hospice. It is recognised that the two environments are very different and we would like to understand more about that experience from a carer's perspective.

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 carers who care in the way you have. It is further hoped that the information you have provided may help improve services for other carers 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 Marica Binns. Her number is 01422 387111

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 30<sup>th</sup> September 2012 on 07753172834. Or contact one of my supervisors who are Professor Nigel King direct line 01484 472812 email [n.king@hud.ac.uk](mailto:n.king@hud.ac.uk) or Brigid Purcell, (Senior Lecturer in Palliative and end of life care) direct line 01484 4720033 email [B.Purcell@hud.ac.uk](mailto:B.Purcell@hud.ac.uk).

No part of your care by Overgate hospice will be affected by this decision,

Thanking you once again,

*J. Annals-Jawson*

## **Appendix 6 First version of template**

### **Theme 1**

Any and all perceptions of illness trajectory

### **Theme 2**

Opting for a change of environment

### **Theme 3**

Sources of strength upon which carers draw throughout the transition

### **THEME 4**

Revealing [Patient]

### **Theme 5**

The carer's function and identity in home care (the inexperienced expert)

### **THEME 6**

Evaluating a fresh phase of nursing at home

### **Theme 7**

Contrast between care settings

### **Theme 8**

What or who drives the decision to move into hospice care

### **Theme 9**

Doubt and dedication to hospice practices (nursing styles)

### **THEME 10**

Responses to imminent death and the things we hide for love

### **Theme 11**

Who or what drives the place of death decision

**Theme 12**

Reaching the place of non-pretence

**Theme 12**

The role of intuition / sixth sense

**Theme 13**

On reflection

**Theme 14**

Repercussions

### Appendix 7 Final template showing levels of interpretation

THEMATIC AREA	LOWER LEVEL THEMES
<u>Becoming Someone's' Primary Carer</u>	<p>1.1. Points of realisation</p> <ul style="list-style-type: none"> <li>• Becoming aware of a changed future</li> </ul> <p>1.2. Becoming accustomed</p> <ul style="list-style-type: none"> <li>• Accommodating illness</li> <li>• Changes to the home environment</li> <li>• Inexperienced Experts</li> </ul> <p>1.3. Role versus identity</p> <ul style="list-style-type: none"> <li>• The desire to exhibit competency to professionals</li> <li>• The exclusivity of the carers role</li> </ul> <p>1.4. Relative differences</p> <ul style="list-style-type: none"> <li>• Constructing a narrative/ storyline</li> <li>• A different way of caring</li> </ul>

THEMATIC AREA	LOWER LEVEL THEMES
<u>Filtering</u>	<p>2.1. The experience of being at home</p> <ul style="list-style-type: none"> <li>• Enforced changes</li> <li>• A family space and time</li> </ul> <p>2.2 Getting into position</p> <ul style="list-style-type: none"> <li>• Setting the Scene</li> <li>• New priorities</li> </ul> <p>2.3 Right time and place.</p> <ul style="list-style-type: none"> <li>• Emerging awareness</li> <li>• Important alliances</li> <li>• Facilitating carer diversities</li> </ul> <p>2.4. Active Planning</p>

	<ul style="list-style-type: none"> <li>• Marshalling support</li> </ul> <p>2.5. Dancing Around</p> <ul style="list-style-type: none"> <li>• The things we hide for love</li> <li>• Laden dialogue</li> <li>• A little knowledge .....</li> <li>• Collectively navigating</li> </ul> <p>2.5.1. Self and Other Pain</p> <ul style="list-style-type: none"> <li>• Feeling for and feeling with</li> </ul>
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THEMATIC AREA	LOWER LEVEL THEMES
<u>The Slipperiness of time</u>	<p>3.1. Dimensions of Time</p> <ul style="list-style-type: none"> <li>• The kaleidoscopic nature of time</li> </ul> <p>3.2. The Gift of Timeliness</p> <ul style="list-style-type: none"> <li>• The right time</li> </ul> <p>3.3. Buying Time</p> <ul style="list-style-type: none"> <li>• The imminent future</li> <li>• Choosing between the price and the value of time</li> <li>• Shifting sands</li> <li>• Taking control</li> <li>• Allotted time</li> </ul>